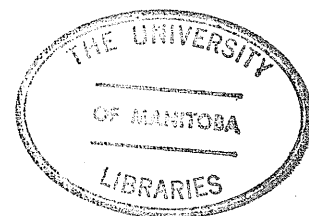


CHRONIC RENAL FAILURE: A STUDY OF DEATH ANXIETY  
IN DIALYSIS AND KIDNEY TRANSPLANT PATIENTS

BY

KAREN B. BLAKELY

A DISSERTATION SUBMITTED IN PARTIAL  
FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY IN THE DEPARTMENT OF PSYCHOLOGY  
OF THE UNIVERSITY OF MANITOBA



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DOCTOR OF PHILOSOPHY

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A B S T R A C T

This research studied death anxiety in fifty-four chronic renal failure patients, half of whom were being maintained on chronic dialysis and half of whom had received kidney transplants. Patients were given the Templer Death Anxiety Scale, the Tennessee Self Concept Scale, the Internal, Powerful Others, and Chance Scales, and the MMPI denial, anxiety, and depression scales. Two death questionnaires were administered during interviews with the patients. Three major hypotheses were tested.

1. High self-esteem patients were expected to report lower death anxiety than were low self-esteem patients. This hypothesis was not supported. As expected, there was a strong trend in the predicted direction, but this difference was not statistically significant.

2. Patients with an internal locus of control orientation were expected to report lower death anxiety than were patients with a chance or powerful others orientation. This hypothesis was not supported.

3. Patients with an internal orientation were expected to have made more anticipatory preparations for their possible death than were patients with a chance orientation. This hypothesis was confirmed.

Further predictions regarding overall treatment group differences were not supported. As expected, transplant

patients obtained higher mean self-esteem scores than dialysis patients, and dialysis patients had higher mean scores than transplant patients on the powerful others locus of control orientation. These differences were not statistically significant. The two groups were nearly equivalent on mean death anxiety scores and internal locus of control scores.

Mode of treatment was contrasted for all variables studied to assess which ones might differentiate between dialysis and transplant patients. Discriminant function analysis predicted correct group membership for 70.4 percent of the transplant patients and 74.0 percent of the dialysis patients, or 72.2 percent of the total population. These predictions utilized coefficients based on the variable subgroup of death anxiety, anxiety, depression, internal locus of control, and length of treatment.

Sources of death anxiety, assessed by having patients rank order anxiety arousing statements, were consistent in focusing around the following areas of concern: grief caused to relatives and friends; the possibility of a painful death; no longer being able to care for dependents; death as facing the unknown; and death as the end of experiences.

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A poem - A BAD DAY AND A GOOD DAY, by Stavus Barton.

## A BAD DAY AND A GOOD DAY

As I lay alone abed  
Without a thought of cure,  
And the frustrations of life  
Still I must endure.

I, to myself, no hope can give.  
Why then, should I further wish to live?

But wait--  
Unknown, some word or perhaps some deed  
Of mine may enter a soul in need,  
And strengthen his faith,  
And lessen his grief.

Oh Lord--  
Forgive me, my disbelief.

Stavus Barton

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This dissertation is dedicated to my father, whose paramount concern was always for others, and who lived and died with dignity.

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## CHAPTER I

### INTRODUCTION

In tracing the history of psychology, one finds that it originated in thoughts about death. Preliterate man came closest to defining mental life in his considerations of death. Man's "soul" or "spirit" was regarded as "that-which-departs" either temporarily from the body, as in dreams, or permanently from the corpse in death. The more sophisticated Greek concept of "psyche" was largely an elaboration of "that-which-departs." Thus, the anticipated loss of one's most valued possession, the "psyche" or "soul," generated not only the discipline of philosophy, but also its offspring, psychology (Kastenbaum & Aisenberg, 1972, pp. 1-3).

Death has been dealt with in as many different ways as there are different cultures. From earliest times, however, it is clear that death was recognized as an event charged with great emotional significance (Toynbee, 1968). The questions of why some people evidence a greater fear of death than others, and exactly what it is that is feared about death, have aroused curiosity but little research attention. Thus, this research study will be of an information

gathering and exploratory nature, with the following goals:

(1) To examine variables of self-esteem and locus of control, which may impede or promote coping with the anxiety experienced when facing personal death, and (2) To investigate the sources of death anxiety and thus attempt to specify what it is about death that is feared.

In studying the psychologically stressful impact involved in facing the reality of personal death, chronic renal failure patients are an appropriate and novel population. Because of the recency of the development of dialysis treatment and of kidney transplantation, upper limits for the length of survival have yet to be reliably established (The Lancet, 1970). Depending upon medical complications which vary across individuals, the majority are not in any immediate danger of dying. However, they have been forced to face the issue of death in very personal terms, unlike many of the subjects with whom death has been studied in prior investigations. Thus, they ". . . have both the occasion and the opportunity to consider the real possibility of dying and to develop an attitude or philosophy toward this inevitable state of affairs." (Norton, 1969, p. 722).

The following review covers the characteristics of chronic renal failure patients, the population in this study,

and the issues and relevant research pertaining to death anxiety.

### Chronic Renal Failure

Normal kidney function is essential to maintain the physiologically constant internal state of the body. Through the processes of glomerular filtration, tubular reabsorption and secretion, and by varying the volume and concentration of urine produced, the kidneys regulate the removal of metabolic waste products, the volume of body fluids, and internal chemical homeostasis. The body's total volume of blood is filtered through the kidneys approximately twenty-five times per day, allowing the kidney processes to maintain a relatively stable blood composition of vital elements, regardless of the person's variation in dietary and fluid intake (Nosé, 1969; Wills, 1971).

Chronic progressive uremia is a terminal illness for which there is no cure. The inevitable result is permanently diminished or destroyed kidney function, leading either to death or to an alternative form of medical intervention after conservative methods of treatment have been exhausted. Currently, the two alternatives to certain death are chronic dialysis and/or renal transplantation (Schreiner, 1969).

### Chronic dialysis

In historical perspective, dialysis is the first successful attempt at mechanically simulating the functions of a

complex living organ (Bluemle, 1971). It has been possible, in theory, to artificially maintain the life of fatally ill uremic patients since the development of an experimental "artificial kidney" by Abel, Rowntree, and Turner in 1913. However, this method of treatment did not begin to approach practicability until the development of the rotating drum dialyzer in The Netherlands by Kolff in the early 1940s (Kolff, 1965). Early attempts to treat uremia patients by repeated dialyses were generally unsuccessful because of the limited number of blood vessel cannulation sites. However, in 1960 Quinton, Dillard, and Scribner solved the problem of permanent cannulation with the development of an arteriovenous Teflon shunt. Concurrently, the first successful applications of dialysis to the long-term treatment of chronic renal failure were reported at the University of Washington School of Medicine in Seattle (Scribner, et al, 1960), and at the Georgetown University Hospital in Washington, D.C. (Maher, et al, 1960).

To achieve an optimal level of general health, patients must be dialyzed three times a week for a period of eight to ten hours per treatment. The patient's blood supply is connected to the artificial kidney either by means of an arteriovenous shunt or, in the case of an internal fistula, by means of venipuncture. Subsequently, the patient's total blood supply is extracorporeally passed through the dialyzer on one side of a cellophane membrane, with a specially

prepared dialysis bath on the other side. This cellophane membrane closely approximates the kidney's glomerular capillary, with about the same pore radius and the same magnitude of permeability to various dissolvable substances in the blood. The membrane is permeable to molecular diffusion in both directions; noxious elements of abnormally high concentration may be removed from the blood, and substances of abnormally low concentration may be added to the blood. Excess fluid is removed from the blood by ultrafiltration (Merrill, 1952, 1960). Because the artificial kidney machine only approximates normal kidney function and treatment is intermittent, patients must adhere to rigid fluid and dietary restrictions when not on dialysis.

#### Renal transplantation

The first attempted human kidney transplantation in 1936 was followed by a series of other unsuccessful attempts through the 1940s (Schreiner, 1969). In 1956, the first successful transplant, between identical twins, was reported from the Peter Bent Brigham Hospital in Boston (Merrill, et al, 1956). Due to improved surgical techniques, drug advances in the early 1960s to help prevent organ rejection and life-threatening infections, and better selection of donor kidneys, overall transplant survival, regardless of the source of donor organs, has been greatly improved (Rubini & Goldman, 1968; Schreiner, 1969). These advances have resulted in kidney transplantation becoming the most

frequently used and most successful procedure in the field of organ transplantation (Bernstein, 1971).

In terms of the quality of life permitted, transplant patients have considerably greater freedom than do patients on chronic dialysis. This freedom, however, is accompanied by the ever-present threat of rejection, the risk of infection and malignancy as a result of immunosuppressive drugs, and the possibility of the acquisition by the transplanted kidney of the original disease (Schreiner, 1969).

#### Psychological aspects of treatment

Several authorities (Ebra & Toth, 1972; Sand, et al, 1966; Schreiner, 1969; Shea, et al, 1965) have stressed the critical importance of psychological factors. In the absence of severe medical problems, these become the most critical determinants of success or failure of treatment and rehabilitation. Selection of candidates generally has been based on both medical and psychological criteria.

On occasion, psychological problems of an extreme nature associated with dialysis treatment have led to:

1. Termination of treatment (Brown, et al, 1962; Gonzalez, et al, 1963; Ratan & Lewis, 1966)
2. Severe depression (Gombos, et al, 1964; Gonzalez, et al, 1963; Kempf, 1966; Ratan & Lewis, 1966; Shea, et al, 1965)
3. Psychosis (Brown, et al, 1962; Cooper, 1967; Gonzalez, et al, 1963; Kempf, 1966)



4. Delusion of spontaneous recovery which resulted in death (Abram, 1968)
5. Psychotic denial of illness (Abram, 1968, 1969b)
6. Patients' refusal of further treatment (Brandon, et al, 1961, 1962; McKegney & Lange, 1971; Ratan & Lewis, 1966; Schreiner & Maher, 1965)
7. Body image disturbances and "umbilical" fantasies (Shambaugh, et al, 1967; Wright, et al, 1966), fantasies of a sick puppet controlled by strings (Kemp, 1966), and fantasies with an underlying science fiction or Frankenstein theme (Abram, 1969b)

These occurrences of extreme psychological breakdown are not, however, representative of the majority of patients currently being maintained on dialysis. To some extent, they were a function of the problems inherent in the development and rapid expansion of a radically new and stressful treatment. In general, it is held that the chronic stresses of dialysis treatment magnify pre-existing emotional problems. Because these patients must cooperate to such a significant extent in the management of their illness, selection procedures tend to eliminate those individuals whose lack of emotional stability would constitute a barrier to successful treatment management.

Adherence to rigid fluid and dietary restrictions is more crucial for dialysis patients than is the case in many other illnesses because of the immediately resultant danger

to their life and general health. Several accounts have reported what has been referred to as "suicide binges" by patients whose extreme violations of dietary restrictions have resulted in their death (Abram, 1968; Abram, et al, 1971; Glassman & Siegel, 1970; Johnson, et al, 1970; Kaplan-DeNour & Czaczkes, 1972; National Dialysis Committee, 1966). Patients may manifest a preoccupation with food in terms of conversational topics (Shea, et al, 1965), and in reporting dreams similar to those experienced by prisoners of war (Cramond, et al, 1967).

Goldstein and Reznikoff (1971) offered an alternate explanation for "suicidal behavior." They proposed that one of the ways by which dialysis patients cope with the continuous responsibility and anxiety occasioned by following a rigid treatment regimen to maintain their life is by adopting ". . . an external locus of control, with the result that his behavior is no longer perceived as life-sustaining and a threatening area of responsibility is avoided." (Goldstein & Reznikoff, 1971, p. 1205).

Dependency is a problem inherent in the treatment of any chronic illness. "Sometimes diagnosis is the beginning of a cure, but for the patient with a chronic or crippling illness it is an admission that complete cure is unattainable." (Krupp, 1968, p. 109). For the chronically ill patient, ". . . regression and dependency represent a tempting retreat from the overwhelming and unsatisfying task of incomplete rehabilitation." (Krupp, 1968, p. 111).

In this regard, many reports have mentioned the dependency-independency conflicts related to treatment as a major psychological problem in chronic dialysis treatment (Abram, 1968, 1969a, 1974; Kaplan-De-Nour, et al, 1968; Kaplan-De-Nour, 1970; Kaplan-De-Nour & Czaczkes, 1974; Kempf, 1966; Reichsman & Levy, 1974; Shaldon, 1968; Wright, et al, 1966). Being dependent on a machine and treatment staff for the continuation of their lives, yet expected to function independently when not on dialysis, sets up a dichotomous gap that is often difficult to bridge.

Because he is expected to lead a 'normal' existence outside of the dialysis unit, he is thrown into an extreme independency-dependency conflict. He must reject the 'sick role' and the secondary gains of his chronic illness and accept instead the responsibilities of living and the struggle for survival. (Abram, 1969a, p. 87).

This predicament is compounded if the patient does not feel healthy and if post-dialysis lethargy, intercurrent infections, anemia, and other medical problems are troublesome. (Abram, 1974, p. 51).

Kaplan-De-Nour, Shaltiel, and Czaczkes (1968), in referring to the strong dependency themes noted on psychological tests, have hypothesized that a major problem of patients on dialysis ". . . is the dependency, the aggression resulting from it, and the need to block any expression of this aggression." (Kaplan-De-Nour, et al, 1968, p. 531).

It is not uncommon for the anger resulting from the narcissistic blow to a patient's concept of physical "wholeness" from the loss of a body function or organ to be displaced to the medical staff, with no recognition of the

intrinsic anger by the patient (Beard, 1969; Stein, et al, 1969). Further, patients may defend against their consequent lowered self-esteem by projecting their anger (Tuckman, 1970), or may express irrational anger toward the medical staff for their failure to be omnipotent (Cramond, et al, 1967). Rarely, however, are these feelings of hostility verbalized towards the doctors; they are more often displaced on to the hospital, other staff personnel, or the machine (Daly, 1969; Kaplan-De-Nour, 1970). Patients may endow the machine with human feelings, see it as enjoying a feeling of power because of their dependence upon it, and even have a desire to destroy it (Abram, 1969b; Cooper, 1967).

Shaldon (1968) has pointed out that in addition to being economically wise to involve patients as much as possible in their own hospital treatment, it also changes their attitude. They become less dependent on the hospital staff, less anxious, and show less resentment engendered by dependence.

In an attempt to combat the problem of dependency, as well as to provide a less expensive and broader mode of treatment, the first home dialysis treatment was begun in Seattle in 1964 (Eschbach, et al, 1967). In general, this mode of treatment has been quite successful, to some extent because patient selection favored the most highly motivated and cooperative patients free from other physical complications such as cardiovascular and cerebrovascular complications. Generally the incidence of serious complications has been

(Cummings, 1970; Ebra & Toth, 1972; Goldstein, 1971; Goldstein & Reznikoff, 1971; Kaplan-De-Nour, 1969; MacNamara, 1967; Reichsman & Levy, 1974; Sviland, 1971).

Fear of death, loss of income, reductions in family and social status, uncertainty about the future, lack of stamina, changes in body image, and worry about additional medical problems all contribute to one of the most stressful life situations imaginable. In attempting to cope with the stress, studies reveal that the chronic hemodialysis patient utilizes massive amounts of denial to block aspects of his environment that, if perceived, would result in anxiety (Goldstein & Reznikoff, 1971, p. 1205).

The prominence of denial has also been reflected in test scores on the Minnesota Multiphasic Personality Inventory (MMPI) administered to dialysis patients (Goldstein, 1971; Sand, et al, 1966; Short & Wilson, 1969; Sviland, 1971; Wright, et al, 1966). At the same time, the lowered anxiety scale revealed the effectiveness of denial. Under the added stress of physical complications patients used even more denial, resulting in a yet more pronounced MMPI configuration (Short & Wilson, 1969).

In other test administrations, dialysis patients evidenced a high sense of well being on the California Personality Inventory with concurrent low anxiety and depression scores on the Shipman Anxiety and Depression Scale, in marked contrast to their actual clinical appearance (Glassman & Siegel, 1970), and ratings not significantly different from normal in terms of personal happiness (Wright, et al, 1966).

. . . it is striking to note that on a conscious level the dialysis patients claim just about the same degree of happiness as that indicated by the normal group. Less conscious feelings about personal dissatisfaction associated with being a dialysis patient are revealed by the fact that patients see their fellow patients as relatively less happy than they themselves claim to be. In other words, 'kidney patients' as a group are seen as relatively less happy although the individual denies this in reference to himself. (Wright, et al, 1966, p. 615).

The use of denial to some extent can be beneficial in preventing the patient from being overwhelmed by anxiety and in allowing a more gradual transition to the reality and demands of his illness (Hamburg & Adams, 1967). "Denial of the extent and functional impact of both acute and chronic disease is a common psychological defense and, used up to a point, permits a patient to 'live with his illness.'" (Wright, et al, 1966, p. 614).

Further, Sviland (1971) found that ". . . successful adaptation to a home dialysis program and successful rehabilitation were primarily related to the quality of the patient's functioning psychological defense mechanisms." (Sviland, 1971, p. 296). Patients with effective denial were found to be generally more cooperative in terms of dietary and dialysis management requirements and to evidence significantly better work rehabilitation. As long as the utilization of denial does not exceed optimal limits and become so massive as to prevent cooperation with treatment requirements, ". . . the use of denial as an adaptive mechanism not only helps the

patient cope with the stresses of dialysis, but helps the patient to cooperate with the treatment regime and to carry on his previous life style." (Sviland, 1971, p. 297).

However, the mechanism of denial and patients' feelings of isolation in their stressful situation may significantly affect their families, who must also make many adaptations. While the patient is forced to yield more and more responsibilities at home, the family shares the repeated stresses and disappointments, and the continuous uncertainty wears them down (Hendler, et al, 1967; Shambaugh, et al, 1967; Shambaugh & Kanter, 1969). Initial hope becomes weary accommodation, and spouses may begin to question the decision to continue with dialysis (Short & Wilson, 1969).

It is essential to keep in mind that prolongation of life involves not only adding time to the length of life, but it also involves the matter of the quality and worthwhileness of the life that is thus prolonged. Patients with renal failure fear that their lives will be cut short by an untimely death, and as we listen closely, we also hear these same patients express their fears that even if they live, their lives may not be acceptable. This fear of death, coupled with a fear of life, is the dilemma of the patient with chronic renal failure. (Beard, 1969, p. 373).

The majority of chronic renal failure patients have been subjected to the psychological stresses hereinabove mentioned, since most undergo dialysis for varying periods prior to receiving a transplant. For those patients, however, who do receive transplants, the psychological focus, in addition to the continuing fear of rejection, generally concerns feelings of rebirth, concern with body damage, and guilt of the

recipient (Abram, 1972; Cramond, 1967; Crombez & Lefebvre, 1972; Kempf, 1967, 1970; Kempf, et al, 1969; Muslin, 1971).

Reportedly, it is not uncommon for recipients to view their transplant as a symbolic rebirth, perhaps accompanied by some special task to fulfill in their second chance at life. Patients often speak of changed values and attitudes, and a deeper outlook on life; prior religious convictions may be intensified (Abram, 1972; Cramond, 1967; Muslin, 1971). In some cases, patients have made radical changes in their life style, such as leaving the "rat race" of the competitive business world (Abram, 1972).

Concern with body damage may be exhibited not only in regard to the transplanted kidney, but also evidenced in fears expressed about possible damage to sexual organs and functioning (Cramond, 1967; Kempf, 1966, 1970). Patients may experience the feeling of a changed body configuration, as though the new organ were "sticking out." (Muslin, 1971).

Kidneys for transplant are obtained from two sources: either from a living related donor or an unrelated cadaver, deemed genetically suitable in either case. However, psychological tests have tended to show guilt reactions on the part of recipients regardless of the source of their transplant (Abram, 1972; Kempf, et al, 1969; Kempf, 1970). Stories in response to Thematic Apperception Test pictures often reflected themes of robbery, with an accompanying punishment theme for having stolen something belonging to someone else (Kempf, 1967).



In the case of a cadaver donor, the strong wish for a transplant, either as a life-saving measure or to escape from the chronic stress of dialysis, may be accompanied by the uncomfortable realization that one is waiting, or even perhaps wishing for the death of another (Abram, 1972). While this ambivalent conflict may be rationalized at an intellectual level, e.g., 'He [the donor] was going to die anyway: I'm glad I could use his kidney.' (Abram, 1972, p. 1537), underlying guilt may produce feelings of at least partial responsibility for the cadaver donor's death (Kempf, 1970).

Guilt feelings are generally intensified, as well as complicated by emotional relationships, when the donor is a relative.

After the operation the recipients tended to feel guilty about taking advantage of the donors. They routinely stated that they were the ones who had the illness; other people should not have to suffer for it. They often already felt guilty as though they, because of past misdeeds, deserved their illness; the fact that a relative had to give up a kidney for them only added to their guilt. Occasionally guilt caused them to fear that the donor might be killed by the operation and then they would have this added burden of guilt to bear. (Kempf, et al, 1969, p. 1488).

#### Treatment mortality

Group mortality figures for dialysis and transplant patients are comparable (Rubini & Goldman, 1968). The mortality risk, however, is higher in the transplant group, i.e., a transplant patient is a greater medical risk if rejection occurs. Similarly, the greatest period of mortality risk for dialysis patients is within the first year of treatment (The Lancet, 1970).

Psychological Literature  
on Personal Death

Cultural milieu

As several authors (Hinton, 1967; Kastenbaum & Aisenberg, 1972; Wahl, 1965) have pointed out, one of the most salient features of our present culture is man's continually increasing ability to control the physical environment. The publicity attendant upon numerous and startling scientific advances has tended to promote the cultural expectation that man, through science, is equal to the solution of almost any problem. The glaring exception to our scientific prowess, of course, is the phenomenon of death. "Here man, with all his cleverness, is powerless. He may postpone death, he may assuage its physical pains, he may rationalize it away, or deny its very existence, but escape it he cannot." (Wahl, 1965, p. 57). However, the inescapable fact of personal death impels some kind of solution. Inasmuch as it has not come from science, the cultural tendency has been to resort to irrational defenses (Wahl, 1965). These have mainly consisted of various forms of denial. In many ways, our culture is one which promotes insulation from death. The word death itself has been replaced by various euphemisms, greater longevity means that death is no longer a constant menace to the general population from early childhood on, those most susceptible to death (i.e., the sick and the elderly) have been relegated to a semi-invisible state in institutional settings, and an

expensive funeral industry offers protection from the reality of death by corpse beautification to create an illusion of temporary sleep (Kastenbaum & Aisenberg, 1972; Kubler-Ross, 1969; Wahl, 1965). "Perhaps more than any other society the world has known, we have succeeded in relegating death to a small, peripheral corner of our conscious mental life."

(Kastenbaum & Aisenberg, 1972, p. 207).

In addition, Toynbee (1968) has pointed out that the rise of Christianity, with its belief in personal immortality of the human soul, placed man in a central position in his life in this world and in later life after death. However, the religious recession in the Western world, with the concurrent turning of interest to science and technology, has reduced man's position to one of insignificance in space and time. The decline in religious belief, however, has not been replaced by any alternative philosophy, and the questions formerly satisfied by adherence to religious faith have simply tended to be postponed or ignored. "As a result, when death does come, it tends to catch us more than ever unprepared."

(Hinton, 1967, p. 8).

### Theoretical viewpoints

Psychological theories have generally agreed that the affect related to personal death is anxiety. However, there has been divergence over two issues. The first is related to the nature of death anxiety, i.e., whether it is a primary or

a derivative affect. The second issue is concerned with the role of death anxiety within the process of psychological development.

Psychoanalytic theory has regarded death anxiety as a secondary phenomenon, and as peripheral to one's psychological or personality development. Freud believed the ego to be incapable of conceptualizing personal death. Thus, he initially assigned death anxiety a relatively minor role in his theory, as a derivative of Oedipal problems. "Two antecedent conditions were postulated, either of which could serve as a basis for this fear: separation anxiety or castration anxiety." (Alexander & Adlerstein, 1960, p. 66). Later theoretical revision of Freud's instinct theory resulted in his postulating a biological death instinct, "The tendency of organic life to return to the inorganic state whence it came. . . . There is a drive within us which aims always towards death, which is a release of tension." (Thompson, 1950, p. 50). The energy force of this death instinct was assumed to be aggression, directed either against the self (as in suicide), or outward against others. Throughout his writings, however, Freud maintained a conceptual distinction, with no theoretical linking of the death instinct to the phenomenon of death anxiety.

In an intermediary position between psychoanalysis and existentialist theories, both Jung and Erikson viewed resolution of personal death as a significant, though not central, task in psychological development (Jung, 1959;

Maier, 1965). Preparation for death is the major task of the individual's second half of life in Jung's theory, and of the eighth and final stage of Erikson's developmental cycle. Although they used different terminology, the conceptualizations were somewhat similar. Erikson spoke of the merging of individual life cycles into a collective life cycle of mankind, with particular emphasis on the individual's continuity with the future of new developmental cycles or new generations. Jung, on the other hand, saw a gradual reuniting of the individual psyche with the collective psyche, bringing full circle the process of development. Failure to achieve this reunion with the collective unconscious (Jung) or a sense of integrity and continuity (Erikson) leads in either case to the same result, a reaction of panic toward death as the end of an unfulfilled life.

Existential psychologists approach awareness of personal death as the central point of all psychological functioning, with the ensuing primary anxiety being so pervasive as to provide the basis for all fears. Paul Tillich based his theory of anxiety squarely on man's finiteness, his being subject to non-being (Feifel, 1969a). This awareness of non-being is what gives life direction and meaningfulness. According to Heidegger, ". . . the idea of our eventual nothingness is always with us, in each moment of time, providing a background upon which both existence and time can be made meaningful." (Alexander & Adlerstein, 1960, p. 67). Only by

integrating the concept of death into the self is it possible to achieve an authentic and genuine existence and to be a true participant in life; denial leads to anxiety and self-alienation (Feifel, 1969a). The anxiety resulting from the thought of death of the self is to be expected; through direct confrontation, however, one comes to accept one's life and is no longer threatened. "Once we fully and realistically accept it, then it will no longer be something which happens to us (coming upon us, as it were, externally and as a meaningless destruction of our endeavors.)" (Smart, 1968, p. 34). Thus, for the existential psychologists, dealing with and accepting death is the critical task of psychological development.

#### Empirical studies

Early studies with adult subjects focused upon the issue of whether or not anxiety is experienced in connection with personal death. Bromberg and Schilder (1933) and Middleton (1936) reported spontaneous death-thoughts to be a relative rarity, and usually occurring in response to some external stimulus, such as the death of a friend or relative, a narrow escape from an accident, etc. In addition, many subjects reported thinking about death only in an abstract philosophical vein, rather than in personal terms, and found it difficult to think of their own death as compared to the death of other people.

In contrast, Alexander, Colley, and Adlerstein (1957) reported a definite increase in affective response to the stimuli of death-related words. This conflict in findings was explained on a methodological basis. The Bromberg and Schilder and the Middleton studies utilized questionnaires and brief interviews, which likely sampled conscious and public attitudes. Alexander, et al, used latent response time and psychogalvanic response as their dependent measures. Further, they reported that subjects occasionally gave verbal reports of an indifferent attitude in contrast to their physiological reactions. Subsequently, Templer (1971a) measured both verbalized and nonverbalized death anxiety, using his Death Anxiety Scale questionnaire and galvanic skin response, and found a modest though significant correlation between the two measures ( $r=+.30$ ,  $p < .05$ ).

Research studies on the relationship between religion and death anxiety have produced equivocal results. Some report no significant relationship between these two variables (Feifel, 1974; Lester, 1970a; Templer & Dotson, 1970). Others have found less death anxiety in religiously active persons (Templer, 1972), or increased verbalized death fears but more positive imagery regarding personal death by individuals who rated themselves as highly religious (Alexander & Adlerstein, 1960; Feifel & Branscomb, 1973). Feifel (1969a) found two prevailing outlooks on death: a philosophic view of death as the

natural end process of life, and a religious perception as ". . . the dissolution of bodily life and, in reality, the beginning of a new life." (Feifel, 1969a, p. 62). He suggested the possibility that those with a strong fear of death may turn to religion to cope with their fear. The results of these various studies are difficult to interpret and compare because of differences in subject selection, the possible effect of other contaminating variables (e.g., age differences), and different measuring techniques. The most systematic study (Burrows, 1971) reported that an individual's feeling of comfort with his religious beliefs, whatever they may be, is the critical variable related to less negative affect toward personal death.

Numerous studies have investigated such demographic factors as sex, occupation, marital status, and education, as well as type of illness (Diggory & Rothman, 1961; Feifel, et al, 1973; Handal, 1969; Jeffers, et al, 1961; Lester, 1970b, 1971; Middleton, 1936; Rhudick & Dibner, 1961; Templer & Ruff, 1971b). However, the results are equivocal. For example, the question of whether females obtain higher death anxiety scores has been confirmed nearly as often (Berman & Hays, 1973; Lester, 1970b, 1971, 1972; Selvey, 1973; Templer & Ruff, 1971b) as it has failed to find support (Dickstein, 1972; Durlak, 1972; Handal, 1969; Middleton, 1936; Pandey & Templer, 1972; Templer & Dotson, 1970; Templer, 1972; Templer, et al, 1974a).



The better designed studies. . . show that within a single group, demographic variables have little effect on death attitudes. Age will obviously affect attitudes until mental development is complete. Thereafter, it would seem that personality factors and life experiences are the important determinants of the fear of death. (Lester, 1967, p. 31).

Lucas (1972) did a comparative study among three medical populations: hospital dialysis patients and their wives, home dialysis patients and their wives, and Veterans' Administration surgical patients and their wives. Utilizing the Templer Death Anxiety Scale (Templer, 1970), he did not find significant differences between the three groups on either death anxiety or general anxiety measures. Mean death anxiety scores for the home dialysis patients and their wives was less than the other two groups, as predicted, but did not reach significance. Lucas' prediction that patients' death anxiety and general anxiety scores would be positively and significantly correlated with their wives' scores was supported.

Beard (1969) studied patients being evaluated for dialysis and/or transplantation, all of whom described a fear of imminent death upon learning of their diagnosis of chronic renal failure. Their next reaction was denial, through simple disbelief, refusing to take it seriously, or trying to ignore the diagnosis. After the period of denial, the patients described feelings of discouragement, depression, and hopelessness.

It was during such times that these patients also indicated awareness that they felt alone in their plight and that it was impossible for them to communicate

fully, even to significant people in their life, the severity of their feelings of fright, of estrangement, and of loneliness. (Beard, 1969, pp. 379-380).

The question of exactly what it is that is feared about personal death has not been directly investigated; however, there are suggestions from numerous studies which are related to this topic. For the adult, emotional meanings of death may be based to some extent on fears acquired in childhood. Some of the work done with children suggests that death is initially conceptualized as separation and loneliness or as the result of aggression (Anthony, 1940; Nagy, 1948; Natterson & Knudson, 1965). Between the ages of five and nine years, children personify death, imagining it as a separate person or as a dead person (Nagy, 1948). Death fears in children have also been related to fear of pain or mutilation and fear of the unknown (Caprio, 1950; Moellenhoff, 1939; Natterson & Knudson, 1965).

Adults' earliest memories of death are often related to rituals and death accessories, e.g., funeral and burial scenes, or a corpse (Kastenbaum & Sherwood). For the adult, however, death may possess other meanings in addition to those surviving from childhood. Collett and Lester (1969) found a significantly greater fear of death than of dying, and greater anxiety in relation to the self than when another was the referent.

For some, death may connote violence and mutilation (Lowry, 1966), escape from an unbearable situation (Bromberg & Schilder, 1933), or a final illicit sexual surrender with accompanying punishment (Greenberger, 1965). Death has also been viewed as the elimination of opportunities to pursue goals important to one's self-esteem (Diggory & Rothman, 1961), as failure and helplessness (Lowry, 1966), a fear of personal extinction (Kastenbaum & Aisenberg, 1972), or a fear of the unknown and loneliness (Pattison, 1967). While religious individuals may emphasize what a future life on a new plane of existence may hold, the nonreligious person may fear death through emphasizing what is left behind (Alexander & Adlerstein, 1959; Feifel, 1959). Sometimes the focus is upon the losses inherent in death, including loss of pleasure (Feifel, 1959), loss of loved ones and friends (Lowry, 1966; Pattison, 1967), or loss of identity and self control or mastery (Feifel, et al, 1967; Pattison, 1967; Rosenthal, 1957). Some individuals have been noted to view death as an appropriate closure to a fulfilled life and to approach it with calm composure (Weisman & Hackett, 1965).

#### Theoretical Rationale for the Present Study

This investigation provided a novel opportunity to study death anxiety in two groups of patients with the same life-threatening illness of chronic renal failure, but with each group undergoing a radically different mode of life-sustaining treatment, i.e., kidney transplant or chronic

dialysis. The variables of self-esteem and locus of control were examined as possible factors which may promote or impede patients' coping with the impact of personal death. Mode of treatment was contrasted for all variables studied to assess which ones differentiated between dialysis and transplant patients. In addition, an exploratory attempt was made to identify specific sources of death anxiety.

The idea of personal death may be the most difficult and stressful challenge with which one must come to terms. Resolution of the psychological impact of personal death is a task ultimately faced by everyone, the point at which this occurs in one's life cycle varying according to individual circumstances. The concept of death is, however, no more than a concept, for in reality one can never know what it feels like to be dead.

Death as a concept may be invested with a variety of personalized meanings, influenced by personality and situational variables, and one's prior experiences. For one person the focal point of anxiety may be upon the losses accompanying death, for another it may center around facing the unknown, the possibility of pain accompanying death, and so on. Although the concept of death is undoubtedly multidimensional in nature, for any given individual the various consequences or meanings of death may not be equivalent in terms of the anxiety aroused or the difficulty required for successful resolution. The extent to which this differential anxiety

related to death meanings or consequences varies from one individual to another, or reflects some commonalities related to specific personality variables, is unknown.

In considering the reaction of individuals to the psychological impact of personal death, there is less variation than is the case in considering the meanings with which personal death may be endowed. Basically, one may deny or refuse to consider death, be overwhelmed with anxiety and depressive affect at the possibility of its occurrence, or approach death with equanimity. Admittedly, these are trichotomous and possibly categorizations which, in reality, may not be so readily differentiated. Based on their experience, Weisman and Hackett are of the opinion that, "For the majority of dying patients, it is likely that there is neither complete acceptance nor total repudiation of the imminence of death." (Weisman & Hackett, 1965, p. 324).

Based upon extensive work with dying patients, Kubler-Ross has differentiated their reactions into five stages, of which denial is the first. Almost all patients used at least partial denial, not only when initially learning of their terminal illness but later on from time to time. Denial, ". . . the conscious or unconscious repudiation of all or a portion of the total available meaning of an illness in order to allay anxiety and to minimize emotional stress," (Hackett & Cassem, 1970) provides a buffer against overwhelming shock and allows the patient time to mobilize other, more sophisticated

coping resources. Very rarely does a patient maintain denial to the time of death; for most patients it is a temporary defense and yields to partial acceptance. However, the recurrence of some degree of denial is, according to Kubler-Ross, a healthy way to deal with a painful situation, especially for patients living with the possibility of impending death for a long period of time. "These patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life."

(Kubler-Ross, 1969, p. 39). Blacher has also pointed out this double adaptation these patients face: "1) to illness and impending death, and 2) to living as productive a life as possible in the time left to them." (Blacher, 1970, p. 196).

In regard to death, Kubler-Ross stated that "Each one of us has the need to avoid this issue, yet each one of us has to face it sooner or later." (Kubler-Ross, 1969, p. 17). However, very little is known regarding the critical variables related to an individual's reaction to considering personal death, when one ". . . has to face it sooner or later." Kubler-Ross observed that terminal patients who had previously relied on denial as a major defense tended to do so to a greater extent than other patients, and that "Patients who faced past stressful situations with open confrontation will do similarly in the present situation." (Kubler-Ross, 1969, p. 32).

Coping with the impact of personal death is a uniquely stressful situation. A situation may be considered to involve stress when substantial imbalance exists between the task demand and the individual's response capability (McGrath, 1970). However, personal death poses demands unlike any an individual has had to cope with previously. "One is faced with a new experience with no prior experience to fall back on for although one lives amidst death, that is far different from one's own death." (Pattison, 1967, p. 35). The concept of cognitive appraisal of stress, introduced by Lazarus (1966), wherein stress is conceptualized as imbalance between perceived demand and perceived response capability, introduces an additional aspect in investigating why 'One man's stress is another man's challenge.' (McGrath, 1970, p. 49). That there are individual differences in coping with stress is not at issue; the problem lies in how to conceptualize these differences.

### Self-esteem

Fitts (1969, 1972) has characterized a person's self-concept or self-esteem as the best representation of the kind of personality integration or strength that promotes effective functioning in a stressful situation, stating that "The more optimal the self concept the more effectively the individual will function." (Fitts, 1972, p. 3). Further, he has stressed that the most significant coping resource in any situation (e.g., rehabilitation, stress, radical change, personal

adjustment) is the individual himself (Fitts, 1969, 1972). Thus, the theory one constructs, often without awareness, about himself as a functioning individual is not only the frame of reference through which the individual interacts with his world and a powerful influence in human behavior, but a crucial variable in regard to how a person will adapt to a new and stressful situation (Fitts, 1969). In somewhat similar terms, Lazarus (1966) has pointed out that certain personality traits such as high self-esteem are assumed to reduce vulnerability to threat and to facilitate adaptive coping. If an individual has an uncertain and unclear opinion about himself, this deprives him of his potentially most valuable frame of reference and may be highly anxiety arousing.

One's self-esteem, or the theory an individual develops about himself as a functioning human being, may be conceptualized as part of a broader theory that people construct regarding their total range of significant experience (Epstein, 1973). Thus, in keeping with the general human preference for order over chaos, people develop theories about the nature of the world, the nature of the self, and their interaction. Self theory, then, not only provides a framework for individuals to organize their observations and experience in a meaningful way, but one which facilitates the maintenance of self-esteem and serves to organize one's experience in such a way that it can be coped with effectively (Epstein, 1973).



Contained within one's self theory are postulates, or an individual's assessment of his standing on certain variables. Within this hierarchical arrangement under the postulate evaluating one's overall self-esteem are second-order postulates regarding one's general competence, physical attractiveness, and so on. Examples of lower order postulates under competence would be one's assessment of general mental and physical ability, and the lowest order would consist of assessments of one's specific abilities. Individuals can achieve the same overall level of self-esteem by a high appraisal of the inner or psychological self and a low appraisal of the body self, or vice versa (Epstein, 1973).

These attributes on which self-esteem is built are endangered when one suffers from a serious illness.

One may also lose some aspect of the 'self.' By self, we refer to the over-all mental representation or image each of us has of his body and of his person. This self-representation includes ideas and feelings about the self, its worth, attractiveness, lovability, special qualities and capacities. Loss of health, for example, is usually experienced as a change in some aspect of the self. It may be felt as loss of a positive feeling state replaced with vague malaise, weakness, pain, easy fatigability, or other symptoms. There may be partial or total loss of a body function, . . . Visual acuity, hearing, memory, intellectual power, motor coordination, sensation, and strength may be lost to varying degrees. . . . Reduced bodily drives such as appetite and sexual interest are also experienced as loss. Loss of positive self-attitudes such as attractiveness, pride, esteem, independence, or control, as well as important ideals, can also have marked psychological and physiological consequences. Loss of self-definitions--social roles such as occupation, profession, position in the family, and the status associated with each--frequently has dramatic impact on a person's life. (Peretz, 1970, p. 5).

Wright, Sand, and Livingston (1966) are of the opinion that there is, perhaps, no illness as stressful to patients as chronic renal failure because of the major readjustment in living and thinking and the often recurring medical crises. Patients may experience such psychological stresses as:

1. Loss of urinary function or changed physical appearance after transplantation, and aroused feelings about one's general functional capacity as a result of recurring states of ill health as a consequence of dialysis treatment and/or medical complications.

2. Restrictions in social activities, particularly for dialysis patients, due to decreased energy, recurring ill health, dietary and fluid restrictions, and limitations upon free time. This investigator noted that because of their feelings about their illness, single patients may avoid serious relationships with the opposite sex, or pre-existing marriages may be dissolved. Physical recreation and vacation travel are generally not possible for patients on dialysis.

3. Loss of job and/or educational and occupational advancement. Patients may have to change jobs in order to meet treatment requirements, or may lose jobs if medical complications demand too much time away from work. With a diagnosis of chronic renal failure, employers are often unwilling to risk the necessary investment in hiring either a dialysis or a transplant patient. Job promotions may fail to materialize; a business built up over many years may be lost.

Depending on their physical state and medical complications, patients may be restricted to part-time employment or may be too ill to work at all. Spouses may have to seek employment and this possibility, together with the material deprivations incurred by a patient's family, are a source of guilt and stress.

Just as there are wide variations across individuals in terms of their physical reaction to treatment, whether it be failing to reject a transplanted kidney or adjusting to dialysis without complications, there are similar individual differences in psychological reactions. The foregoing sources of stress may serve to decrease one patient's previously low level of self-esteem, while another patient may be able to cope more successfully with stress because of high self-esteem. Cummings (1970) has stated that:

In our unit, we have come to regard self-concept as one of the most important areas of psychologic reaction. One's self-concept . . . is a relatively stable, powerful core of self-regulating attitudes which serves as a steerer or director of much of a person's reaction to the world about him. It is truly dynamic in that it is shaped and affected by things that happen to us . . . and at the same time it shapes and affects our responses to those surroundings. Among the factors that can alter this personality 'keel' are significant changes in reality circumstances around us and shifts in how we are viewed by people who are important to us. These two types of changes are very much a part of the effects of kidney disease and dialysis; thus these medical factors can come to exert an adverse effect on the self-concept and vice versa. (Cummings, 1970, pp. 73-74).

Based on four years' experience of counseling with renal failure patients, Landsman (1975) has characterized them as "marginal

men." "They tend, after the initial impact of illness dissipates, to find themselves adrift somewhere between the world of the sick and the world of the well . . ." (Landsman, 1975, p. 268). Further, ". . . it must be acknowledged that medical complications of the patient can only be aggravated by an inability to live comfortably with an appropriate and viable self-image." (Landsman, 1975, p. 269).

It is generally assumed that one's self-esteem is to some extent responsive to the evaluative feedback a person receives from his own behavior and from the reflected appraisals of other people. Therefore, in terms of the two modes of treatment, chronic dialysis would appear to present more external threats to a person's self-esteem because of the psychological stresses mentioned by Wright, Sand, and Livingston (1966) being augmented, and additionally because of the limited opportunities for self-esteem enhancement occasioned by the greater restrictions imposed by dialysis treatment. As Lipp, et al (1968) have pointed out, there is the likelihood of a disability being perceived as a threat to self-esteem if it interferes with a person's ability to meet social standards, whether those of society at large or in terms of the individual's own social goals. Numerous theorists, such as Erikson, have stressed the importance of work, family, and social roles in the development and maintenance of a sense of adult adequacy and competence in our society.

To counteract lowered self-esteem resulting from perceived threat, there is the possibility of defensive self-concept distortion on the part of dialysis patients. Such behavior was noted by Malmquist, et al (1969) in twenty-one dialysis patients given the Tennessee Self Concept Scale within six weeks of commencing treatment. The most salient results were the patients' uniformly low concept of physical self, together with the above average scores on the Moral-Ethical Self, Personal Self, and Family Self Scales, resulting in a slightly above average Total Positive Score. The tentative interpretation of these patients' score pattern was that, ". . . having lost a major outlet for the expression of and maintenance of self-esteem through their loss of physical functioning, and being unable to deny this loss realistically, they have turned to over-affirmation of themselves in other areas in order to maintain some self esteem."

(Malmquist, et al, 1969, p. 2). Inasmuch as these patients were tested quite early in treatment, the effect of extended time in treatment on such defensive distortions is unknown.

The possible relationship between self-esteem and death anxiety has been alluded to in the literature but not directly investigated. The notion raised by Weisman and Hackett (1965) that death is the appropriate closure to a completed life span in which one's major goals have been achieved suggests that self-acceptance and a sense of accomplishment may be related to successful resolution of death fears.

Working with boys from five through sixteen years of age, Alexander and Adlerstein (1965) noted a decrease in death anxiety between the ages of nine and twelve and suggested that this might be due to the developmental quiescence and relatively fewer demands upon self-esteem associated with this period. Motor skills are well developed, school demands and separation from home have been mastered, social roles and peer relationships are established, and there are few demands calling for the development of new skills. Thus, they inferred that this is a period when self-esteem is relatively high, as well as confidence in one's abilities, and the self image is relatively stable (vis-a-vis the stressful period of adolescence). Further, there are the suggestions by Lowry (1966) and Diggory and Rothman (1961) that death anxiety is an extension of general attitudes regarding helplessness and impotence and stems from a threat to the goals valued by a person as most important to self-esteem.

One study approximating an investigation of a relationship between self-esteem and death anxiety is that by Farley (1970), who asserted considerable theoretical overlap between the notion of self-esteem and White's theory of competence (White, 1959). According to White, the subjective aspect, the sense of competence, refers to an individual's assessment of or confidence in his abilities to effectively deal with various aspects of his environment.

Farley conceptualized death as a challenge to be faced and mastered, the demands of which may be perceived as a threat to one's sense of competence. Inasmuch as any environmental demands which are perceived by an individual as exceeding his abilities or beyond his sense of competence arouse anxiety, Farley predicted that individuals with a high sense of competence should feel more able to deal with the challenge of death, as they have mastered other challenges in their lives. Working with a population of young college males, Farley confirmed the hypothesis that high death anxiety subjects had a lower sense of competence. This finding was replicated by Nogas, Schweitzer, and Grument (1974) in a population of young college females. In addition, both Farley and Nogas, et al, supported Handal's (1969) and Dickstein's (1972) findings that while there is a small but positive degree of association between death anxiety and general anxiety, death anxiety is ". . . composed of special and distinct feelings, specific to the threat of death alone." (Farley, 1970, p. 29).

Other research has shown a relationship between high self-esteem and perseverance in a university program among blind college students (Smith, 1969), success in esophageal speech therapy among laryngectomy patients (DiBartolo, 1969), and significantly greater follow through and subsequent contacts by rehabilitation applicants after the first interview at a vocational rehabilitation agency (MacGuffie, et al, 1969). Schwab, Clemmons, and Marder (1966), in studying hospitalized

medical patients, found that those with low self-esteem significantly more often believed their illnesses to have had adverse effects on their lives and accomplishments, expected poorer prognoses (regardless of actual severity of illness and prognosis as rated by their doctors), and were more anxious about their illnesses and the competence of the medical staff. Malmquist (1973a, 1973b) and Hagburg and Malmquist (1974) reported a positive attitude toward treatment and rehabilitation and "the patient's way of dealing with traumatic situations and their attitude towards changes in their lives . . ." (Malmquist 1973b, p. 343) to be a significant difference between rehabilitated and non-rehabilitated dialysis patients. Although not investigating self-esteem per se, they suggested that these characteristics may be related to ego strength and high self-esteem.

The other variable of interest in this study in relation to death anxiety and mode of treatment was Rotter's locus of control construct, which has been shown to have a tangential relationship to self-esteem (i.e., a modest association between high self-esteem and internal locus of control orientation).

#### Social learning theory and locus of control

According to social learning theory (Rotter, Chance, & Phares, 1972), the basic unit for the study of personality is the interaction of the individual and his meaningful environment. Thus, situational variables are particularly important in making accurate predictions about human behavior. Each



situation contains cues which arouse certain reinforcement expectancies within an individual. Inasmuch as social learning theory focuses on learned behavior, the meanings given to these situational cues are based on a person's prior learning history.

Social learning theory also emphasizes the directional aspect of behavior. In other words, an individual's behavior is basically goal directed, as well as representing the interaction of the person with his meaningful environment. Considering in addition the concept of expectancy, "the potential occurrence of a behavior is considered to be not only a function of the nature and importance of the goal or reinforcement that will result from these behaviors but also of the person's anticipation or expectancy that these goals will occur." (Rotter, 1967, p. 490). These expectancies are determined by previous experience, and defined as a subjectively determined assessment by an individual, of which he may or may not be consciously aware, ". . . that a particular reinforcement will occur as a function of a specific behavior on his part in a specific situation." (Rotter, 1967, p. 490). In social learning theory, "The value of a reinforcement is defined as a degree of preference for that event to occur relative to other possible events in any given situation, class of situations, or time segment of the individual's life." (Rotter, 1967, p. 490). Thus, taking into account the four principal concepts of social learning theory, i.e., behavior potential,

expectancy, reinforcement value, and the psychological situation, Rotter presents the following formula for predicting human social behavior:

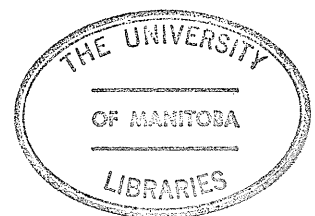
$$BP_{(x-n), s} R_{(l-n), (a-n)} = f \left[ E_{(x-n), s} R_{(l-n), (a-n)} \text{ \& RV}_{(a-n), s} \right]_{(l-n)}$$

Simply expressed, this formula states that the behavior potential for a set of related behaviors x to n to occur in specified situations l to n in relation to a set of potential reinforcements a to n, is a function of the expectancies that these behaviors will lead to these reinforcements in these situations (Rotter, 1967). Thus, the potential for any behavior to occur in a particular situation is a function of the individual's expectancy that that particular behavior will result in an available reinforcement and the value that available reinforcement holds for the individual.

Although reinforcement has widespread recognition as an important variable in learning and behavior, social learning theory focuses on the individual's perception of and reaction to reinforcement. The critical determinant in this regard is the degree to which reinforcement is perceived to be contingent upon the individual's behavior, as opposed to occurring independently of his actions. Rotter (1966) suggests that as an individual develops and encounters varied experiences, he tends to evaluate his experiences, often without awareness, in terms of whether reinforcements are contingent upon his own behavior. He differentiates between those events which are perceived to occur as a result of his own actions

and those which take place independently of his own behavior. When an individual recognizes a connection between his actions and the occurrence of some external event, expectancies are created within the individual for the consequences of his behavior which are reinforced each time the event occurs. Expectancies rise as a result of reinforcements which are perceived to follow directly from his own behavior, or decrease if he is unable to perceive any relationship between his behavior and an external event. Expectancies generalize across situations, so that an individual's reinforcement history affects the extent to which he perceives reinforcement as being contingent upon his own behavior. Locus of control, one of the constructs in social learning theory, was a variable of interest in this study.

Rotter's locus of control construct (Rotter, 1966; Rotter, Chance, & Phares, 1972) specifies two opposite generalized expectancies along a continuum of one's perception of his role as a causal agent in obtaining reinforcements. Rotter's assertion is that the individuals who tend to view their behavior as producing changes in the environment have adopted the personality characteristic of internal control. They believe that their behavior influences their lives and their future, and take on the responsibility for their successes and failures. At the other end of the continuum are those persons who tend to view their behavior as having no effect upon the environment, and have adopted the personality



characteristic of external control. Such individuals perceive reinforcements as occurring independently of their acts. They believe that their behavior has no effect upon their lives and no influence upon what happens to them. Regardless of how they behave, they perceive a world operating upon them and they feel helpless to change their situation.

Levenson (1972) has modified Rotter's unidimensional conceptualization of locus of control and has proposed multidimensional concepts of internal control, chance control, or control by powerful others. Her new I, P, and C scales were developed to correct deficiencies previously noted in the literature pertaining to Rotter's I-E scale. These were primarily criticisms that within the internal control construct a distinction was required between personal control and control ideology regarding people in general, or between one's generalized expectancy of control of reinforcement and one's political and social beliefs (Abramowitz, 1973; Berzins & Ross, 1973; Collins, 1974; Crandall, et al, 1965; Gurin, et al, 1969; Joe, 1972; Mirels, 1970; Reid & Ware, 1973, 1974; Thomas, 1970). The new I, P, and C scales are phrased so as to assess the degree to which an individual feels he has control over what happens to him, not what he believes applicable to "people in general." Further, no reference is made to the modifiability of specific issues (e.g., racial discrimination), because system modifiability, as well as personal versus ideological control, were reported to be contaminating factors in Rotter's

I-E scale (Abramowitz, 1973; Gurin, et al, 1969; Joe, 1972; Reid & Ware, 1973, 1974). Within the external control construct, a separation was deemed necessary between control by other people versus control by impersonal forces such as chance or luck (Crandall, et al, 1965; Gurin, et al, 1969; Hersch & Scheibe, 1967). Thus, Rotter's unidimensional I-E scale was separated by Levenson into a tripartite differentiation on the basis of differential cognition and behavior between those who believe the world to be unordered (operating according to chance), or to be ordered but under the control of powerful others.

Rotter (1967) also discusses the variable of freedom of movement as being equated with the concept of expectancy. The concept of freedom of movement allows one to make predictions regarding the behavior of an individual with low freedom of movement and high need value for a particular class of reinforcements.

When an individual has low freedom of movement and places high value on some class of reinforcements, he is likely to learn behaviors to avoid the failure or punishments that he anticipates in this area and may make attempts to achieve these goals on an unreal level. That is, the person anticipating punishment or failure may avoid situations physically or by repression, or he may attempt to reach the goals through rationalization, fantasy, or symbolic means. (Rotter, 1967, p. 491).

According to Rotter, low freedom of movement and high need value is the basis for a variety of pathological behaviors, defenses, conflicts, and lack of feelings of satisfaction

and/or constructive activities. Low freedom of movement need not only result from an individual's lack of knowledge or adequate behaviors by which he may attain his valued goals. It also may be a function of the reality of a situation in which an individual realistically has very little control or freedom of movement in achieving his goals. An individual's freedom of movement may be increased either by learning and being reinforced for new, more successful behaviors, or by changing the values of his goals.

As previously noted, the quality of life possible for patients with functioning transplants is radically different from the quality of life possible for those patients maintained on chronic dialysis. Receiving a transplant is reinforcing not only because it eliminates the need to spend many hours each week in a passive, boring treatment, but also because it leads to additional reinforcements of greater independence, removal of dietary and fluid restrictions, freedom to travel or to change one's residence, freedom to spend more time in social interaction and with one's family--in summary, the opportunity to lead a more "normal" and enjoyable life without excessive restrictions. Thus, the reinforcement value placed on receiving a kidney transplant would depend significantly upon the value of the numerous consequent reinforcements. Understandably, most patients on dialysis strongly hope for a transplant.

In reality, however, whether or not a patient receives and fails to reject a transplanted kidney is beyond his control.

The availability of a kidney for transplantation depends upon finding a suitably matched donor organ from either a living genetically related donor or from a cadaver donor, usually the latter. In the event a donor organ should be an adequate match for more than one dialysis patient, the medical staff would have to select the ultimate recipient. Further, subsequent to a transplant operation, the recipient is dependent upon the medical staff for his care and treatment and a successful outcome. Thus, the majority of dialysis patients are in a situation of high need value and low freedom of movement.

Phares (1971) reasons that,

To have a high expectancy that one will not attain an important reinforcement is analogous to being anxious. As a method of reducing this discomfort, one can either increase his expectancies or decrease the value of the reinforcement involved. The first is less probable inasmuch as one's stated expectancies can be checked against past occurrences and distortion can be readily observed. The value that one attaches to reinforcements is a more personal, idiosyncratic matter, however. (Phares, 1971, pp. 386-387).

One way dialysis patients may cope with this situation of high need value and low freedom of movement is to utilize denial or rationalization in an attempt to change the value of their goal (i.e., to make dialysis seem a less aversive treatment than it is in reality and thus decrease the value placed upon receiving a transplant). Support for this coping mechanism was presented by Wright, Sand, and Livingston (1966), who found that dialysis patients reported ratings of personal happiness not significantly different from healthy individuals,

yet rated other dialysis patients as being less happy than themselves. "In other words, 'kidney patients' as a group are seen as relatively less happy although the individual denies this in reference to himself." (Wright, et al, 1966, p. 615).

According to Watson and Baumal (1967), a state of incongruence between the actual environmental locus of control and the individual's locus of control preference is anxiety arousing. An external locus of control orientation may be developed either from one's reinforcement history, or as a rationalization, a means of anxiety reduction by attributing failure to sources external to oneself (Phares, 1971). Coping with the anxiety aroused by virtue of being in a situation incongruent with one's beliefs by adopting a defensive externality orientation is most likely to occur in situations ". . . where the actions of others may have great relevance for the success of his own efforts." (Hersch & Scheibe, 1967, p. 613). Goldstein (1971) found significantly greater externality in male dialysis patients as contrasted with male patients hospitalized for temporary minor medical problems. Wilson, et al, (1974) found that in spite of group counseling designed to increase patients' feelings of control, home dialysis patients' I-E scores became more external over the period of a year in dialysis treatment. Since these studies used Rotter's I-E scale, it was not possible to differentiate this externality into either a chance (congruent externality) or



powerful others (defensive externality) orientation. In a situation where others' actions (e.g., the medical staff, potential related donors, or the accidental death of a stranger and his family's consent are the critical variables which makes a transplant possible) are extremely relevant to the patient's goal attainment, the specific causal forces to which a patient may attribute responsibility for reinforcement may well be powerful others. Thus, the powerful others orientation may be an important conceptual distinction in terms of the reality of dialysis patients' situation in this study.

The defensive external is said to use his external orientation solely as a defense against failure, or other such negative events. When a threat such as failure at a task is not present, the external orientation is discarded. The true external, on the other hand, tends to maintain his external orientation at all times, whether the events that occur to him are positive or negative. (Gilmore & Minton, 1974, p. 170).

One is free of responsibility for behavioral outcomes if reinforcement control is attributed to external forces. Thus, ". . . defensive externals are persons who ascribe reinforcement responsibility to powerful others primarily as a defense against possible failure." (Prociuk & Breen, 1975, p. 12). Dialysis patients with an internal locus of control orientation, to reduce the anxiety aroused in an incongruent situation, may adopt the belief that powerful others are responsible for their reinforcements (thus maintaining their general belief in an ordered world), while tending to behave somewhat like internals in regarding reinforcement as obtained by one's

own efforts. This apparent contradiction is resolved if one recalls that according to Levenson (1972), an external belief in powerful others still implies the existence of a potential for personal control (Prociuk & Breen, 1975). For example, in discussing their hope for a transplant and the potential danger of rejection, patients may state that if they do receive a transplant, it is up to them (e.g., by "psyching themselves up," maintaining the right attitude) to make it work (i.e., not be rejected).

In contrasting the two modes of treatment, then, dialysis patients might be expected to more often express a powerful others orientation than would transplant patients. On the other hand, transplant patients might be expected to exhibit either an internal or a chance orientation, depending upon their learning history. Internals would no longer be in an incongruent situation and would no longer need the ego-defensive orientation of defensive externality, whereas individuals with a chance orientation would have this expectancy reinforced by the salient chance factors involved in receiving and not rejecting a transplant.

In terms of a possible relationship between locus of control and death anxiety, several studies were noted that are directly related to this issue. In a population of young college males, Tolor and Reznikoff (1967) found significant relationships between higher death anxiety, external locus of

control orientation, and high sensitization scores on the Repression-Sensitization Scale. Berman (1973), Berman and Hays (1973), Dickstein (1972), and Selvey (1973) failed to find any relationship between death anxiety and I-E scores in college populations.

Other research studies on the locus of control personality variable have demonstrated relationships between internality and active attempts at seeking information relevant to a specific task (Davis & Phares, 1967), more effective utilization of acquired information on a problem-solving task (Phares, 1968), greater retention of information immediately relevant to important personal goals in prison inmates (Seeman, 1963), and greater factual knowledge about their illness and its effects in hospitalized tuberculosis patients (Seeman & Evans, 1962). Additional studies have shown internals to be more active in the civil rights movement and thus actively involved in attempting to bring about environmental changes (Gore & Rotter, 1963; Strickland, 1965), and more inclined to affect the consequences of their own behavior by quitting smoking (James, et al, 1965; Straits & Sechrest, 1963), or engaging in some form of birth control (MacDonald, 1970). Finally, Phares, Ritchie, and Davis (1968) demonstrated that when presented with personally threatening material (i.e., adverse personality test results designed to challenge the person's view of himself), internals showed significantly greater inclinations to directly confront the problem and actively engage in behavior likely to improve their status.

### Possible mediating variables

The research literature reveals a profusion of studies correlating locus of control orientation with numerous personality characteristics. Internals have been reported to make greater use of denial or repression (Efran, 1963; Tolor & Reznikoff, 1967; Tudor, 1970), to more often report feelings of independence, power, assertiveness, efficiency, and achievement (Hersch & Scheibe, 1967), and to experience less anxiety and be more constructive in overcoming frustration (Butterfield, 1964; Liberty, et al, 1966; Ray & Katahn, 1968). Externals have been reported to score higher on measures of anxiety (Butterfield, 1964; Feather, 1967; Hountras & Scharf, 1970; Naditch, et al, 1975; Platt & Eisenman, 1968; Ray & Katahn, 1968; Strassberg, 1973; Tolor & Reznikoff, 1967; Watson, 1967), and to report more feelings of powerlessness, dependency, and lack of achievement (Hersch & Scheibe, 1967), to evidence a greater concern with fear of failure than with achievement (Butterfield, 1964; Liberty, et al, 1966), and to more often report feelings of depression (Abramowitz, 1969; Calhoun, et al, 1974; Dinardo, 1972; Naditch, et al, 1975).

The foregoing survey is by no means exhaustive, but serves only to illustrate awareness of the possibility of some confounding of these variables with the variables of interest in this study. For example, the greater reliance upon the mechanism of denial by internals may be a mediating variable if lower death anxiety is found to be associated with

internality. On the other hand, since Handal (1969) and Farley (1970) reported a small association between death anxiety and general anxiety (i.e., Farley found that general anxiety level accounted for approximately twelve percent of the variance in death anxiety scores), the higher level of general anxiety reported by externals may be a confounding variable in their death anxiety scores.

### Summary and Hypotheses

The research on self-esteem and locus of control shows a relationship between high self-esteem and an internal orientation and the following characteristics: confidence in one's abilities to cope with stressful tasks or situations, directly confronting a threatening problem and persevering when difficulties are encountered, and a belief in one's ability to influence his life and destiny. As might be expected, several studies have found a modest association between high self-esteem and an internal locus of control orientation (Bandt, 1967; Beebe, 1971; Dinardo, 1972; Fish & Karabenick, 1971; Fitch, 1970; Lamb, 1968; Ryckman & Sherman, 1973).

Although death does present a unique challenge, such individuals could draw upon coping resources which have led to successful coping with prior life challenges. Attempting to cope with the impact of personal death as a global challenge may present an overwhelming task. However, attaining a feeling

of having some degree of control over part aspects of the total situation would be expected to decrease one's feelings of helplessness and to reduce threat. Thus, internals would be more likely to demonstrate attempts at some kind of anticipatory planning for the possibility of their death, and thereby achieve some degree of control. When faced with personal death, one is likely to feel the need to review one's life and to make some kind of sense out of the life process one has been involved in prior to its termination. Those with high self-esteem would be less likely to perceive their life as a failure and thus to be overwhelmed by death as the ultimate failure with accompanying feelings of worthlessness. The degree to which one achieves the feeling of having accomplished one's reasonable goals in life would be influenced not only by where in the life cycle death occurs, but also by one's attitude or feelings about himself as a unique individual.

#### Major hypotheses.

The following predictions were tested:

1. High self-esteem patients will report lower death anxiety than will low self-esteem patients.
2. Patients with an internal locus of control orientation will report lower death anxiety than will patients with a chance or powerful others locus of control orientation.
3. Patients with an internal locus of control orientation will be more likely to have made anticipatory preparations for the possible occurrence of their death than will patients with a chance locus of control orientation.

Secondary hypotheses regarding treatment group differences

Relationships between the dependent variables and mode of treatment were also of interest in this study. Unfortunately, no measures of the dependent variables were available for these patients prior to their commencing either dialysis or transplantation. However, as a result of chance factors, one could expect the dependent variables of high and low self-esteem, high and low death anxiety, and the locus of control orientations of internal, powerful others, and chance to be evenly distributed between dialysis and transplant patients prior to treatment. Because the two modes of treatment are so radically different, and in line with the emphasis of social learning theory (Rotter, Chance, & Phares, 1972) that the basic unit for the study of personality is the interaction of the individual and his meaningful environment, the data collected was examined with the expectation of finding:

1. A positive association between high self-esteem and treatment by renal transplantation.
2. A positive association between an internal locus of control orientation and treatment by renal transplantation.
3. A positive association between a powerful others locus of control orientation and dialysis treatment.
4. A positive association between high death anxiety and dialysis treatment.

## CHAPTER II

### METHOD

#### Selection of Participants

Patients were invited to participate in the study only after obtaining the permission of the Director of the renal unit. Nine patients who were in treatment at the inception of the study were not considered for participation; four due to their inability to read English and five because of their young age. To maintain ethical standards and to avoid deception as to the nature of the study, initial correspondence described the project as a study of patients' attitudes related to illness, treatment, and the consequences of a serious illness. It was also stressed that participation was on a voluntary basis, the questionnaires could be answered anonymously, and all information conveyed to the researcher would be treated as confidential. The patients were also aware that since their participation was voluntary, they had the option of deciding not to continue at any time, and the research conducted by a psychologist not involved in their treatment was independent of their medical treatment.

A total of sixty-eight patients were invited to participate in the study. Two patients initially refused to



participate; one because of time demands and one who was moving out of the province. Of the eight deaths that occurred during the period of the study, three patients died prior to completing any of the questionnaires and two died when only partial data had been obtained. Unexpected transplants prevented two patients from completing questionnaires. Several patients who had initially agreed to participate did not do so, simply by failing to return the first or subsequent questionnaires sent to them. For some dialysis patients this was understandable in terms of their numerous medical complications; a few who were dilatory in returning questionnaires complained of time demands, which probably accounted for their subsequent failure to return later questionnaires.

A total of fifty-four patients (twenty-seven in each treatment modality), or 92 percent of the available dialysis and transplant population in the Province of Manitoba in the fall of 1974 completed all of the questionnaires, and partial data was obtained on five additional dialysis patients. There was a total of thirty-three males (seventeen dialysis patients and sixteen transplant patients) and twenty-six females (fifteen dialysis patients and eleven transplant patients) in the sample. The mean ages of the transplant and dialysis groups were approximately thirty-eight years and thirty-nine years, respectively. Both groups were equated in terms of the advancement of their illness in that all patients had incurred irreversible kidney damage and were dependent upon either a

functioning renal transplant or chronic dialysis for their survival.

### Measures

#### Death anxiety

The Death Anxiety Scale (DAS) developed by Templer (1970), consisting of the fifteen items listed in Appendix I, was used to assess degree of death anxiety of the patients. Templer (1970) reported a test-retest reliability of 0.83, and that embedding the DAS items in MMPI items had no effect upon death anxiety scores (Templer & Ruff, 1971a). The DAS items were embedded in the Repression, Anxiety, and Depression scales of the MMPI and presented to the patients as a single questionnaire, utilizing two different randomized orders. The DAS items require either a true or false response. On nine of the items, agreement with the statement reflects concern about death. Six of the items are stated in the reverse, so that disagreement indicates death concerns. The possible range of scores is from zero to fifteen.

#### MMPI scales

Three MMPI scales were administered for the dual purpose of providing a questionnaire within which to embed the death anxiety scale items and as a check against the possibility of several mediating and/or confounding variables in this study. The three MMPI scales used were: (1) the R or denial scale, (2) the A or anxiety scale, and (3) the D or depression scale.

Subsequent to a number of factor analytic studies on the MMPI, Welsh (1956) developed the R and A scales, which were based upon the two previously identified major factor loadings. The R scale, which was used to measure denial, consists of forty items, all of which are scored if answered in the false direction, and has a test-retest reliability of 0.74. The A scale, employed as a measure of general anxiety, consists of thirty-nine items, thirty-eight of which are scored if answered true, and has a test-retest reliability of 0.70. Since the death anxiety scale items were embedded in the MMPI items, the A scale items were also used to preclude the possibility of a response set, although Welsh cites studies to indicate that the effects of response set are negligible. The depression scale, which was based upon criterion validity (Hathaway & McKinley, 1956), consists of sixty items and has a reliability coefficient of 0.77.

#### Self-esteem

The Tennessee Self Concept Scale was used to assess patients' level of self-esteem. The TSCS, consisting of one hundred self descriptive statements, was individually administered with standardized instructions. Only the Total Positive (Total P) score, which reflects an individual's overall level of self-esteem, was considered in categorizing patients into high and low self-esteem groups. Fitts (1965) reports a test-retest reliability of 0.92 on the Total P score.

### Locus of control

The Internal, Powerful Others, and Chance Scales developed by Levenson (1972) were used to assess patients' locus of control orientation. The I, P, and C scales each consist of eight items answered along a six-point continuum from strongly agree (+3) to strongly disagree (-3). The scales are administered as a single twenty-four item attitude scale. The scales consist of items adapted from Rotter's I-E scale in addition to new items written specifically for the new scales. Each scale has a possible score range of zero to forty-eight. Although research is understandably limited since this measure is a new one, Levenson presents encouraging reliability data. Internal consistency estimates (Kuder-Richardson reliability coefficients) of 0.64, 0.77, and 0.78 for the I, P, and C scales respectively are in the expected moderately high range, since the items sample a wide variety of different situations. Test-retest reliability coefficients are 0.64, 0.74, and 0.78 for the I, P, and C scales respectively.

### Consequences of death scale

To assess the basis of death anxiety, the patients were given a list of consequences of death, as set forth in Appendix II. Six items were drawn from the scale developed by Diggory and Rothman (1961). To provide a broader measure, an additional six items were added by this investigator. The statements were presented in two randomized orders so as to counteract any possible order effect.

Anticipatory preparations for possible death

Hypothesis number three was tested by having the patients answer the following questions:

Have you done any of the following?

	<u>Yes</u>	<u>No</u>
1. Have you prepared a Will?	_____	_____
2. Have you made any provisions for your minor children (for example appointing a legal guardian)? If you have no minor children and this does not apply to you, check here _____	_____	_____
3. Have you made any spiritual or religious preparations of any kind?	_____	_____
4. Have you obtained any information about the cost of a funeral, casket, and/or burial plot?	_____	_____
5. Have you communicated to anyone any decision you have made such as charitable donations instead of flowers at a funeral?	_____	_____
6. Have you made any arrangements such as donating your eyes to an eye bank?	_____	_____

Procedure

Potential participants received an initial letter from the Director of the renal unit, informing them of the research and requesting their voluntary participation. It was emphasized that the research data would be used anonymously, and that the renal unit was not interested in knowing any patient's answers, but only in the overall anonymous results. A

follow-up letter from the investigator explained the purpose of the research as a study of patients' attitudes related to illness, treatment, and the consequences of a serious illness. It was also explained that the first phase of the study would involve patients anonymously answering standard attitude questionnaires, and the second phase would consist of a few brief anonymous questionnaires and a confidential interview.

Subsequently, transplant patients and those self-care dialysis patients residing outside of Winnipeg were contacted by telephone. Dialysis patients at the main hospital unit and the self-care unit were personally contacted during their scheduled dialysis runs. They were again reminded of the voluntary and anonymous nature of their participation. Before obtaining an indication of whether or not they wished to participate, patients were given the opportunity to ask questions about the study. The majority of patients did not ask questions. To specific procedural questions (e.g., when the research would begin, when and where the interview would take place), specific answers were given. To substantive questions regarding the nature of the study, where a direct answer might have influenced patients' responses to the questionnaires, the investigator reiterated the information contained in previous correspondence and emphasized the goal of obtaining information on how patients cope with a serious illness and difficult treatment. In this initial contact, patients were also cautioned against discussing the questionnaires with members of their

family or other patients, and the reasons therefor. In addition, the memorandum set forth in Appendix III was circulated among the nursing staff at both dialysis units to deal with the curiosity aroused by the investigator's presence at the unit and enlist the staff's cooperation in not discussing questionnaires with the patients. Questionnaires administered were not discussed with or shown to the staff in advance.

In the first phase, patients were administered the MMPI scales with the embedded Death Anxiety Scale items, the Tennessee Self Concept Scale, and the Internal, Powerful Others, and Chance Scales as the first cluster of three individual tests, with the order of presentation randomized. Questionnaire administration in this phase was done by mail with the transplant patients and out-of-town self-care dialysis patients, to make their participation more convenient. It was originally assumed that most dialysis patients would prefer to answer the questionnaires during treatment, as a means of occupying their time. However, most preferred to do them at their convenience at home and to return them to the investigator on subsequent trips to the unit.

To maintain anonymity in answering the questionnaires, patients were asked to use an identification number in lieu of their name and to specify only their mode of treatment and sex. So that the investigator could later ascertain which questionnaires filled out at different times all belonged to the same patient, without knowing that patient's name, a number such as driver's license or social insurance number was

suggested, as it would not be accidentally duplicated by another patient and was easy to refer to for future use. However, on completion of the study, those patients who wished to know their own results, in addition to the overall anonymous results, could obtain same by breaking the anonymity and identifying their number. Structured in this way, the patients had the prerogative of responding anonymously without precluding the possibility of later receiving individual feedback if such was their wish.

In the second phase of the study, interviews were conducted with dialysis patients during their regularly scheduled treatment periods. Transplant patients and out-of-town self-care dialysis patients were interviewed at the time of their periodic checkups or, if they preferred, during the evenings or week ends. During the interview, the Consequences of Death Scale and the Anticipatory Preparations for Possible Death Questionnaire were given with the following verbal instructions:

One of the areas I'm studying is how patients who have been seriously ill deal with the possibility that serious illness may at some point become fatal. Later on in the study I may want to talk with you about this aspect of a serious illness. Right now, though, I have two short questionnaires on this topic I'd like you to fill out. As you know, this is a voluntary study, so if you would prefer not to deal with this topic, we can go on to the next part of the study.

The following areas were generally covered in the interviews.



1. The patient's initial reaction on learning the diagnosis of a serious illness.
2. What things the patient felt had helped in coping with illness and treatment. At what point in treatment was it most difficult to cope and why.
3. What the patient had learned about himself as a result of illness and treatment experiences.
4. In terms of his present treatment modality, what would be the best and the worst possible thing that could happen.
5. Had the patient ever talked with anyone regarding his feelings about the possibility that his illness could at some point become fatal. Did he feel that he had the opportunity to do so if he wanted to. If so, how helpful he found it.
6. Whether there were any circumstances under which the patient thought death would be preferable to continuing to live.
7. Transplant patients were asked if their transplant had fulfilled their expectations and about the effects of steroid drugs. This was done to check on pre-existing unrealistically high expectations for a "cure" by transplant, and to ascertain patient sophistication about potentially harmful side effects from steroids.
8. It was planned to ask dialysis patients about their reactions to deaths occurring on the unit during the

period of their treatment. However, after a few deaths had occurred during the study, this topic was pursued when it spontaneously arose in general conversation.

#### Analysis of Data

Prior to data analysis, all raw scores were converted to T-scores in order to equate variability on the different instruments and to facilitate comparison of the results. To ascertain a valid basis for T-score conversion, preliminary t-tests were done on the following group contrasts:

1. Hospital vs. self-care dialysis patients
2. Dialysis vs. transplant patients
3. Male vs. female patients

The results of these preliminary t-tests are presented in Appendix IV. Since there were no significant differences between the mean scores of the hospital and self-care dialysis groups, these two groups can be assumed to be drawn from the same population. The only significant differences between the transplant and dialysis groups occurred on the variable of depression (i.e., the dialysis group had a higher mean score) and in terms of the number of anticipatory preparations made for possible death (i.e., the transplant group had a higher mean score). However, there were significant sex differences on a majority of the personality variables and definite trends on the two variables that did not quite reach significance. Therefore, T-score conversion was done on the basis of separate T-score derivations for males and females.

## CHAPTER III

### RESULTS

#### Findings

##### Hypothesis 1

It was predicted that high self-esteem patients would obtain lower death anxiety scores than low self-esteem patients. This hypothesis was not confirmed.

Patients were categorized as high or low self-esteem based upon their scores falling above or below a T-score of 50.00 on the Total P score of the Tennessee Self Concept Scale. This resulted in two groups of comparable size, i.e., twenty-five high self-esteem patients and twenty-nine low self-esteem patients. The mean death anxiety scores for these two groups were 48.21 and 51.91, respectively. There was a trend for high self-esteem patients to report lower death anxiety, as predicted, but the results were not statistically significant ( $t=1.38$ ,  $df=52$ ,  $p < .10$ , one tailed).

##### Hypothesis 2

It was predicted that patients with an internal locus of control orientation would obtain lower death anxiety scores than would patients with a powerful others or a chance orientation. This hypothesis was not confirmed.

The mean death anxiety scores for each locus of control orientation were as follows:

<u>Internal (N=20)</u>	<u>Powerful Others (N=18)</u>	<u>Chance (N=16)</u>
49.53	52.34	48.62

The comparison of DAS scores for internal patients and patients with a powerful others orientation was not significant, although in the predicted direction ( $t=0.82$ ,  $df=36$ ,  $p > .20$ , one tailed). Internal and chance oriented patients obtained nearly equivalent DAS scores ( $t=0.28$ ,  $df=34$ ,  $p < .40$ , one tailed). Thus, the results do not support any relationship between locus of control orientation and death anxiety.

### Hypothesis 3

It was predicted that patients with an internal locus of control orientation would more likely have made anticipatory preparations for possible death than patients with a chance orientation. This hypothesis was confirmed, using chi square goodness of fit.

TABLE 1

ANTICIPATORY PREPARATIONS OF PATIENTS  
BASED ON LOCUS OF CONTROL ORIENTATION

	No	Yes
Internal (N=17)	1	16
Chance (N=12)	6	6

The comparison between internal and chance oriented patients was in the predicted direction and significant at a 5% level ( $\chi^2=5.26$ ).

### Secondary hypotheses regarding treatment group mean differences

Relationships between the dependent variables and mode of treatment were also of interest in this study. The T-score means and standard deviations for the two treatment groups on all variables are presented in Appendix V. None of the expected relationships were significant, as follows:

1. A positive association was predicted between higher self-esteem scores and treatment by renal transplantation. Group differences did not reach significance, but were in the predicted direction ( $t=1.22$ ,  $df=53$ ,  $p > .10$ , one tailed).

2. A positive association was predicted between an internal locus of control orientation and treatment by renal transplantation. Internal scores for the two groups were nearly equivalent ( $t=0.42$ ,  $df=53$ , n.s.).

3. A positive association was predicted between a powerful others locus of control orientation and dialysis treatment. Group differences did not reach significance, but were in the predicted direction ( $t=0.75$ ,  $df=53$ ,  $p < .25$ , one tailed).

4. A positive association was predicted between higher death anxiety scores and dialysis treatment. Death anxiety scores for the two groups were nearly equivalent ( $t=0.16$ ,  $df=55$ , n.s.).

### Discriminant function analysis

To determine which subset of the variables effectively discriminated between the dialysis and transplant groups, a stepwise discriminant function analysis was carried out.

Ten variables were utilized in this analysis: death anxiety, depression, anxiety, internal locus of control, length of treatment, self-esteem, repression, powerful others locus of control, chance locus of control, and sex. The F tests included in this analysis indicated that depression was the sole variable on which the two groups were significantly different ( $F=8.64$ ,  $p < .01$ ), with the dialysis group scoring higher on this scale.

The predictor variables of depression, anxiety, length of treatment, death anxiety, and internal locus of control emerged as the most effective discriminant subset of variables for the criterion of correct group membership. Except for length of treatment, the dialysis group had higher mean scores on these variables. This subset predicted correct group membership for 72.2 per cent of the total patient population (70.4 per cent of the transplant group and 74.0 per cent of the dialysis group). The standardized discriminant function coefficients and the relative positive or negative contribution of each variable to classification into group membership, were as follows:

1. Depression	-0.59656
2. Anxiety	0.42830
3. Length of Treatment	0.23964
4. Death Anxiety	-0.17867
5. Internal Locus of Control	-0.17780

### Sources of death anxiety

The Consequences of Death Scale (see Appendix II) instructed patients to eliminate those statements that did not cause discomfort and to rank order the remainder from least to most anxiety arousing. In examining the results of this questionnaire, these rankings were reversed and only those statements consistently ranked highest, or most anxiety arousing, were included in the analysis. These statements, in order of frequency selected, were:

1. My death would cause grief to my relatives and friends. (Question No. 10)
2. My death might be painful. (Question No. 6)
3. I could no longer care for my dependents. (Question No. 4)
4. Death means facing the unknown. (Question No. 11)
5. I could no longer have any experiences. (Question No. 12)
6. I could no longer enjoy life or pleasurable activities. (Question No. 7)
7. I am uncertain as to what might happen to me if there is a life after death. (Question No. 9)

A chi square test of independence was utilized to ascertain possible associations between sources of death anxiety and the variables of high and low self-esteem and locus of control orientations. No relationships were found, as reflected in Table 2.

TABLE 2

ASSOCIATION BETWEEN SOURCES OF DEATH ANXIETY  
AND VARIABLE OF SELF-ESTEEM

	Consequences of Death Scale Item No.					Totals
	10	6	4	11	12	
High self-esteem (N=19)	13	11	9	7	5	45
Low self-esteem (N=21)	15	13	9	9	6	52

$\chi^2=0.104$ , n.s.

TABLE 3

ASSOCIATION BETWEEN SOURCES OF DEATH ANXIETY  
AND LOCUS OF CONTROL ORIENTATION

	Consequences of Death Scale Item No.							Totals
	10	6	4	7	11	12	9	
Internal (N=16)	13	11	10	7	4	4	2	51
P.O. (N=11)	9	6	6	3	5	5	2	36
Chance (N=12)	6	7	2	0	7	3	7	32

$\chi^2=18.634$ ,  $p < .10$



## CHAPTER IV

### DISCUSSION

#### Examination of Hypothesis 1

In line with related research (Farley, 1970; Nogas, Schweitzer, & Grument, 1974), it was predicted that high self-esteem patients would obtain lower death anxiety scores than low self-esteem patients. This hypothesis was not confirmed. However, there was a definite trend in the predicted direction at the 10% significance level, and a significant negative correlation between death anxiety and self-esteem (Appendix VII, Tables 11 and 12).

The studies by Farley (1970) and Nogas, Schweitzer, and Grument (1974) found significant inverse relationships between death anxiety and sense of competence in male and female college student populations. Although the concepts of self-esteem and sense of competence share some theoretical overlap, there is no clearly defined measuring instrument for the sense of competence. Farley (1970) used structured interviews covering interpersonal relationships and feelings of self worth. These interviews were rated by independent judges, but presented considerable difficulties in obtaining a quantitative index of the sense of competence. To correct this

methodological problem, Nogas, Schweitzer, and Grument (1974) used several California Psychological Inventory scales also related to interpersonal relationships and feelings of self worth. The fact that both of these studies used death anxiety scales on which no validation data are available also presents some difficulty for comparison of results from the present investigation.

The significant negative correlation between death anxiety and self-esteem in this study is in agreement with the significant negative correlation between death anxiety and sense of competence obtained by Nogas, Schweitzer, and Grument (1974). The fact that this study did not find significant  $t$  values for mean differences in death anxiety scores between the high and low self-esteem patient groups may have been influenced by two factors: (1) the small number of participants in this study, or (2) the decision not to preselect participants on the basis of clearly differentiated levels of self-esteem, or death anxiety as Farley (1970) did. Patients in this study were categorized as high or low self-esteem based upon their scores falling above or below a T-score of 50.00. As a result, some patients who obtained scores slightly above or below the T-score mean on this continuous variable were arbitrarily categorized into supposedly non-comparable groups. The consequent loss of information about clear differences between high and low self-esteem patients may have reduced the sensitivity of the statistical analysis.

In differentiating behavioral coping from self reported death anxiety, it was interesting to note that of the eight patients who refused to answer the death questionnaires included in the interview, six patients were in the low self-esteem group.

### Examination of Hypothesis 2

It was predicted that patients with an internal locus of control orientation would report lower death anxiety than would patients with a chance or powerful others locus of control orientation. This hypothesis was not confirmed.

The lack of a relationship between locus of control orientation and death anxiety in this study is in agreement with the majority of prior research findings (Berman, 1973; Berman & Hayes, 1973; Dickstein, 1972; Selvey, 1973). Three of these studies used Templer's Death Anxiety Scale (Berman, 1973; Berman & Hayes, 1973) and Boyar's Fear of Death Scale (Selvey, 1973). These are instruments on which validation procedures have been conducted by their respective authors. The significant relationship between an external locus of control orientation and higher death anxiety reported by Tolor and Reznikoff (1967) was obtained with a death anxiety scale on which no validation data is available. The foregoing studies made exclusive use of college students. Thus, the lack of relationship obtained in the present study extends this finding to an additional, and perhaps more situationally appropriate, population.

### Examination of Hypothesis 3

This hypothesis was related to the question of whether locus of control orientation ". . . in conjunction with a specific situation, leads Ss to behave differently from one another." (Nelson & Phares, 1971, p. 667). As predicted, patients with an internal locus of control orientation were significantly more likely to have made anticipatory preparations for their possible demise than were patients with a chance orientation. A discussion of the specific preparations made by patients in this study is presented in Appendix VI.

This hypothesis made no prediction about the behavior of patients with a powerful others orientation. Such individuals, also referred to as defensive externals, have been characterized as ". . . people who behave in an internal fashion under certain conditions and in an extremely external fashion under other conditions." (Hochreich, 1974, p. 544). Research to date has focused primarily upon competitive, achievement-oriented situations, and little information has been accumulated about the behavior of defensive externals in other situations, such as the one in this study.

Defensive externals, or patients with a powerful others orientation, in this study did not significantly differ from either internal or chance oriented patients regarding anticipatory preparations. However, the behavior of such patients with a powerful others orientation in this regard was more like that of internal patients, as shown in the following table.

TABLE 4

ANTICIPATORY PREPARATIONS OF PATIENTS  
BASED ON LOCUS OF CONTROL ORIENTATION

	No	Yes
Internal (N=17)	1	16
Powerful Others (N=12)	2	10
Chance (N=12)	6	6

These results for patients with a powerful others orientation are logically consistent with the conceptualization of defensive externality. That is, the potential for personal control is still relevant in that defensive externals behave like internals in perceiving their own efforts and those of powerful others as the salient factor in obtaining reinforcement. In encountering failure, they may verbally externalize blame to powerful others as a mechanism for anxiety reduction.

Examination of Secondary Hypotheses  
Treatment Group Differences

Treatment group differences in self-esteem

A positive association was predicted between higher self-esteem scores and treatment by renal transplantation. Group differences did not reach statistical significance, but were in the predicted direction. Furthermore, dialysis patients scored significantly higher than transplant patients on the MMPI Depression Scale. The concurrent finding that dialysis patients obtained higher depression scores and lower self-esteem scores is in line with the position adopted by

some writers (cf. Bibring) that failure to fulfill such common aspirations as maintenance of individual self worth, independence, and high regard from others can lead to a reduction in self-esteem and depression as the consequence (Mendelson, 1960).

There is general agreement that chronic dialysis demands a stricter therapeutic regime and affords greater psychological stress with fewer outlets for discharge of tension as compared to renal transplantation (Cramond, et al, 1967; Sampson, 1973). The anemia and resultant low energy level inherent in chronic dialysis often lowers patients' capacities to tolerate little more than limited social interactions; to a greater extent they are denied the typical tension outlets most people utilize to restore equilibrium; and their anergia and other physical failure associated with chronic renal failure are often more salient than is the case with transplant patients. Thus, the failure leading to reduced self-esteem and depression, including physical failure, is likely to affect most dialysis patients to a greater extent than transplant patients. Gergen (1968) has empirically demonstrated that ". . . along the single and very central dimension of self-esteem, a person will shift in either a more positive or negative direction depending on situational influence." (Gergen, 1968, p. 306).

Sampson's (1973) thesis is that although research has suggested that patients psychologically tolerate dialysis less well than transplantation, there is a necessary period of time

which must elapse after successful surgery before subjective psychological well being is achieved by the transplant patient. Due to the small number of participants in this study, the factor of length of time elapsing since successful transplantation was not included in the statistical analysis of this hypothesis. Beard (1971) believes this post-transplant period to be of six to nine months' duration before patients begin to experience a return of healthy self-esteem and active involvement with the environment; Cramond (1967) feels this post-transplant period of adjustment may last for a year or longer. Sampson did find, however, that ". . . despite the fact that patients with shorter graft survival show poorer emotional and social adjustment than the patients with longer survival time, they are nevertheless better adjusted than the in-center dialysis patient." (Sampson, 1973, p. 11). Further,

The long term dialysis patient and the transplant patient with shorter graft survival time are indicated to experience like problems such as impaired social relationships, depressive symptomatology and home and family stress; however, there is a decided difference in the degree of severity with which it effects the dialysis patient as opposed to the transplant patient. (Sampson, 1973, p. 11).

#### Treatment group differences in internal locus of control

A positive association was predicted between an internal locus of control orientation and treatment by renal transplantation. Internal scores for the two groups were nearly equivalent.

The possibility of a differential survival rate for patients with an internal orientation could account for the

lack of meaningful difference between the two treatment groups. Kilpatrick, Miller, and Williams (1972) found that a sample of patients on dialysis for a longer period of time (twenty-three months) obtained higher internal scores than did a sample of patients whose time on dialysis was shorter (fifteen months). Consequently, they proposed:

. . . as a sample's mean length of time in dialysis increases, the composition of the sample will change because of the deletion from the sample of individuals who have been unable to follow their treatment regimen. (Kilpatrick, Miller, and Williams, 1972, p. 728).

These investigators studied locus of control in relation to dialysis patients only. However, since most transplant patients have previously been on dialysis and generally in treatment for a longer period of time, a differential survival rate could apply to both dialysis and transplant patients. The present investigation did find a significant negative correlation between length of treatment and chance locus of control orientation for the total patient population.

Wilson, Muzekari, Schneps, and Wilson (1974) obtained results contrary to those of Kilpatrick, Miller, and Williams (1972). Re-testing of eleven dialysis patients after an additional year in treatment revealed a significant change toward a more external orientation. Small sample sizes and varying treatment lengths in different studies make comparison of results difficult. Without further investigation, one can only speculate on the possibility of a differential survival rate for patients with an internal orientation.



### Treatment group differences in powerful others locus of control

A positive association was predicted between a powerful others locus of control orientation and dialysis treatment. Group differences were not significant, but were in the predicted direction. In addition, the raw scores of hospital dialysis patients revealed a trend in the direction of higher powerful others scores as compared with the scores of self-care dialysis patients. This is not surprising since self-care patients, after an initial training period, are primarily responsible for their own treatment, while treatment in the hospital unit is conducted by the nursing staff.

Although not statistically significant, these results do lend some support to Levenson's conceptual distinction and refinement of the external locus of control construct into chance and powerful others dimensions. While the I, P, and C Scales have had somewhat limited application because of recency of development, they did reflect to some extent the differential aspects of control by powerful others in the hospital dialysis, self-care dialysis, and transplant patients' treatment situations as to the role played by the medical staff.

### Treatment group differences in death anxiety

A positive association was predicted between higher death anxiety scores and dialysis treatment. Death anxiety scores for the two groups were nearly equivalent.

This prediction was based upon the investigator's prior assumption that the possibility of returning to dialysis in the event of organ rejection might provide some feeling of security for transplant patients. It was surmised that if medical progress was less than satisfactory for transplant patients, they might experience additional security in knowing that they could return to dialysis. In the case of less than satisfactory progress for dialysis patients, however, there is no alternative treatment, other than the chance procurement of a matching kidney transplant.

The powerful effect of length of treatment on death anxiety, which predominantly affected transplant patients, was not anticipated. The two treatment modalities are differentially structured in terms of the quality of life allowed and the degree of patient participation demanded. However, both are equal in terms of the uncertainty of individual prognosis and the possibility of death. Of the eight fatalities which occurred during the course of this study, five were patients on dialysis and three were transplant patients.

The only other study assessing death anxiety in dialysis patients was that by Lucas (1972), who also used Templer's Death Anxiety Scale. His respective T-score means of 47.25 and 49.80 for twenty home and twenty hospital dialysis patients were comparable to the T-score means of 50.66 and 49.70, respectively, obtained on sixteen self-care and fourteen hospital dialysis patients in this study.

### Examination of Sources of Death Anxiety

The five most anxiety arousing consequences of death, in order of frequency of selection, were:

1. My death would cause grief to my relatives and friends.
2. My death might be painful.
3. I could no longer care for my dependents.
4. Death means facing the unknown.
5. I could no longer have any experiences.

According to Becker (1973), fear of one's death because it may bring grief to others represents a denial of our mortality through the defense of displacement.

One is frightened by the emptiness, the gap that would be left by one's disappearance. One can't cope easily with it, but one can cope with someone else's grief over one's disappearance. Instead of experiencing the stark terror of losing oneself as a disappearing object, one clings to the image of someone else. (Becker, 1973, p. 103).

The second concern, that death or the dying process will be painful, has some logic in this chronically ill population. Pain is associated with many illnesses and chronic renal failure is no exception. Some degree of pain is inherent in treatment, such as proneness to severe leg cramps during dialysis or extremely painful fistula arteriograms. Transplant patients have endured not only the pain of major surgery, but some are aware of the increased risk of certain forms of cancer as a side effect of steroids, and cancer is often synonymous with a painful death. Thus, if illness can

be painful, ". . . there is a certain logic in maintaining that the ultimate physical failure must be the ultimate in pain. This is not at all necessarily true." (Neale, 1973, p. 39). Lucas (1972) also observed a general fear of the dying process because of anticipated pain in his interviews with dialysis patients. Possibly, the promotion of open discussions of such fears by the medical staff, and provision of information to eradicate possible misconceptions, might offer patients some reassurance on this issue.

Inability to care for dependents as a result of one's death may be related to the fear of an incomplete life, or premature termination before reaching old age and seeing one's children grown and established on their own. Also relevant is a frustration of the life goals to which one is committed. For many patients, because of the difficulty of obtaining life insurance, the ability to financially provide for one's family may be a realistic concern. Professionals working in this field might be alerted to these concerns and utilize aids in opening lines of communication between patients and spouses, as well as investigating potential resources. For example, counselors might explore whether patients and spouses are aware of all the financial benefits to which they are entitled. It might also be helpful for the patient and family to discuss future plans for care of dependents. This could validate the soundness of their decisions, clarify areas of uncertainty, or provide alternatives of which they were previously unaware.

Facing the unknown aspects of death was the other fear observed by Lucas (1972) in his interviews. At first glance, it appears to support the uniqueness of the challenge of death. However, Neale (1973) adopts the position that:

It is perfectly natural to wonder about the unknown, and perhaps even to have some trepidation about any great and permanent change. But to really fear what comes next is something else. Those who are afraid of what comes after death because it is unknown may tend to be those who cannot face the unknown in life. (Neale, 1973, p. 38).

Hopefully, the present trend by mental health professionals toward a reversal of the flight away from discussing such a formerly taboo or morbid topic as death will aid in developing new philosophies. The decline in formerly held religious beliefs, which have not been replaced by any alternative ideologies, and the resulting void may have highlighted the unknown aspects surrounding death. As Kubler-Ross has said, ". . . if we cannot anticipate life after death, then we have to consider death." (1969, p. 15).

The cessation of experience would seem to be an underlying basis for all other fears. Although this item was ranked fifth in terms of its anxiety arousing nature, several patients mentioned this point of view. Cessation of experience is the kind of analysis existentialists encourage in order to discover the real meaning of death in human existence. Such confrontation ultimately leads to a transformation of life values, and it is only through confronting one's own death that a psychology of life is constructed. From the

painful realization and acceptance of one's mortality and tenuous existence comes a reassessment of the meaning of one's life experience. (Koestenbaum, 1971).

#### Examination of Correlational Analyses

As part of the discriminant function analysis, correlational analyses were obtained for each treatment group, as well as the total patient population, to assist in interpreting the data collected in this study. The results of these correlational analyses are presented in Appendix VII.

The significant positive correlation between scores on Templer's Death Anxiety Scale and the MMPI Anxiety Scale is consistent with other studies which have reported a positive association between death anxiety and general anxiety (Dickstein, 1972; Farley, 1970; Handal, 1969; Lucas, 1972; Nogas, et al, 1974; Templer, 1973). However, the significant positive correlation between length of treatment and death anxiety and lack of corresponding relationship between length of treatment and general anxiety supports the conclusion of Templer and other authors that death anxiety scales are measuring a more specific and circumscribed anxiety than general anxiety, ". . . composed of special and distinct feelings, specific to the threat of death alone." (Farley, 1970, p. 29).

The significant positive correlation in this study between death anxiety and depression is in agreement with similar results by Lucas (1972) with female dialysis patients and Templer (1969, 1973) with psychiatric patients. Templer

(1971b) found the same relationship between death anxiety and depression in retired individuals aged fifty-one to ninety-two years, and tentatively suggested that high death anxiety in the elderly is a concomitant of a depressive syndrome. The fact that such a relationship in the present study was significant for dialysis patients but not for transplant patients lends support to Templer's conclusion, since the dialysis group scored significantly higher on depression.

However, in his research on the relationship between death anxiety and depression in the elderly, Templer also concluded:

Apparently, decline of somatic integrity is ordinarily not a crucial determinant of death anxiety level. . . . It is concluded that death anxiety is usually related more to degree of personality adjustment and subjective state of well-being than to reality-based factors; and it seems reasonable that high death anxiety states can often be understood in terms of a breakdown of defense mechanisms. (Templer, 1971b, p. 522).

In the present study, as well as that of Lucas (1972) on death anxiety in dialysis patients, the mean Death Anxiety Scale scores were within normal limits. Templer, Ruff, and Franks (1971) found no relationship between age and death anxiety, and Templer (1971b) did not find any significant relationship between degree of somatic pathology and death anxiety. However, this study did find a significant positive correlation between death anxiety and length of treatment, which assumes a corresponding nearness to death. Apparently, the relationship between one's physical health, subjective state of well-being, personality adjustment, and closeness to death is a complex one requiring further investigation.

### Implications for Further Research

Length of treatment may have been a confounding variable affecting several findings in this study. A greater number of participants would enable the effects of length of treatment to be controlled and allow a clearer relationship of the other variables under investigation.

In testing Hypothesis 1, that high self-esteem patients would report lower death anxiety than low self-esteem patients, it was unfortunate that the limited number of participants prevented matching the two self-esteem groups on length of treatment. This study found a significant positive correlation between death anxiety and length of treatment. Patients kept alive by extraordinary medical procedures may well see themselves as closer to possible death the longer they are in treatment and, indeed, several patients subtly alluded to or directly verbalized this concern. Had it been possible to match the high and low self-esteem patients on length of treatment, the group differences in death anxiety might have been more clearly attributable to self-esteem level without the confounding powerful situational effect of length of survival by extraordinary treatment. Length of treatment was not calculated in exact figures; patients were categorized as having been in treatment for periods of less than one year, one to three years, three to five years, or more than five years. A rough calculation of the data indicated that patients in the high self-esteem and low death anxiety group had an average treatment length of three and three-fourths



years, as compared to two and one-half years for the low self-esteem and high death anxiety group. Further, the significant positive correlation between death anxiety and length of treatment predominantly affected transplant patients, undoubtedly because most had been in treatment longer than dialysis patients. In the high self-esteem and low death anxiety group, 60 percent were transplant patients, as compared to transplant patients constituting 41 percent of the low self-esteem and high death anxiety group.

Self-esteem level has been regarded as a relatively stable characteristic over time (Linkowski & Dunn, 1974), but also responsive to some extent to the situational demands of one's social environment. (Gergen, 1968). As treatment progresses and patients adjust to their illness and treatment demands, overcome initial medical crises, and are physically capable of resuming work and social roles, their effective coping could lead to greater satisfaction of their self-esteem needs. Because of fewer treatment restrictions and a more positive quality of life possible for transplant patients, it is assumed that they have greater opportunities for fulfillment of self-esteem needs.

However, it would not necessarily be paradoxical for both self-esteem and death anxiety to increase as a function of length of treatment. Zuehlke and Watkins (1975) worked therapeutically with terminally ill patients and found that they demonstrated significantly increased death anxiety and perceived purpose in life as compared to a non-treated control

group. Since post-treatment death anxiety scores were within the normal range, the authors explained this increase in death anxiety on the basis that increased awareness of death leads to the admission of previously denied fears. Along with the acceptance of this reality, patients also perceived their therapeutic experience in a positive vein, and their lives as more meaningful and worthwhile.

Hypothesis 2, that internal patients would report lower death anxiety than patients with a chance or powerful others orientation, may also have been affected by length of treatment influencing both death anxiety and locus of control orientation. There was a significant positive correlation between length of treatment and death anxiety and a significant negative correlation between length of treatment and chance locus of control orientation.

There is, of course, the possibility that locus of control is a deeply ingrained orientation and not influenced by a situation such as the one under investigation. However, in a powerful realistic situation such as the present one, which contains elements of all three control orientations, it would be interesting to investigate whether there is a point in treatment at which the situation exerts an effect upon control orientation. Such a study would require longitudinal data and a greater number of participants. Wendland (1973), for example, suggested the possibility of increased influence from external forces during the critical period following

disability onset. In males hospitalized for muscular-skeletal impairments, he found that patients with more recent disability onsets were significantly more external than were patients with long-term disabilities.

Although this finding may suggest a decrease in external control perceptions with advancing chronicity of disability, a more promising explanation is that it represents an increase in the external perceptions of the more recently disabled. In this case, the result could be attributed to the function of some factor related to the initial reactions to finding oneself disabled. The S may rightfully view his predicament as overwhelming; a perception that is counter to self determination or personal control. Greater reliance upon external resources for direction and help may subsequently occur during this critical period of time. (Wendland, 1973, p. 184).

Hypothesis 2 was related to the generality of the locus of control construct vis-a-vis death anxiety regardless of the psychological situation, which may have lowered the predictive power of the construct (Mischel, 1973; Rotter, 1975). For dialysis patients only, there was a significant negative correlation between internal locus of control and death anxiety. Whether an internal orientation comes to have greater survival relevance for dialysis patients can only be speculated on in the present study. Both groups must assume an active role in their treatment program and face daily reminders of their illness, for example, taking medications and maintaining a vigil for signs of physical deterioration. However, transplant patients may be able to develop some degree of psychological distance in contrast to the nearly complete immersion required of dialysis patients. Unless complications

develop, transplant patients must make only a brief outpatient visit every six to eight weeks, as opposed to dialysis patients being hospitalized three days each week. In addition, the potentially dangerous consequences of dialysis patients' actions may be more immediate and direct, as for example in risking cardiac arrest resulting from potassium intake or making a fatal error in operating the dialysis machine. Consequently, dialysis patients may perceive a more direct connection between their actions and chances for survival and believe that they have a greater personal role in the success of their treatment. It would be interesting to explore whether internality has differential meanings for these two groups. Internality vis-a-vis dialysis treatment involves patients' adherence to dietary and fluid restrictions for the positive outcome of survival and maintaining oneself in good condition for a possible transplant. For transplant patients, however, a salient aspect of internality is taking steroid medications which, in addition to the positive outcome of preventing rejection, may lead to potential deleterious side effects. The powerful situational effects of treatment by dialysis or transplantation can exert an influence on patients' locus of control orientations in numerous and conflicting ways. For example, dialysis patients may exercise some control over their treatment outcome by maintaining rigid fluid requirements and keeping themselves as physically fit as possible so as to be a "healthy" surgical candidate for transplantation. However, whether or not this opportunity arises is dependent on such

chance factors as a suitably matched kidney becoming available. Similarly, transplant patients may exercise some control over their treatment outcome by taking steroid medications. Whether or not they incur harmful side effects may be perceived by them as dependent upon chance factors. Possibly, locus of control as measured by presently available scales, may not assess all of the relevant aspects of control orientations in this particular powerfully structured situation.

While other studies have not found a relationship between death anxiety and age (Templer, Ruff, & Franks, 1971), or degree of somatic pathology (Templer, 1971b), this study did find a significant positive correlation between death anxiety and length of treatment, which assumes a corresponding nearness to death. On the basis that anxiety arousal is dependent upon the cognitive appraisal of threat, Beck (1971) has stated that:

Anxiety is enhanced by (1) appraisal that the individual cannot cope with or neutralize the threatening object; (2) immediacy of the perceived danger; (3) unpredictability of when the actual damage will occur; (4) high probability attached to the occurrence of the noxious event; (5) high degree of damage expected as a result of the noxious event. (Beck, 1971, p. 497).

These criteria fit the assumption of nearness to death corresponding to increased length of treatment for a serious illness which limits one's life span and keeps one alive by extraordinary medical procedures. The relationship between one's physical health, subjective state of well-being, personality adjustment, and closeness to death appears to be a complex one requiring further investigation.

Closeness to death may be a necessary but not sufficient condition to elevate death anxiety. The possible interactional effects of life experiences and personality variables remain largely unexplored. Feifel and Branscomb (1973) studied closeness to death, defined in terms of whether participants were terminally or seriously ill, physically disabled, mentally ill, or healthy, and found no relationship to death anxiety with their own assessment techniques. In contrast, however, Feifel, Freilich, and Hermann (1973), studied heart and cancer patients as compared to healthy individuals, and found that ". . . patients close to impending death are markedly more afraid of death on an unconscious level than healthy individuals." (Feifel, et al, 1973, p. 165). However, with Feifel's emphasis upon differences in death attitudes at the conscious, fantasy, and "gut" level, their unique methodology precludes comparison with other studies. Chronic renal failure denotes a limited life span, but individual prognoses and the possibility of death are ambiguous. Whether this ambiguity hampers individuals from adapting to the inevitable, as compared to individuals with progressively deteriorating health and more clearly structured and time limited outcomes due to certain types of cancer, for example, remains to be studied in comparative fashion.

Seligman's (1975) learned helplessness model could be applied to dialysis patients, since this group exhibited higher levels of depression and anxiety than the transplant group.

Langer, Janis, and Wolfer (1975) instructed surgical patients in techniques for coping with stress. This decreased their anxiety level and increased their stress tolerance, presumably because the patients' feelings of helplessness were decreased. Sviland (1971) found that dialysis patients without effective denial who had high anxiety scores had significantly poorer rehabilitation and emotional adjustment. Furthermore, dialysis patients with high depression scores could encounter greater psychological difficulties in following rigid treatment demands. All individuals need to periodically achieve a healthy psychological distance from any source of stress, in order to recharge their "emotional battery" so to speak, so as to more objectively and effectively deal with their problems. Patients with high anxiety and depression levels may be more likely to become totally absorbed with their illness and treatment. By utilizing staff evaluations, it would be possible to assess the effect of systematic instruction in coping techniques upon dialysis patients' rehabilitation and successful accomplishment of treatment requirements, as well as their emotional adjustment.

Templer, Ruff, and Simpson (1974b), using hospitalized mentally ill patients, demonstrated that symptomatic treatment of depression alone resulted in significant post-treatment reductions of both depression and death anxiety scores. These results could be replicated with a seriously ill patient population with corresponding high depression. It would also be

of interest to investigate whether open discussion and exploration of sources of death anxiety serves to reduce patients' death anxiety scores.

### Conclusion

As Sviland (1971) found, ". . . continued long-term hemodialysis does not necessarily result in other medical problems." (Sviland, 1971, p. 290). However, all presently available modes of treatment pose particular problems, and it is not possible to generalize which is preferable without considering each individual's situation.

For example, home dialysis in particular requires strong emotional family support in terms of the marital adjustment required. Dialysis nights may be integrated into family activities with a real partnership between the spouses to break up the monotony of preparation and clean up routines. On the other hand, due to greater family involvement in the patient's treatment, home dialysis may be perceived as an imposition and additional strain upon the family.

Whatever the mode of treatment, patients experience a considerable degree of anxiety related to regression. The underlying fear is the ultimate regression to death, which increases the longer patients are in treatment. As Kubler-Ross (1974) has pointed out, "There are days when the critically ill patient wants to talk about brighter things in life and you cannot schedule talks about dying." (Kubler-Ross, 1974, p. 91). Thus, a critical factor in talking with patients



about this topic is repeated patient contacts over time and an alertness to subtle clues in patients' conversations which point to their readiness and desire to talk about death.

In describing the omnipresent fear with which patients face illness and treatment, Williams (1945) wrote the following.

It is the hard lot of the doctor to know that in the end he is always defeated; his victories at best are temporary. Death he can never finally conquer. But death's ally is fear, and this ally the doctor can defeat. Let him help the patient to conquer fear, and he will win many a skirmish; and if he can never hope to win the last grim battle, he can at least do much to rob that ultimate defeat, for his patient and for the patient's family, of the terror that is its most grievous pain. (Williams, 1945, pp. 197-198).

## APPENDIX I

## DEATH ANXIETY SCALE

Below are a series of items which you are to rate as they apply to you. Read each statement and decide whether it is true or mostly true as applied to you, or whether it is false or mostly false as applied to you. Remember to give your own opinion of yourself and to answer each item. This information will be kept confidential and used anonymously only for research purposes.

- |   |      |       |
|---|------|-------|
| 1. I am very much afraid to die.                                | True | False |
| 2. The thought of death seldom enters my mind.                  | True | False |
| 3. It doesn't make me nervous when people talk about death.     | True | False |
| 4. I dread to think about having to have an operation.          | True | False |
| 5. I am not at all afraid to die.                               | True | False |
| 6. I am not particularly afraid of getting cancer.              | True | False |
| 7. The thought of death never bothers me.                       | True | False |
| 8. I am often distressed by the way time flies so very rapidly. | True | False |
| 9. I fear dying a painful death.                                | True | False |
| 10. The subject of life after death troubles me greatly.        | True | False |
| 11. I am really scared of having a heart attack.                | True | False |
| 12. I often think about how short life really is.               | True | False |
| 13. I shudder when I hear people talking about a World War III. | True | False |
| 14. The sight of a dead body is horrifying to me.               | True | False |
| 15. I feel that the future holds nothing for me to fear.        | True | False |

## APPENDIX II

## CONSEQUENCES OF DEATH SCALE

Below are 12 statements related to the meanings or consequences of death. Please draw a line through each statement that does not make you feel uncomfortable. After eliminating these statements, please rank order the remaining statements. Place the number "1" in front of the statement which makes you feel the least uncomfortable, the number "2" in front of the statement which makes you feel a little more uncomfortable, and so on. The highest number you use should be in front of the statement which makes you feel the most uncomfortable. Your answers will be used anonymously only for research purposes.

- \_\_\_ 1. I could no longer care for my dependents.
- \_\_\_ 2. All my plans and projects would come to an end.
- \_\_\_ 3. My death might be painful.
- \_\_\_ 4. I am uncertain as to what might happen to me if there is a life after death.
- \_\_\_ 5. My death would cause grief to my relatives and friends.
- \_\_\_ 6. I could no longer have any experiences.
- \_\_\_ 7. My achievement capacity would end and I would not be able to accomplish anything of importance.
- \_\_\_ 8. I would cease to exist.
- \_\_\_ 9. I could no longer have opportunities to improve my skills.
- \_\_\_ 10. I could no longer enjoy life or pleasurable activities (e.g., hobbies, recreation, sports, etc.)
- \_\_\_ 11. I may be all alone and lonely.
- \_\_\_ 12. Death means facing the unknown.

## APPENDIX III

The renal unit is initiating a research program involving the voluntary participation of dialysis and transplant patients. I am a psychologist from the University of Manitoba, and will be conducting the study under Dr. Thomson's supervision.

The purpose of this research is to obtain information regarding how people cope with a serious illness and a difficult treatment. Since dialysis and renal transplantation are relatively new, you're probably aware that very little psychological research has been done in this area. Therefore, our goal is to gather information regarding the human or emotional aspects of illness and treatment, as opposed to the strictly medical aspects. No treatment or staff evaluation will be included in the study.

I'll be collecting research data from the patients by means of anonymous standardized questionnaires which have been used in many areas of research. Subsequently, since there are no standard questionnaires developed for this area, I'll be conducting confidential interviews with the patients covering aspects of a serious illness and treatment. All information conveyed to me during the study will be given either anonymously, as on the questionnaires, or regarded as confidential if given in personal contacts with the patients. The renal unit is not interested in knowing any individual's answers, but only in the overall anonymous results. After the study has been completed, I'll convey to the staff and patients a full explanation of the research and anonymous results.

Naturally, the research is going to arouse a lot of curiosity, which can lead to a major difficulty in doing research in this kind of close setting. I wanted to mention to the staff the same problem about which I'll be cautioning patients. It's critically important that there be no discussion among the staff or patients about the research, and particularly about the questionnaires I'll be administering. This is necessary in order to avoid the possibility of anyone's answers on the questionnaires being influenced by comments from other people. I find that I also have to keep reminding myself of this possibility in talking with patients. This is essential because any such influence on patients' responses to the questionnaires could make it impossible to interpret the results of the research. This would not only mean that the preparation for this study would be wasted, but also waste the time of the patients who are participating in the study. Because this is a unit with close and continuous contact between staff and patients, it's quite possible that patients

may question the staff about the research. If so, I'd appreciate it if you would suggest that they bring these questions up with me. I hope the staff will also feel free to ask me questions; I'll answer questions from patients and staff as fully as I can while the research is in progress, and in complete detail when the study is completed.

As a personal favor, I hope you all will introduce yourselves to me while I'm around the unit. Frankly, I'm a bit overwhelmed right now trying to put names and faces together, but I hope to get to know you individually while I'm working on the unit.

Sincerely,

Karen B. Blakely

## APPENDIX IV

TABLE 5

PRELIMINARY T-TESTS ON RAW SCORES OF  
HOSPITAL VS. SELF-CARE DIALYSIS PATIENTS

Variable	Hospital Dialysis	Self-Care Dialysis	t value †
SELF-ESTEEM	N=13	N=15	
M	332.77	340.60	0.66 n.s.
SD	29.31	31.96	(df=26)
DEATH ANXIETY	N=14	N=16	
M	5.36	5.75	0.31 n.s.
SD	3.10	3.67	(df=28)
REPRESSION	N=14	N=16	
M	18.64	20.44	1.20 n.s.
SD	2.81	4.85	(df=28)
ANXIETY	N=14	N=16	
M	16.79	13.81	0.85 n.s.
SD	8.29	10.20	(df=28)
DEPRESSION	N=14	N=16	
M	29.71	28.13	0.61 n.s.
SD	6.36	7.45	(df=28)
INTERNAL L/C	N=12	N=16	
M	34.67	35.88	0.50 n.s.
SD	3.78	7.21	(df=26)
POWERFUL OTHERS L/C	N=12	N=16	
M	21.25	15.63	1.27 n.s.
SD	11.16	10.83	(df=26)
CHANCE L/C	N=12	N=16	
M	23.17	16.69	1.58 n.s.
SD	10.34	10.09	(df=26)
ANTICIPATORY PREPARATIONS	N=10	N=7	
M	1.30	1.14	0.30 n.s.
SD	1.10	0.99	(df=15)

†two-tailed t-tests

## APPENDIX IV

TABLE 6

PRELIMINARY T-TESTS ON RAW SCORES OF  
DIALYSIS VS. TRANSPLANT PATIENTS

Variable	Dialysis	Transplant	t value
SELF-ESTEEM	N=28	N=27	
M	336.96	348.11	† 1.30 n.s.
SD	31.05	32.59	(df=53)
DEATH ANXIETY	N=30	N=27	
M	5.57	5.26	† 0.36 n.s.
SD	3.42	2.99	(df=55)
REPRESSION	N=30	N=27	
M	19.60	18.37	‡ 1.06 n.s.
SD	4.13	4.51	(df=55)
ANXIETY	N=30	N=27	
M	15.20	12.78	‡ 0.99 n.s.
SD	9.47	8.53	(df=55)
DEPRESSION	N=30	N=27	
M	28.87	23.63	‡ 3.06*
SD	7.01	5.53	(df=55)
INTERNAL L/C	N=28	N=27	
M	35.36	34.63	† 0.42 n.s.
SD	6.04	6.84	(df=53)
POWERFUL OTHERS L/C	N=28	N=27	
M	18.04	15.96	† 0.77 n.s.
SD	11.33	8.56	(df=53)
CHANCE L/C	N=28	N=27	
M	19.46	18.85	‡ 0.22 n.s.
SD	10.70	10.25	(df=53)
ANTICIPATORY PREPARATIONS	N=17	N=24	
M	1.24	2.21	‡ 2.38**
SD	1.06	1.38	(df=39)

† one-tailed t-tests

\*  $p < .01$ 

‡ two-tailed t-tests

\*\* $p < .05$

## APPENDIX IV

TABLE 7

PRELIMINARY T-TESTS ON RAW SCORES OF  
MALE VS. FEMALE PATIENTS

Variable	Males	Females	t value
SELF-ESTEEM	N=32	N=23	†
M	348.03	334.65	† 1.57**
SD	27.64	36.42	(df=53)
DEATH ANXIETY	N=33	N=24	†
M	4.70	6.42	† 2.05*
SD	2.79	3.51	(df=55)
REPRESSION	N=33	N=24	+
M	18.55	19.67	+ 1.56*
SD	4.71	3.72	(df=55)
ANXIETY	N=33	N=24	+
M	12.79	15.79	+ 1.24**
SD	8.45	9.70	(df=55)
DEPRESSION	N=33	N=24	†
M	24.94	28.38	† 1.92*
SD	6.74	6.52	(df=55)
INTERNAL L/C	N=32	N=23	†
M	36.41	33.04	† 2.01*
SD	5.26	7.39	(df=53)
POWERFUL OTHERS L/C	N=32	N=23	†
M	14.41	20.65	† 2.40*
SD	9.57	9.72	(df=53)
CHANCE L/C	N=32	N=23	+
M	16.88	22.35	+ 2.00*
SD	9.44	11.01	(df=53)
ANTICIPATORY PREPARATIONS	N=26	N=15	+
M	1.96	1.53	+ 0.96 n.s.
SD	1.45	1.08	(df=39)

† one-tailed t-tests

‡ two-tailed t-tests

\* p &lt; .05

\*\*p &lt; .10



## APPENDIX V

TABLE 8

VARIABLE T-SCORE MEANS AND STANDARD DEVIATIONS  
FOR EACH TREATMENT GROUP\*

Variable	Transplant	Dialysis
SELF-ESTEEM	N=27	N=28
M	51.65	48.42
SD	10.38	9.31
DEATH ANXIETY	N=27	N=30
M	49.77	50.21
SD	10.00	10.01
REPRESSION	N=27	N=30
M	48.49	51.37
SD	10.36	9.46
ANXIETY	N=27	N=30
M	48.73	51.13
SD	9.58	10.22
DEPRESSION**	N=27	N=30
M	45.90	53.69
SD	8.28	17.59
INTERNAL L/C	N=27	N=28
M	49.42	50.56
SD	10.39	9.57
POWERFUL OTHERS L/C	N=27	N=28
M	48.98	50.99
SD	8.49	11.16
CHANCE L/C	N=27	N=28
M	49.63	50.36
SD	9.10	10.79

\*T-scores based on sex grouping

\*\*p < .01

## APPENDIX VI

PATIENTS' ANTICIPATORY PREPARATIONS  
FOR POSSIBLE DEATH

Seventy-six percent of the patients in this study answered the Anticipatory Preparations Questionnaire. In regard to legal preparations, 49 percent of the respondents had executed a Will and 70 percent with minor children had made provisions for a legal guardian. Lucas (1972) found that approximately one-third of dialysis males had prepared a Will, and cited 1970 statistics which indicated that only one-fourth of the general adult population had Wills. Twenty-four percent of the respondents in this study reported having made religious or spiritual preparations for death. Within the practical realm, only 15 percent had obtained information regarding funeral and/or burial costs. Since several patients mentioned that they should have attended to some kind of preparations for death but had not gotten around to it, this item may be more anxiety arousing and thus subject to greater avoidance than the other preparations. Along altruistic lines, 32 percent had communicated their desire for charitable donations in lieu of flowers at their funeral, and the same percentage had made arrangements to donate their eyes for corneal transplants. This idea had not occurred to a few dialysis patients who were waiting for kidney transplants, and they indicated that they would make such arrangements in the near future.

## APPENDIX VII

## CORRELATIONAL ANALYSES

Several correlational analyses were obtained to replicate relationships found between the variables in this study with others which utilized different populations.

Given the sex differences previously reported on death anxiety measures (Berman & Hays, 1973; Lester, 1971; Selvey, 1973; Templer & Ruff, 1971a, 1971b) and on measures of psychological discomfort (Chesler, 1971; Silverman, 1968), the finding that females scored significantly higher on the Death Anxiety Scale and the MMPI Depression Scale is not atypical.

Since self-esteem has been conceptualized as the best representation of personality strength promoting effective functioning in a stressful situation (Fitts, 1969, 1972), the negative correlations with anxiety and depression were not unexpected. Further, anxiety and depression were positively correlated.

Significant correlations were also obtained which replicated prior research findings regarding locus of control orientation. Self-esteem was positively related to internality, and negatively associated with powerful others and chance locus of control orientations. Internality was negatively related to anxiety and depression, chance locus of control was positively related to anxiety and depression, and the same

relationship was found for powerful others and anxiety as well as depression. In line with Levenson's (1971) research on the development of the I, P, and C Scales, the Chance and Powerful Others Scales correlated significantly with each other, and both were negatively related to the Internal Scale.

Significant sex differences were found on the I, P, and C Scales. Females scored significantly higher on the Powerful Other and Chance Scales, and males scored significantly higher on the Internal Scale. It may be, as Nowicki has suggested, that sex role expectations reinforce internal responding in males, while externality is more in agreement with the behavior expected of females.

Rotter's I-E Scale was administered after data collection had been completed in order to obtain correlations with the I, P, and C Scales. The I-E scale was mailed to fifty patients (four of the original fifty-four patients had died) and of these, thirty-eight were returned. The correlations between these two scales are presented in Table 9.

TABLE 9

## CORRELATIONS BETWEEN I-E AND I,P,C SCALES

	Internals	Powerful Others	Chance	F(1, 36)
I-E Scale	r= -0.544*			15.156*
(scored in external direction)	r <sup>2</sup> = 0.296	r=0.509* r <sup>2</sup> =0.259	r=0.533* r <sup>2</sup> =0.284	12.599* 14.274*

\*p &lt; .01

TABLE 10

## INTERCORRELATIONS OF VARIABLES FOR TRANSPLANT PATIENTS (N=27)

Variable	Sex	Length of Treatment	Self Esteem	DAS	Repr	Anx	Depr	Int	PO	Chance
Sex	1.000									
Length/ Treatment	0.151	1.000								
Self- Esteem	0.088	0.109	1.000							
DAS	-0.079	0.407**	-0.246	1.000						
Repr	-0.099	-0.118	0.150	-0.035	1.000					
Anx	-0.004	-0.062	-0.592*	0.512*	0.019	1.000				
Depr	-0.151	-0.163	-0.414**	0.241	0.464**	0.682*	1.000			
Int	0.297	0.051	0.060	0.188	-0.183	0.170	-0.237	1.000		
PO	-0.294	-0.018	-0.441**	0.147	0.232	0.502*	0.565*	0.078	1.000	
Chance	-0.424**	-0.319	-0.324	0.057	0.056	0.535*	0.551*	-0.095	0.613*	1.000

\*p &lt; .01    \*\*p &lt; .05

TABLE 11

INTERCORRELATIONS OF VARIABLES FOR DIALYSIS PATIENTS (N=27)

Variable	Sex	Length of Treatment	Self Esteem	DAS	Repr	Anx	Depr	Int	PO	Chance
Sex	1.000									
Length/ Treatment	-0.010	1.000								
Self- Esteem	0.283	0.074	1.000							
DAS	-0.446**	0.217	-0.503*	1.000						
Repr	-0.150	0.004	-0.105	0.142	1.000					
Anx	-0.317	-0.220	-0.646*	0.615*	0.025	1.000				
Depr	-0.327	-0.157	-0.588*	0.476**	0.353	0.725*	1.000			
Int	0.288	0.030	0.389**	-0.535*	-0.329	-0.416**	-0.354	1.000		
PO	-0.332	-0.365	-0.241	-0.001	-0.024	0.232	0.230	-0.265	1.000	
Chance	-0.139	-0.337	-0.225	-0.021	-0.003	0.396**	0.368	-0.119	0.655*	1.000

\*p &lt; .01    \*\*p &lt; .05

TABLE 12

INTERCORRELATIONS OF VARIABLES FOR  
DIALYSIS AND TRANSPLANT PATIENTS (N=54)

Variable	Sex	Length of Treatment	Self Esteem	DAS	Repr	Anx	Depr	Int	PO	Chance
Sex	1.000									
Length/ Treatment	0.064	1.000								
Self- Esteem	0.183	0.091	1.000							
DAS	-0.276**	0.297**	-0.378*	1.000						
Repr	-0.124	-0.054	0.030	0.058	1.000					
Anx	-0.169	-0.151	-0.618*	0.570*	0.022	1.000				
Depr	-0.249	-0.159	-0.503*	0.383*	0.396*	0.705*	1.000			
Int	0.292**	0.040	0.208	-0.176	-0.249	-0.119	-0.294*	1.000		
PO	-0.313**	-0.230	-0.324**	0.056	0.087	0.338*	0.350*	-0.105	1.000	
Chance	-0.278**	-0.329**	-0.275**	0.014	0.027	0.459*	0.442*	-0.106	0.633*	1.000

\*p < .01    \*\*p < .05

## APPENDIX VIII

## PATIENT INTERVIEWS

An additional facet of this study was the investigator's desire to gain a greater understanding of how patients cope with a serious illness and difficult treatment, as well as the consequences of a serious illness.

In talking with terminal cancer patients, Hinton (1975) found that "If the spouse indicated that the marriage was a happy and successful one, both they and the interviewer (who initially knew nothing of the quality of their relationship) found much less depression, anxiety or anger in the ill patients." (Hinton, 1975, p. 102). While this issue was only of tangential interest in this study and was, therefore, not quantitatively assessed, this investigator's subjective observations were in accord with those of Hinton.

Lucas (1972) found that a majority of males on dialysis reported that their wives had provided the greatest assistance in helping adjust to their illness. Similarly, 80 percent of the patients in this study credited family and medical staff support as their most valuable coping resources. Patients were moved by the quality of staff concern and dedication to their welfare; one remarked that the personal concern of the unit Director improved her physical, as well as emotional, condition. It appeared that optimal spouse concern and support not only provided a vehicle for patients to share their feelings, but that an understanding yet not overly sympathetic spouse seemed to be a valuable resource in helping patients contend with recurring depression.

However, 14 percent of the patients interviewed reported distress over the lack of understanding from family and friends regarding their illness and lack of energy or comprehension of the difficulties involved in dialysis treatment. A possible basis for this lack of understanding may be the fact that dialysis patients, with some exceptions, generally do not appear to be ill. Low hemoglobin level and consequent anergia are not outwardly visible to others. There is also the common misconception that if a patient is undergoing treatment, without knowing the ramifications of such treatment, then all is well.

Several patients expressed anger at being pressured by their families to participate in some activities for which they did not have sufficient energy. A transplant patient, whose condition had severely deteriorated while on dialysis and who still cannot work for extended periods without resting, felt that others sometimes perceive him as lazy. Another



transplant patient was irritated that he had received no visits from friends while undergoing dialysis, as would have been the case had he been hospitalized for a straightforward operation, and by ignorant comments from people who perceived dialysis as "a breeze." In contrast, two female patients, who had childhood histories of renal problems, found it difficult to deal with continued overprotectiveness and being perceived as fragile.

Patients were also asked the best and worst possible things that could happen in terms of their present treatment modality. Not surprisingly, 100 percent of the dialysis patients mentioned a transplant as the best. Of these, 33 percent specified a transplant without complications. As one patient who had already experienced two transplant rejections expressed it, this would be worse than his present situation because he was currently doing well on dialysis. Earlier in treatment when he "didn't know any better," his tolerance for complications was higher, but a long standing stabilized condition had raised his expectations.

Fifty percent of the transplant patients were well satisfied with their status quo, and said "things couldn't be better." Ten percent would have liked a better functioning transplant and were concerned about how long their present one would last. Twenty percent expressed hope for reduced side effects from steroids, or that doctors would be able to treat any that did occur, or develop a drug to permanently prevent rejection.

For 88 percent of the transplant patients, their pre-transplant expectations had been fulfilled or surpassed. Many were aware that it was a temporary reprieve from dialysis; for some their graft had already been functioning longer than originally expected. One patient felt that it would have been easier to return to dialysis had his transplant lasted only two or three years as anticipated, but after more than five years he would have to learn to accept dialysis all over again.

Regarding the worst that could happen, 90 percent of the transplant patients referred to rejection or having to go back on dialysis. Ten percent mentioned dying or developing any form of cancer as a consequence of taking steroids.

The majority of dialysis patients said that the worst that could happen would be to die (42 percent), or to regress to their former level of acute illness or become very ill and be totally dependent (37 percent).

One salient factor emerged in patients' responses to the above question. Within each treatment group there is considerable underlying anxiety related to regression. For dialysis patients, the fear is regression to death or total dependence.

Transplant patients verbalized considerable anxiety over the possibility of regressing back to dialysis. One transplant patient still had to fight back tears when talking about his dialysis experiences. Another referred to his "total abhorrence" of dialysis, saying it was a part of his life he had "wiped out," and said he would commit suicide rather than return to dialysis.

Thirty-three percent of the patients reported that they never thought of chronic renal failure as fatal, or that a shortened life span may have been of brief concern when initially diagnosed, just beginning treatment, or during acute illness, but no longer. One transplant patient specifically expressed greater fear of "getting sick again" but never thought of the possibility of dying. Of this group who verbally denied any current death fears, 78 percent were transplant patients. Thus, despite the significant positive correlation between length of treatment and death anxiety for transplant patients, some exhibited reactions in the interviews in line with that described by Crombez and Lefebvre (1972). These authors described transplantation as providing a new "screen" defense against death anxiety, to wit: "Transplantation is invested with magical powers, by which death is thrown back into the past and free access opened to an unlimited future." (Crombez & Lefebvre, 1972, p. SS-20). However, the same patient often exhibits considerable variance in his willingness at any point in time to discuss feelings about death. The fact that the investigator had more continuous contact with dialysis patients over an extended period of time, and occasionally happened to talk with them at an opportune time, as compared to transplant out-patients, may have influenced the foregoing results.

An equal number of patients (16 percent) indicated never having had the desire to talk with anyone regarding their feelings about death as those who had done so. Of the latter group, most had not found it helpful because of the frustrating inability of their spouses to discuss what they perceived as a morbid subject.

Thirty percent of the patients said they would prefer death to continuing to live under certain circumstances. Most often mentioned were total dependency resulting from a stroke, paralysis, or blindness, which patients sometimes referred to as a "living death" or being "buried alive." Two patients said it would be better than suffering severe physical deterioration and becoming a burden upon their families, and three said it would be preferable to the alternative of being on dialysis "forever."

For 19 percent of the patients, death was too anxiety arousing a subject for discussion. This was communicated in such statements as trying not to think about it very much and

having no desire to do so, or being too frightened or depressed by such thoughts. A few patients who were unable to deal with this topic for any length of time admitted considerable anxiety in between flitting back and forth from irrelevant topics to their illness and its consequences. One patient was unable to talk about death at all in relation to his illness, but after blocking that avenue of conversation, continued throughout the interview to insert references to death in terms of various hazardous occupations and other dangerous situations. Another was unable to discuss any aspect of his illness, and avoided dealing with any emotional topics by focusing the interview exclusively on the machine and dialysis procedure.

Of the patients who had given considerable thought to imagining what death would be like, several had traditional religious conceptions. These ranged from a belief that one is tested by struggles on earth for a later and better life in heaven, certainty of the existence of a supreme being although not necessarily God as traditionally conceptualized, to "peace" and a belief in reincarnation. One patient defined death as "no feeling, you're no place," and another as "total thought," rejecting the traditional conception of heaven and hell but believing that the soul survives in some kind of energy form.

Many patients exhibited marked ambivalence in their discussions of death. Feifel (1969b) has described this ambivalence as ". . . a subtle equilibristic balance between realistic acceptance of personal death and its simultaneous rejection. Denial of death is chaperoned by a coexisting realization of advancing death. Avoidance, anxious hope, uneasy resignation, calm acceptance--all display themselves in fluctuating array." (Feifel, 1969b, p. 670). Patients on varying occasions appeared to vacillate between statements which indicated an acceptance of dying whenever one's time comes, learning from childhood experiences to live one day at a time, and so on, to admissions of fear or unreadiness should they learn that death was imminent.

Because of its finality, death may be an inherently ambivalent area. However, the nature of chronic renal failure and treatment therefor may to some extent add to this ambivalence, since individual prognosis and the possibility of death is ambiguous. Some patients pull through acute crises; others may die suddenly and unexpectedly. It was often difficult to ascertain whether patients sometimes simply did not wish to confront their underlying feelings regarding the gravity of their situation, or whether they felt that since it was pointless to worry about a possible future occurrence, the best approach was to continue with their life activities as best they could and enjoy life as long as possible. Because of the

temporary nature of the relationship with these patients in a research study, the interviewer was apprehensive about probing into patients' verbal contradictions and ambivalence.

However, it was the investigator's impression that many patients utilized suppression, rather than repression, in their discussions of death. The importance of having an empathic listener available when patients are psychologically ready to ventilate their feelings appears to be essential. For example, one patient verbalized his own concerns about how long he could survive on dialysis in relation to the death of another patient which had occurred several months earlier. Another explicitly stated his unwillingness to discuss such an upsetting subject just after the sudden death of a patient who had been on dialysis for a number of years, and admitted heavy reliance upon control over his feelings and allowing others to know him only at a superficial level. As Cutter (1970) pointed out, "The death of someone close forces individuals to evaluate their own termination, a subject most seek to avoid." (Cutter, 1970, p. 46). Apparently, the death of another dialysis patient necessitates temporary avoidance because of overwhelming anxiety, until the passage of time allows sufficient distance for conscious defenses to subside and enables patients to deal with their feelings. Because of their possible death, the risk of becoming too involved with other patients was directly referred to by only one patient, but this feeling was also subtly perceived to exist in other patients.

Patients' initial reactions to their diagnosis of chronic renal failure can be divided into four general categories: denial, anxiety, relief, or anger. These are overlapping rather than discrete categories, with some patients mentioning more than one reaction.

From previous reports in the literature, it was not surprising that denial was most often mentioned. Thirty-three percent of the patients reported this reaction, and this figure is undoubtedly a conservative one, since nearly 40 percent of the patients could not recall their initial reaction.

Many patients related what Weisman (1972) has referred to as "first-order denial." This was often expressed through denial of the need for any treatment beyond medication and diet management, with the accompanying belief that following the doctor's orders and taking care of oneself would maintain good health. Frequently, patients remembered resisting the need to institute dialysis while they still had some kidney function remaining.

There were also numerous indications of "second-order denial," referring to the inferences that a patient does or

does not make about the extension and implications of his illness (Weisman, 1972). When initially diagnosed, one patient remembered his determination to "lick it [chronic renal failure] and get well and be perfect again." Another patient, who associated transplantation with cure, refused to answer some questions on the basis of not being sick.

For 17 percent of the patients, the diagnosis of chronic renal failure led to overwhelming anxiety, especially on learning that there was no cure. Patients reporting this reaction were generally given no information regarding the possibility of dialysis treatment at the time of diagnosis, possibly because they were diagnosed by physicians not associated with a renal unit. If death fears were alluded to by patients, generally they were not adequately dealt with by the original physician.

A discouraging number of patients (30 percent) reported a feeling of relief on being diagnosed, often mentioning their prior inability to adapt to the unknown. Often these were patients who were ill for a considerable period of time and had sought medical attention, but did not receive proper diagnosis. Sometimes they were labeled as a "hypochondriac," suffering from nerves, or "suburban housewife syndrome," and began to doubt themselves as a result. On occasion, rapid deterioration in their condition resulted in acute illness and fortuitous last-minute referral to the dialysis unit.

Not surprisingly, the anger reported by 30 percent of the patients was often related to their perception of unnecessary suffering due to lack of correct early diagnosis and proper follow-up treatment.

In describing which aspects of treatment had been most difficult to cope with, 16 percent of the patients referred back to their period of either lack of correct diagnosis or subsequent ignorance of available treatment. One patient, who had heard of occasional renal failure fatalities, assumed that his illness was terminal during the first three weeks after diagnosis. When he first learned of dialysis, he imagined it to be like the artificial lung, requiring permanent attachment and a life of complete machine dependence. This same patient was one of the 8 percent who felt that a critical coping factor in treatment was to be able to dialyze at home and to "live essentially a normal life."

In view of the improved quality of life permitted by transplantation, it was not unexpected that transplant patients described various facets of dialysis as being the most difficult to cope with in treatment. An exception to this was the mention by one dialysis patient of a transplant rejection

causing particular problems, not only because of disappointment but due to a significantly changed physical appearance and weight gain.

Most patients (76 percent) referred to the salient characteristics of their restricted quality of life due to dialysis treatment: the time demands of treatment and long hours on the machine, diet and fluid restrictions, inability to travel or disruption of retirement plans, and tension due to the pain and potential problems associated with inserting needles during venipuncture.

Reichsman and Levy (1974) referred to the first six months on dialysis as the "Honeymoon Period," defining it as a ". . . period of marked improvement, physical and emotional . . . accompanied by a marked emergence of joie de vivre, confidence, and hope." (Reichsman & Levy, 1974, p. 36). However, 51 percent of the patients in this study cited their physical adjustment to dialysis during the first year of treatment as one of their most difficult coping periods. In addition to lack of energy and the unpredictability of not feeling well, or often feeling worse after a dialysis run, they found it difficult to accept their new limitations and mood swings, or to tolerate being around other people for any length of time.

The guilt of self doubt and fear of total physical regression were also prominent feelings during the early phase of treatment. One new dialysis patient, who was unable to work on the days after dialysis runs, was struggling with the issue of whether he was really that sick or was forming the bad habit of not going to work on those days, thinking he was more tired than he really was. High expectations for physical improvement from dialysis led to mood swings and feelings of despondency in a new patient, who admitted that if his present state of low energy and general malaise was "going to be the way it is from now on, it would be very very hard to accept." The inability to carry on former activities, some of which required only minimal effort, occasionally made him feel "stupid." Another patient was frightened by minor problems with eye-hand motor coordination and decreased concentration abilities while on dialysis, not knowing to what degree these deficits would extend.

Several of the patients who had been on dialysis for a number of years and whose hope for a transplant had greatly diminished, sometimes for physical reasons, experienced considerable difficulty in coping with their physical deterioration and uncertainty for any improvement. One patient, who did not require a bilateral nephrectomy for the first five years on dialysis, was subsequently required to readjust to dialysis. Not only was he then more dependent on the machine, but his resulting inability to work for an extended period of time after surgery led to total dependence on his family.

Consequently, it appeared that his prior adjustment by denial of illness and perceived superiority to more dependent patients, as well as his inability to compensate for his strong dependency needs, led to severe depression and emotional problems prior to his death.

Several patients reported significant effects on their life style or role fulfillment, including their inability to fulfill family responsibilities. Two female patients reported instances of tense and anxious behavior in their children which were directly related to their illness. One patient referred to three non-productive years at a critical time in his professional training, and the difficulty of regaining confidence in himself and his abilities after resuming his college studies. Another was wrestling with the monotony of not working and concerned about future employment, inasmuch as his illness precluded returning to his former occupation. A few patients had experienced permanent detrimental effects on their careers and accomplishments, and were despondent at not having been able to achieve sufficient independence from their parents.

When asked what they had learned about themselves as a result of illness and treatment, 30 percent of the patients responded in the negative. This may have reflected their reliance upon the mechanism of denial, as a few mentioned that it would be too upsetting to think about their situation very much. Eighteen percent reported less emphasis upon planning for the future and greater enjoyment of the present. One patient said that since life is very short, he tries to appreciate each day.

For a number of patients, their experiences had been growth enhancing. Eighteen percent discovered that they possessed previously untested strengths, 15 percent had grown spiritually and were less materialistic, and 9 percent reported being less frustrated now over minor problems. Fifteen percent had gained increased self acceptance and increased closeness as a family unit, and 9 percent subsequently had greater understanding of and empathy for others' illnesses.

## APPENDIX IX

## IMPLICATIONS FOR THERAPEUTIC INTERVENTION

It is clear that the aspects of a serious illness and treatment demands with which chronic renal failure patients must cope is an unenviable situation. The numerous difficulties confronting patients suggested several potential problem areas to which counselors working in the field should be alerted.

In-family organ donation can be a highly sensitive area. With adolescent patients in particular, parents may exert considerable pressure upon reluctant siblings to donate, without the knowledge of the medical staff. In the case of adult sibling donors, altruistic motives may conflict with anxiety and reluctance, to produce guilt and avoidance. Whether or not it is explicitly verbalized, a major source of guilt for the recipient in addition to depriving a healthy non-patient of an important organ, is the potential jeopardy and certain pain of major surgery that the donor must undergo, for a very different motivation from that of the recipient. The recipient's desire to reduce the number of dialysis treatments in any way possible, and angry impatience over delays caused by perceived avoidance on the part of the donor, adds to the recipient's burden of guilt. The resulting pattern of avoidance by both parties of an emotionally sensitive area may jeopardize their subsequent interpersonal relationship, unless it is dealt with directly.

In the case of a cadaver donor, guilt is reduced but still present. Patients may feel like vultures, waiting around to cannibalize the spare parts of unfortunate accident victims. However, in the rare event of the child cadaver donor, guilt may be particularly long lasting and pervasive.

There is also the problem of what Lifton (1967) has referred to as guilt over 'survival priority.' As Lifton developed the concept from his studies of Hiroshima victims, 'the survivor's unconscious sense of an organic social balance . . . makes him feel that his survival was purchased at the cost of another's.' As Foster, Cohn, and McKegney (1974) applied the concept to hemodialysis, they posited that patients' indifference to group life on a renal unit not only insulates them against the ever-present possibility of imminent death, but eases survival guilt by defending against responsibility for another's death. In addition, however, there is also the possibility of patients experiencing guilt when they receive a kidney transplant prior to other patients who are having a much more difficult time on dialysis, or who have been awaiting one for a longer period of time. Several



of the patients who expressed such feelings were also uncomfortable about not having maintained contact with some of the patients who were still on dialysis, and "transplant priority" guilt was suspected as one of the reasons therefor.

Counselors should be aware of Janis' (1958) studies in working with patients who are transplant candidates, as well as those likely to undergo other kinds of surgery in the regular course of treatment. Janis' extensive work with surgical patients demonstrated the effect of pre-operative emotional reactions upon post-operative outcome, and the importance of appropriate preparatory communications for surgical candidates.

For dialysis patients in particular it would appear beneficial to provide a professional counselor who can function in the role of reality testing. One patient reported doing more thinking about herself while on dialysis than at any other time in her life, and statements by other patients in this study reflected the same process. Not only do the long hours on dialysis allow time for taking stock of oneself, but the situation precludes escape from constant reminders of illness and personal shortcomings. Under these circumstances, guilt over past misdeeds or failures appears to be magnified. Patients are more likely to talk openly with someone not directly involved in their treatment, especially in a small chronic unit with close staff contact.

In a chronic unit with close staff-patient contact, there is always the possibility of interpersonal conflict due, for example, to patients' passive-aggressive non-compliance with treatment demands or acting out based on underlying fear. As a liaison between patients and staff, professional counselors could ease such tensions through psychological interpretations of patients' behavior and suggest different approaches to specific problems to help the staff work more effectively with patients.

In addition, counselors could provide the staff with information important in the care of seriously ill chronic patients, such as their reactions to and perception of their illness and treatment, ongoing relationships with significant other people in their lives, and perceptions of the staff. Counselors could also assist in helping to discriminate individual differences in how much realistic information patients desire about their illness and treatment, or point out informational gaps or misperceptions that need to be clarified by the medical staff. There may also be the need to assist some staff members in working out their own feelings about death.

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