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#### Stress inoculation education and counseling with patients on hemodialysis: Effects on psychosocial stressors and adherence

Courts, Nancy Fleming, Ph.D.

The University of North Carolina at Greensboro, 1991

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## STRESS INOCULATION EDUCATION AND COUNSELING WITH PATIENTS ON HEMODIALYSIS: EFFECTS ON PSYCHOSOCIAL STRESSORS AND ADHERENCE

by Nancy Fleming Courts

A Dissertation Submitted to the Faculty of the Graduate School at The University of North Carolina at Greensboro in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy

> Greensboro 1991

Approved by

**Dissertation Advisor** 

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# **APPROVAL PAGE**

This dissertation has been approved by the following committee of the Faculty of the Graduate School at The University of North Carolina at Greensboro.

**Dissertation Adviser**. **Committee Members** 

Date of Acceptance by Committee

august 28, 1991

Date of Final Oral Examination

COURTS, NANCY FLEMING, Ph.D. Stress Inoculation Education and Counseling with Patients on Hemodialysis: Effects on Psychosocial Stressors and Adherence. (1991) Directed by Dr. Nicholas A. Vacc. pp. 169

The purposes of this study were to (a) investigate the effects of the cognitive-behavioral intervention of Stress Inoculation Education (SIE) and counseling on anxiety, depression, psychosocial adjustment to illness, perception of hemodialysis stressors, and adherence to the medical regimen, and to (b) examine the relationship of psychosocial reactions and adherence to physiological problems while on hemodialysis. Two intervening variables, interpersonal support and control, were examined to determine their influence on adherence to the medical regimen and psychosocial variables. While physical and physiological demands of hemodialysis are universal, psychosocial responses to these demands are unique. Hemodialysis requires multiple and radical lifestyle changes and the anxiety and depression experienced by many patients justify the need for examining interventions to assist with the patient's adjustment.

A single-subject experimental design with multiple, repeated measures was used. Six subjects between the ages of 30 and 47, who had been on hemodialysis at least 6 weeks but not longer than 3 months, participated in six sessions of the intervention. SIE, based on the transaction model of stress as a relationship between person and environment, has three phases; i. e., conceptualization phase, skills acquisition and rehearsal phase, and application and follow-through phase.

The instruments used to examine change included the Clinical Anxiety Scale, the Generalized Contentment Scale, the Psychosocial Adjustment to Illness Scale Self-Report, and the Hemodialysis Stressor Scale. In addition, researcher-developed instruments included the Self Assessment Form for subjects to record daily perception of adherence to diet, fluid, and medication regimen and level of feelings, and the Physiological Data Form to document the number and type of problems experienced during hemodialysis. The analyzed data suggested that SIE and counseling was effective in reducing some problems for all subjects. All experienced lower post-test anxiety scores. Four experienced lower post-depression scores. Three subjects experienced a lower perception of hemodialysis stressors and four had a higher level of psychosocial adjustment to illness. There was no evidence, however, that SIE and counseling improved adherence to the medical regimen.

#### ACKNOWLEDGEMENTS

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# CHAPTER I INTRODUCTION

The number of patients who were on dialysis and/or who had a kidney transplant increased from 10,000 in 1972 to approximately 80,000 in 1984 (Jones, 1987). The projected figure for 1995 is an annual enrollment of 90,000 persons on dialysis (Lancaster, 1984). Government expenditures for the dialysis and transplant program each year are almost \$2 billion which does not include private insurance monies or Medicare and Medicaid monies for frequent hospitalizations and disability payments (Jones, 1987). As the population of hemodialysis patients continues to increase, with more patients beginning dialysis sooner and living longer, the costs involved also continue to rise.

As costs escalate, the societal ramifications of dialysis are currently being discussed by health policy makers. The personal and family ramifications of hemodialysis are all-encompassing for patients and their families; end-stage renal disease (ESRD) affects all body systems and all aspects of life (Lancaster, 1983). Hemodialysis, a life-saving treatment for people with ESRD, requires a complex medical regimen and radical changes in every aspect of life; physical, physiological, psychological, social, and cultural. The duration of the treatment often determines how drastic lifestyle changes are perceived to be (Kneisl, 1986). Further, for most hemodialysis patients, the lifestyle changes are difficult because they are permanent.

In order to decrease the physical, physiological, and psychosocial complications of hemodialysis, it is important to follow the medical regimen and adjust to the lifestyle changes. This includes restricted diet, limited fluids, and a rigid medication schedule. Stamina and commitment are required if a patient is to follow the constant, demanding, and unrelenting process of hemodialysis. The actual process of dialysis requires three to four hours of time three days a week. Physiological changes while the patient is connected to the hemodialysis machine can cause nausea, vomiting, hypotension, and leg cramps. Access to the hemodialysis machine is provided by a Gortex graft or a shunt which is used to connect an artery and vein. The graft or shunt is unsightly, requires special care, and often becomes clotted and/or infected. In addition, there are many other common physical and physiological problems such as brittle hair and nails, dry and scaly skin, osteodystrophy, sexual impotence, overwhelming fatigue, pruritus, anorexia, constipation, insomnia, and gastritis.

The restrictions of the medical regimen, amount of time involved in the process of hemodialysis, overwhelming fatigue, and dependency on a machine stimulate a variety of emotions. Depending on the personality of the patient, these emotions may include grief, anger, aggression, reduced self-esteem, dependency-independency conflicts, helplessness, hopelessness, depression, and/or anxiety (Kasch, 1984; Reichsman & McKegney, 1978). Demands upon the patient can lead to losses in other aspects of life such as an inability to keep a job or community commitments, to enroll in school, to assure financial security, social position, and family roles, to plan for the future, and to maintain sexual potency.

The physical and physiological problems resulting from hemodialysis are concrete, obvious, and universal to all patients, but the psychological and social responses are unique to the individual. Psychological and social responses are incorporated in the term "psychosocial" (Weisman, 1984). Psychosocial includes both the mental processes (e. g., mood, affect, and quality of thought) and interactions among and between individuals and the environment (e.g., vocational, social, and domestic roles) (Barry, 1984; Derogatis, 1986; Derogatis & Lopez, 1983). Psychosocial health is the emotional and social counterpart of physical and physiological health and is as important to total well-being as physical health (Weisman, 1984). Since the extent to which patients follow the complex medical regimen influences the course of hemodialysis (Stevenson, 1984), physical, physiological, and psychosocial health are important for the total well-being of patients on hemodialysis.

Psychosocial problems of hemodialysis include loss of control and helplessness; problems that often result in depression (Folkman, Lazarus, Gruen, & DeLongis, 1986). Understandably, depression resulting from these losses and physical and physiological changes is common for patients on hemodialysis. In fact, it is viewed by most investigators as the most prevalent psychological problem of this population (Burton, Kline, Lindsay, & Heidenheimk, 1986; De-Nour & Czaczkes, 1976; Levy, 1979; Schreiber & Huber, 1985). Depression significantly affects compliance or the ability to follow the medical regimen (Craven, Rodin, Johnson, & Kennedy, 1987; De-Nour & Czaczkes, 1976). Burton et al. (1986) found that depression is a predictor of outcome for patients on hemodialysis; those with elevated depression had a greater risk of dying. Depression in patients on hemodialysis, moreover, is often accompanied by anxiety.

Anxiety, which is the most general human reaction to illness (Lambert & Lambert, 1985), is a response to threats of biological integrity and/or personal security. Anxiety affects thinking, behavior, and feeling (Kneisl, 1986). It is experienced as uneasiness, apprehension, or dread (Lambert & Lambert, 1985), and nervousness, tension, restlessness, and panic (Reichsman & McKegney, 1978). The degree of anxiety is associated with the severity of the threat or challenge, past experiences, learning, age, and emotional resources (Lambert & Lambert, 1985). Not surprisingly, anxiety is a problem for patients on hemodialysis because they experience severe threats to physical, physiological, and psychosocial integrity (K. P. Parker, 1981; Siegal, Calsyn, & Cuddihee, 1987; Stevenson, 1984); many rate themselves as anxious (Schreiber & Huber, 1985). Patients with high anxiety have been found to have increased fluid overload, episodes of cramping during hemodialysis, and an increased number of clinic appointments for problems (K. P. Parker, 1981). Because depression is the most common psychological problem of hemodialysis patients (De-Nour & Czaczkes, 1976; Hall, Root, & Vogel, 1979; Levy, 1979; K. P. Parker, 1981) and high levels of anxiety increase the problems of patients on hemodialysis (K. P. Parker, 1981; Siegal et al., 1987), alleviation of depression and anxiety are important for psychosocial adjustment.

Patients on hemodialysis share many of the physiological and psychosocial stressors that are common to people with other chronic illnesses. Stressors which are unique to this group of patients, however, include dependence on a machine for survival, limited fluid intake, physiological stressors that occur during hemodialysis, frequent intravenous needle insertions, and an inability to travel freely. Adjustment to hemodialysis is determined by how well patients manage these physiological and psychosocial stressors. The physiological stressors are influenced by the medical regimen, and the ability to manage the medical regimen is influenced by a number of psychosocial factors. Psychosocial adjustment is multidimensional in nature because it is composed of multiple domains that are strongly associated with salient role behaviors (Derogatis & Lopez, 1983).

The ability to follow the unrelenting medical regimen (i.e., the extent to which patients do what the health care providers prescribe) is known as compliance (Meichenbaum & Turk, 1987). Compliance and adherence (i. e., following the medical regimen) are terms used more or less interchangeably. Yet, there are subtle distinctions between them that require clarification. Compliance is affected by the degree of difficulty of the medical regimens (J. F. Miller, 1983; Yoos, 1981). To comply means to give in to requests or orders from an authority (Brown, 1979); it implies a passive acceptance or acceptability of one person with power over another. In contrast, adherence implies more active and collaborative involvement of patients in their own care (Meichenbaum & Turk, 1987). Adherence is the active, decision-making involvement of patients that occurs on a continuum; patients follow the rules and regulations at one extreme and violate them at the opposite extreme. Because adherence for patients on hemodialysis presents significant physical, physiological, and psychosocial challenges, interaction with and support of the family and other significant persons are important (O'Brien, 1980).

The process of adherence as defined by health care professionals, is a multifaceted phenomenon (Diamond & Jones, 1983). The attitudes of significant people in the patient's social environment impact on the process of adherence, just as extensive and complicated medical regimens affect the family as well as the patient (Meichenbaum & Turk, 1987). Quality rather than quantity of social support contributes to adherence. Although social support is multifaceted and has both positive and negative outcomes, it can

be a resource for patients on hemodialysis to increase adherence and psychosocial adjustment to illness. Support involves both giving and getting within interpersonal relations (Pearlin, 1985). Interpersonal support, then, involves both the opportunity and ability to "communicate with another person about personal problems" (Wills, 1985, p. 76).

Interpersonal support can increase the perception of control. When personal competence affects outcomes, individuals tend to perform at a higher level than they do in situations where, from their perception, they have no control (J. F. Miller, 1983). As Carpenito (1983) indicated, response to loss of control, such as that experienced by patients on hemodialysis, "depends on the meaning of the loss, individual patterns of coping, personal characteristics (psychological, sociological, cultural, spiritual), and the response of others" (p. 334). Loss of control also contributes to anxiety. Three types of control exist; behavioral, cognitive, and decisional (Averill, 1973). Behavioral control is action-oriented and, thus, can directly influence an event, cognitive control involves interpretation and/or evaluation of an event, and decisional control involves choices (Fuchs, 1987; J. F. Miller, 1983).

A number of studies have been conducted with patients on hemodialysis, but their findings are too divergent to present a clear picture (Schreiber & Huber, 1985). Problems with the research include a large number of variables, relatively small observed groups, differing methodologies, and samples from only one hemodialysis facility (Reichsman & McKegney, 1978). Further, the picture of adjustment has been confounded because patients have been interviewed at various points in the hemodialysis process (Hall et al., 1979). An additional challenge exists because many defense mechanisms that are considered maladaptive are adaptive for this population (Czaczkes & De-Nour, 1978). For example, people who exhibit external locus of control are frequently better able to handle the dependency on the machine than those who exhibit internal locus of control (De-Nour & Czaczkes, 1972). The consensus, however, is that psychosocial adjustment to illness and level of adherence are important aspects of overall adjustment to hemodialysis.

Response to hemodialysis appears to be affected by the ability of the patient and family to adapt to changes. Prater (1985) found that patients who are able to comply with the treatment regimen tend to cope better; they have infrequent episodes of clinical depression and are able to use well-developed support systems. Schreiber and Huber (1985) recommended that guidance and counseling for patients on hemodialysis and their significant others include both physiological and psychosocial interventions. Although both physiological and psychosocial factors are important for the well being of patients on hemodialysis, as supported by the literature, psychosocial and demographic variables are more important in terms of survival (Burton et al., 1986; Wai, Burton, Richmond, & Lindsay, 1981). There is evidence that depression significantly influences dietary adherence (Burton et al., 1986), so identification and incorporation of therapeutic interventions can have a positive impact on the experience of patients on hemodialysis and their families. Thus, early and effective counseling is needed (Cerlen, 1978).

#### Purpose of the Study

Interventions to help patients cope with hemodialysis stressors and lifestyle changes are important for a patient's psychosocial adjustment and adherence to the medical regimen. The purpose of this study, therefore, was to investigate the effectiveness of the cognitive-behavioral counseling intervention, Stress Inoculation Education (SIE) and counseling, with patients who have been on hemodialysis between six weeks and three months. SIE and counseling, which is comprised of three phases (i.e., conceptualization, skills acquisition and rehearsal, and application and follow-through) is especially appropriate for this population.

More specifically, the study focused on three questions: What are the effects of SIE and counseling on a patient's psychosocial reactions to hemodialysis?, What are the effects of SIE and counseling on a patient's adherence to the medical regimen? and What is the relationship of psychosocial reactions and adherence to the medical regimen to physiological reactions while on dialysis? The dependent variables were anxiety, depression, psychosocial adjustment to illness, identification of stressors, adherence to the medical regimen, and physiological responses

while on dialysis (i.e., nausea, vomiting, hypotension, and leg cramps). Two variables, interpersonal support and perception of control, were expected to influence the effect of the treatment on the dependent variables. The degree with which these variables are correlated with adherence and levels of anxiety and depression was also studied.

#### Need for the Study

The emotional difficulties of patients on hemodialysis have long been recognized, but no efficient method for meeting emotional needs has been identified (Lieber, Schlanger, & Levi, 1978). The hemodialysis population has been studied extensively with much research focused on psychological reactions to hemodialysis (David-Kasdan, 1984; Levy, 1978; Siegal et al., 1987). Research to facilitate psychosocial adjustment, however, has been minimal and unifocussed (Tucker, Mulkerne, & Ziller, 1982). The most frequently studied intervention with hemodialysis patients has been group therapy (Campbell & Sinha, 1980; Lieber et al., 1978; Tucker, Chennault, Green, Ziller, & Finlayson, 1986), while research using a cognitive behavioral intervention with people on hemodialysis, in terms of anxiety, depression, psychosocial adjustment to illness, stressor identification, and adherence, is nonexistent. However, as the number of patients on hemodialysis increases, the need for interventions that facilitate adjustment increases so that morbidity can be decreased, thus conserving resources and increasing "quality of life."

#### Significance of the Study

Identifying the therapeutic effects of SIE and counseling with patients on hemodialysis may (a) have a positive impact on the health care plan, (b) lead to incorporation of specific counseling interventions for patients and families, (c) provide workshop content to increase the expertise of hemodialysis nurses and technicians, (d) decrease morbidity and costs, (e) increase patient productivity, and (f) improve the quality of life for patients and families.

The relationship between counseling interventions and improved ability to maintain the medical regimen has implications for counselors working with other types of medical patients. There are a number of physical illnesses that have serious consequences if not controlled by the medical regimen (e.g., diabetes, hypertension, lupus, glaucoma). If individuals can be helped to incorporate the medical regimen into their lifestyles with minimum disruption of roles, responsibilities, and self-esteem, they may cope with the physiological and psychosocial demands of illness, be more cooperative with the health care regimen, and experience fewer complications. Therefore, a higher level of coping could decrease the physiological complications experienced, decrease the number of physician and hospital visits, lower costs of care for the patient and society, and increase the quality of life for patients and families.

## **Definition of Terms**

Definitions vary according to professional orientation and experience. Therefore, the definition of dependent and independent variables as they relate to this study and how they were measured are presented below. <u>Adherence</u>

Adherence is the active, decision-making involvement of patients in their treatment (J. F. Miller, 1983) and is based on a true partnership (Yoos, 1981). In this study, adherence to medications, diet, and fluids were measured by the Self Assessment Form found in Appendix A. The related physiological parameters of interdialysis weight gain, blood pressure, and serum levels of calcium and phosphorus were collected from the medical record when available. A form to collect this data, the Physiological Data Form, is included in Appendix B. Anxiety

Anxiety is an emotional state that is "characterized by feelings of tension, apprehension, nervousness, and worry" (Spielberger, 1983, p. 1). Anxiety was measured by the Clinical Anxiety Scale (CAS) (Corcoran & Fischer, 1987) which is included in Appendix C. <u>Control</u>

The perception of personal control as described by Averill (1973) is behavioral (i.e., direct action on the environment), cognitive (i.e., the interpretation of events), and decisional (i.e., having a choice among alternative courses of action). Perception of control was measured by questions on the psychosocial interview which is found in the Stress Inoculation Education and Counseling Manual in Appendix D.

#### **Depression**

Depression, as described by Wetzel (1984), occurs on a continuum and includes affective (i.e., sad, fearful, and hopeless), cognitive (i.e., agitation, poor concentration, and negative view of self), behavioral (i.e., dependence and control by others), and physical (i.e., low energy and anorexia) symptoms. Depression was measured by the Generalized Contentment Scale (GCS) (Hudson & Proctor, 1977) in Appendix E. Hemodialvsis Stressors

Many stressors to hemodialysis are unique and specific to this condition and process. The Hemodialysis Stressor Scale (HSS), in Appendix F, developed by Murphy, Powers, and Jalowiec (1985), was used to evaluate perception of the incidence and severity of stressors specific to hemodialysis. Both psychosocial and physiological stressors are included. Interpersonal Support

The definition of interpersonal support is derived from the writings of Pearlin (1985) who stated that support results from interpersonal relations, and the writings of Wills (1985) who distinguished between activities that divert from those that provide an opportunity to communicate about personal problems. Interpersonal support, then, is the ability to identify a significant person with whom one can and does talk about personal thoughts and feelings. Interpersonal support was measured with questions on the psychosocial interview in the Stress Inoculation Education and Counseling Manual in Appendix D.

#### **Physiological Responses**

Physiological responses while the patient is on hemodialysis are nausea, vomiting, hypotension, and leg cramps. These were measured by the Hemodialysis Experience Form, a self-report form in Appendix G. <u>Psychosocial Adjustment</u>

Psychosocial adjustment involves management of anxiety and depression and the interactions between the individual and the environment (Barry, 1984; Derogatis, 1986; Derogatis & Lopez, 1983). Measurement of psychosocial adjustment was based on the Psychosocial Adjustment to Illness Self-Report (PAIS-SR) (Derogatis & Lopez, 1983) in Appendix H.

#### Stress Inoculation Education (SIE) and Counseling

Based on Miechanbaum's Stress Inoculation Training (SIT), SIE and counseling, a cognitive behavioral counseling intervention based on the transaction model of stress as a relationship between person and environment, has both treatment and prevention components (Lazarus & Cohen, 1977; Meichenbaum, 1985). It is based on the assumption that functioning is controlled by thinking, feeling, and doing; i.e., cognitive, affective, and behavioral processes (Cameron & Meichenbaum, 1982). This intervention was implemented in six counseling sessions. The manual is in Appendix D.

## Organization of the Study

Depression, anxiety, and perception of hemodialysis stressors are frequent reactions for patients on hemodialysis and affect overall psychosocial adjustment to illness. Compliance or adherence is affected by and, in turn, affects psychological states. These categories are used to organize the literature review of hemodialysis research in of the first section of Chapter II. Research data on the use of social supports and issues of control are included. The second section of the literature review provides the theoretical base of stress as a transaction since this forms the framework for SIE and counseling.

Chapter III describes the methodology used to study the effects of SIE and counseling on psychosocial stressors and adherence. Included are the research questions and hypotheses, criteria and methods of subject selection, instruments, procedures, and data analyses. The results of the study are presented in Chapter IV. Summary, conclusions, implications for practice, limitations of the study, and recommendations are found in Chapter V.

# CHAPTER II REVIEW OF RELATED LITERATURE

This literature review is divided into two sections. The first section focuses on the hemodialysis literature concerning descriptions of the phases of psychosocial adjustment to hemodialysis, psychological issues and hemodialysis, compliance with the hemodialysis regimen, and interventions with patients on hemodialysis. The second section focuses on the literature concerning stress as a transaction between person and environment; the conceptual framework for stress inoculation training.

The Hemodialysis Literature

Hemodialysis provides a unique opportunity to study psychological adaptation and reaction to an artificial organ (De-Nour & Czaczkes, 1976), chronic illness, and radical lifestyle changes. Studies addressing hemodialysis have focused on a variety of aspects of adaptation: psychosocial factors affecting the adaptation of patients and their families, problems of interaction between facility staff and patients, quality of a patient's life, and rehabilitation levels (Reichsman & McKegney, 1978). Because there are serious consequences for those who do not follow the hemodialysis regimen which includes restrictions in fluid intake and diet, medication protocols, and drastic lifestyle changes, compliance or adherence and adjustment have been studied extensively. <u>Phases of Psychosocial Adjustment</u>

Adjustment to the restrictions and process of hemodialysis is considered to evolve through phases. In the early era of hemodialysis, people usually developed full uremic symptoms before beginning hemodialysis. Hemodialysis, therefore, drastically improved physiologic status and the patients quickly felt better. More recently, however, people are beginning hemodialysis when laboratory values first indicate the illness, (i.e., before the development of uremic symptoms) and, therefore, the necessity of hemodialysis has tended to be more difficult for them to accept. Three longitudinal studies examined the stages of adaptation to hemodialysis and one study has looked at role identities of patients on hemodialysis.

Abram (1969), a psychiatrist who was involved with selecting patients for hemodialysis and working psychotherapeutically with selected patients over a two-year period, described four stages in adaptation; (a) the Uremic Syndrome, (b) the Shift to Physiological Equilibrium (dialysis), (c) Convalescence or Return to the Living (third week to third month), and (d) the Struggle for Normalcy or the Problem of Living Rather than Dying (third to twelfth month). Abram found that during the second stage, Shift to Physiological Equilibrium, the focus was on a "return from the dead" since patients were moribund before dialysis. Apathy, euphoria, and anxiety were the dominant psychological reactions as this stage began. It was during the third stage, Return to Living, that patients became aware of the permanence of hemodialysis and experienced depression that required psychotherapy. During the Struggle for Normalcy, by which time the patients had usually returned to work, they again experienced depression as they dealt with the problems of living and the complications of dialysis, and questioned the worth of the process. In contrast, the average patient today probably begins dialysis before symptoms appear, has an automatic opportunity for dialysis, and is not employed but receives disability monies.

Reichsman and Levy (1972) described three stages of adaptation to hemodialysis on the basis of their study of 25 patients. The first stage, Honeymoon, occurred with the initial physiological improvement in the first three weeks after beginning hemodialysis. This stage which lasted from six weeks to six months, ended abruptly when patients began to resume roles and activities. The second stage, the Period of Disenchantment and Discouragement, was accompanied by stress, feelings of sadness, helplessness, and medical complications as patients began to struggle with the permanence of life on the machine. In the final stage, Long-term Adaptation, patients showed wide variations in coping and depressive affects.

Abram (1969) and Reichsman and Levy (1972) conducted their studies during the period when patients were uremic before beginning a dialysis program. When hemodialysis became available for more patients, Levy (1973) concluded that the stages were probably less well delineated for patients who began dialysis sooner.

A more recent adaptation model was proposed by Ulrich (1987), who identified a five-stage model as follows: (a) Fear, (b) Honeymoon, (c) Self-perception of Reality, (d) Effort Toward Maximum Potential or Exaggeration of Limitations and Deemphasis of Potential, and (e) Stabilization. The initial reaction to hemodialysis is fear, confusion, and a general feeling of being overwhelmed; feelings that are appropriate and are experienced by most patients to some extent. The first stage, Fear, lasts from several days to a few weeks. The Honeymoon lasts from a few weeks to several months. During the third stage, Self-perception of Reality, patients begin to recognize the permanence of hemodialysis and their limitations and potentials. During the fourth stage, patients decide whether to emphasize limitations or potentials, but it is unclear what factors influence this crucial decision (Ulrich, 1987). Whatever role patients choose, Stabilization (the fifth stage), tends to occur. However, crisis events and complications such as access failure or infection can reinstitute the process.

Artinian (1983) focused on roles instead of stages and examined how the lifestyle of patients on hemodialysis changed, forcing people to restructure the self in terms of roles. She conducted two or three interviews over a two-year period with 45 young adults between the ages of 18 and 30 to determine how these patients redefined their roles after the impact of dialysis. Five separate dialysis roles were identified; worker role, waiter role, emancipated role, undecided role, and true dialysis patient role. According to Artinian (1983), patients, following the diagnosis of ESRD, must decide whether to reject the sick role, accept the sick role and define themselves as sick, or accept the rights and privileges of the sick role but refuse its obligations. She found that those refusing the sick role were in the worker, waiter, or undecided roles. Patients who chose the worker role did not concentrate on dialysis and, as a result, others also tended to forget their limitations. Those in the waiter role could barely tolerate dialysis and were waiting for a transplant or waiting to die. Those in the undecided role had, in general, begun dialysis based on laboratory findings and had not experienced the physical and physiological problems of uremia. At the opposite end of this continuum were those in the true dialysis role; they had accepted the sick role and centered their lives around dialysis and the dialysis center. If the true dialysis role patients received a transplant or changed to peritoneal dialysis, they became emancipated. Each of these roles involved different patient needs and different interventions from health personnel.

In summary, each of the models of adaptation presented above describes an initial stage of disruption, a middle stage of working through problems and deciding about the future, and a final stage of positive or negative adaptation. Although the role descriptions do not describe stages of adaptation, they do describe levels of adaptation to hemodialysis, with numerous psychological variables appearing to influence a patient's ability to adapt.

#### **Psychological Issues and Hemodialysis**

A meta-analysis of 40 studies on variables predictive of hemodialysis adjustment found the best predictors to be pre-dialysis functioning, family relations, and personality (Olsen, 1983). Pre-dialysis functioning accounted for 28% of the variance in adjustment and family relations accounted for 20% of the variance. Also, support and family closeness were strongly related to compliance and vocational adjustment. Although personality accounted for only 18% of the variance in adjustment, it had the highest statistical significance. Sub-analyses of personality variables demonstrated that anxiety, locus of control, and depression were significantly related to adjustment. High anxiety was associated with poorer emotional adaptation, and internal locus of control was related to adjustment and to compliance and vocational adjustment. Interestingly, although depression was not a statistically significant predictor of adjustment, it was a significant predictor of compliance. The personality variables of anxiety, locus of control, and depression, which have been identified as predictors of adjustment and/or compliance with hemodialysis, and interpersonal support are discussed in more detail below.

Anxiety. K. P. Parker (1981) administered the Spielberger State-Trait Anxiety Scale to 43 subjects and then observed the 10 with the highest scores and the 10 with the lowest scores for four months. She found that, except for hypotension (low blood pressure), all the complications of hemodialysis were more common among the high anxiety group. Hypotension was more frequent in the low-anxiety group. Also, those in the high-anxiety group had a greater number of clinic appointments for problems and significantly more fluid overload.

Schreiber and Huber (1985) conducted a regional survey in Germany of 185 hospital hemodialysis patients and their significant others, to explore the patient's psychological well-being after beginning dialysis. Sixty-six per cent of the patients were rated by themselves and their significant others as more anxious after beginning hemodialysis, 64% as more nervous, 68% as more tense, and 53% as more irritable. In an attempt to explore health related problems after 4 to 6 months of hemodialysis, Stevenson (1984) conducted one-hour private interviews with 10 patients on hemodialysis asking 43 open-ended questions. More than half of the patients identified anxiety as a problem. In another study, 101 hemodialysis patients completed the Brief Symptom Inventory (BSI), a self-report measure of psychological adjustment (Siegal et al., 1987). Results indicated that hemodialysis patients have more psychological symptoms than those who are not ill. Prevalent symptoms were somatic complaints, anxiety, and depression (Siegal et al., 1987).

Anxiety, obviously and understandably, is a problem for patients on hemodialysis. Some of the anxiety probably results from the dependenceindependence issues connected with the process of hemodialysis. Dependence on a machine for life itself is a fact, yet at the same time, patients are expected to be independent and to manage diet and fluid restrictions, lifestyle changes, and the process of hemodialysis. Therefore, an important aspect of psychosocial adjustment to hemodialysis is control.

<u>Control.</u> Control is a complicated issue because hemodialysis demands are somewhat paradoxical. A loss of control is experienced by patients on hemodialysis since life is regimented, complicated, and compromised. Freedom is lost in every aspect of life; freedom to make health care

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decisions, freedom to chose one's diet, freedom to work at one's occupational choice, and even freedom to chose activities because of the fatigue and time constraints of dialysis (Kasch, 1984). This loss of control leads to feelings of dependency and powerlessness. In a year-long psychiatric study of nine patients in Israel, De-Nour, Shaltiel, and Czaczkes (1968) identified the main problem for patients on hemodialysis as dependency.

Describing 15 years of group therapy with patients on hemodialysis, Lieber et al. (1978) found that ambivalence about being in a dependent position was a predominant theme. This dependency, according to the researchers, fostered an orientation toward external locus of control. However, they concluded that with therapy there was a gradual shift on the control continuum from external to internal. As patients became more internally oriented, they also became more self-confident and assertive. As De-Nour and Czaczkes (1972) found, hemodialysis can be a solution for those with a long-standing dependence-independence conflict. There are, however, some patients who choose to remain dependent (Lieber et al., 1978).

Goldstein and Reznikoff (1971) found that patients on hemodialysis evidenced a significantly greater degree of external locus of control than did patients with minor medical problems. They suggested that this might be because the patients on hemodialysis did not experience a return to health as did most medical patients. People on hemodialysis who had external orientation perceived that their behavior had little effect on their condition. In contrast, J. Parker (1984) administered Rotter's Internal-External Scale to a random sample of 29 hemodialysis patients and found that, although locus of control was important for assessing patients on hemodialysis, it was not predictive of adaptation. She found that 69% of the patients scored higher on the internal scale than on the external scale. Patients over 55 years old, on dialysis more than two years, men, and unmarried patients scored higher on the internal scale.

Perception of control is an important concern for patients on hemodialysis. Hartman and Becker (1978) interviewed 50 patients on hemodialysis and found that those who were able to maintain the medical regimen tended to report feelings of greater control over life events than did those who were less successful in maintaining the medical regimen. In addition, those who had an external or fatalistic orientation or a feeling of inability to control events were more easily frustrated. Somer and Tucker (1988), who administered a questionnaire to 68 patients on hemodialysis and their spouses, also documented that personal control over some aspects of life was conducive to compliance with diet. They concluded that personal control appears to be an important aspect of the quality of life for patients on hemodialysis.

Perception of control has important implications for the care of patients on hemodialysis. Patients who perceive that they have no effect on what happens and that their behavior is unrelated to their condition, may experience disastrous consequences (Goldstein & Reznikoff, 1971). Knowledge of a patient's perception of control could increase the effectiveness of interventions to increase adherence (J. Parker, 1984). Since maintaining some control is one of the most frequently used coping methods of patients on hemodialysis, interventions to increase control when and where possible are needed (Baldree, Murphy, & Powers, 1982). Patients on hemodialysis who perceive control as external also experience feelings of helplessness and hopelessness (Lieber et al., 1978). Not surprisingly, then, a major psychological problem for patients on hemodialysis is depression.

<u>Depression</u>. Depression is consistently identified as a consequence of hemodialysis. In a predictive study of the influence of personality on adjustment to hemodialysis, a predialysis personality assessment on 136 subjects was undertaken by De-Nour and Czaczkes (1976). The semistructured interview was followed by a detailed psychiatric report and a prediction of compliance, rehabilitation, and psychological condition, with an emphasis on anxiety, depression, suicidal ideation, and psychosis. Follow-up assessments, made at 6 (100 patients), 12 (86 patients), 24 (51 patients), and 36 (28 patients) months, demonstrated that depression was the most common problem; 53% of the patients were moderately to severely depressed. Depression significantly affected compliance, suggesting that dietary abuse had suicidal implications. De-Nour and Czaczkes (1976) were able to predict which patients would develop anxiety and depression, and to identify those who were at risk for suicide and/or psychotic complications. They concluded that predictable psychiatric complications resulted in death for a high proportion of patients in the early stages of hemodialysis.

Glassman and Siegal (1970) noted that dietary "indiscretion was tantamount to suicide" (p. 569). They studied seven patients and found that although their clinical impressions of patients on hemodialysis indicated lethargy and depression, the results of the California Personality Inventory (CPI) and the Shipman Anxiety and Depression Scale (SADS) were within normal ranges. They concluded that these patients dealt with stress using denial as an adaptive mechanism. The authors noted that the danger of such massive use of denial is that it might develop into delusion. They strongly suggested using clinical assessment in addition to pencil tests to identify depression in the hemodialysis population.

Wai et al. (1981) examined differences between survivors and nonsurvivors in a sample of 285 patients on a form of home dialysis. They looked at both physiological and psychosocial variables over an 18 month period. Psychosocial and demographic variables were more significant than physiological variables in determining survival. The survivors were younger and less depressed than the nonsurvivors. Stress related to the dialysis procedure was significantly higher (p<0.01) for the survivors. This finding was supported by Burton et al. (1986), who also found that depression was the primary variable for discriminating survivors from nonsurvivors. They studied a sample of 167 home dialysis patients and compared the 124 who survived with the 43 who died after a two-year period. Although the mean depression scores of dialysis patients were significantly higher than those of the general population, the mean depression scores of hemodialysis survivors were significantly lower than the scores of those who did not survive. Burton et al. (1986) identified two independent profiles of depression. Type I depression was associated with profound anxiety, social introversion, hypochondrias, and self-depreciation and was found in the survivor group. Type II depression was found in the nonsurvivor group; those with this type complained often, tended to

degrade themselves, and described themselves as worthless, undeserving, and downhearted.

Craven et al. (1987), who interviewed 99 hemodialysis patients, found that, overall, 20% had experienced a major depressive episode. For a majority (i.e., 70%) the depression followed renal failure. Common problems of these depressed patients (i.e., insomnia, loss of energy, and decreased sexual interest) were common problems of all patients on dialysis and they did not distinguish between the depressed and the nondepressed subjects. However, anorexia with weight loss was a symptom that distinguished the depressed group. Patients who had had a recent depressive episode tended to be female, younger in age, living alone, and unemployed. In another study, patients on hemodialysis who had limited ability to participate in physical activities exhibited more depressive symptoms than those who exercised moderately (Carney, Wetzel, Hagberg, & Goldberg (1986).

Depression, obviously, is a significant problem for patients on hemodialysis. It is, therefore, important that health care personnel not minimize depressive symptoms and dismiss them as normal symptoms among this population. Some of the somatic symptoms of depression tend to be similar to the somatic problems of hemodialysis (insomnia, anorexia, fatigue). Hence, it is particularly important that health care personnel caring for patients on hemodialysis be cognizant of other depressive symptoms so that appropriate interventions can be incorporated into the plan of care. One intervention that may prove helpful is identification of a confidant or interpersonal support person.

Interpersonal Support. Resources provided by interpersonal relationships are important in determining adaptation (Wills, 1985). However, the relationship between social support and illness adaptation is ambiguous, and findings of research are sometimes contradictory (Dimond, 1979). There are several models of social support. Social support can operate in main effect processes (i.e., operate irrespective of stress) and in buffering processes (i.e., operate during high stress times) (Wills, 1985). Support structure is the existence of interpersonal relationships, and support function is the extent to which the relationships are helpful (Cohen & Wills, 1985).

In spite of the research controversies, social support has been documented as helpful for patients on hemodialysis. Dimond (1979) assessed family support and looked at two indicators of adaptation: morale and changes in social functioning. She found that the social support variables were significantly associated with morale. Subjects with greater family expressiveness, a confidant, and higher morale had fewer medical complications. Free expression of feelings and encouragement of open expression of feelings within the family were significantly associated with better morale. Dimond (1979) concluded that social support aids adjustment to hemodialysis.

In a study by Siegal et al. (1987) psychological adjustment of patients on hemodialysis was also found to be enhanced by the quality, but not the quantity of social support. The quality of social support (helpfulness) of a confidant rather than the frequency of contact aided psychological adjustment as measured by the Brief Symptom Inventory. Overall, helpfulness of friends and a confidant, enjoyment of moderately strenuous exercise, and social services received were related to psychological adaptation. The higher the score on social support, the better the adaptation and the fewer symptoms experienced by the patient on hemodialysis. Neither the quantitative nor the qualitative measure of social support used by the medical staff was predictive of psychological adjustment. However, patients on hemodialysis for a shorter time reported more symptoms than those on hemodialysis longer.

Cummings, Becker, Kirscht, and Levin (1982) interviewed 116 subjects from two dialysis centers to determine the effects of social support on adherence to regimens. They used a three-item index to determine the extent of helpfulness of spouse, family member, and friends as perceived by the subject, and found no relationship between the measures of support and compliance.

In summary, anxiety and depression are commonly experienced by patients on hemodialysis. In addition, depression may be masked by the somatic symptoms of hemodialysis, so careful assessment is necessary.
Dependence on the dialysis leads to issues of control; the perception of lack of control increases feelings of helplessness and hopelessness and thus contributes to depression. Interpersonal support has been identified as a mediator of stress and may aid in the psychosocial adjustment of patients on hemodialysis. Anxiety, control, depression, and interpersonal support are all related to the issue of compliance.

### Compliance with the Hemodialysis Regimen

The terms compliance and adherence have been used interchangeably in the literature. More recently the term adherence has been used to stress active decision-making involvement by the client. However, because much of the hemodialysis research uses the term compliance, the same term will be used throughout this section.

There are three overall criticisms of the research on compliance to the hemodialysis regimen. First, measurement of the dependent variables of compliance has differed from study to study making it is difficult to compare results across studies (Ferraro, Dixon, & Kinlaw, 1986). A second weakness is that the research protocols to assess compliance may have biased the compliance data by functioning as interventions (Ferraro et al.,1986). A third criticism is that the importance of the time on dialysis is a significant variable that has been ignored (Ferraro et al., 1986; Hall et al., 1979). In spite of these problems, the research on compliance has contributed to an understanding of the problems of patients on hemodialysis.

Hartman and Becker (1978), using the Health Belief Model along with the additional concepts of control, family problems, and faith in doctors, interviewed 50 patients on hemodialysis and reviewed chart data for physiological compliance. They found that patients who were less likely to adhere to the regimen were also less worried about their disease, had less faith in all aspects of therapy, were less worried about the consequences of noncompliance, and had a more externally oriented control attitude. Conversely, patients who were more compliant believed that adherence to the regimen was important and reported higher levels of control over life events with less eagerness to accept the sick role. Also, the less adherent patients were more likely to be young, unmarried females with less social support who had been on dialysis for a shorter period.

In a study to identify the psychosocial correlates of compliance, Cummings et al. (1982) interviewed 116 patients and asked about their knowledge of treatment, health beliefs, treatment history, social support resources, personal characteristics, and adherence to the medical regimen. There was a strong correlation between self-report of medication and fluid intake and the physiological measures, indicating accurate patient reporting. There was no relationship between social support measures and compliance measures. However, patients who viewed their illness as disruptive to family life had poorer compliance. Older patients were somewhat more compliant and women were more compliant with fluid restrictions than men. Those who had been on dialysis for a longer period of time were poorer compliers, as were those who anticipated receiving a kidney transplant. Level of knowledge about treatment and medical regimen was not associated with compliance.

Lee, Patel, Bluestone, and Kaufman (1978) utilized the Current and Past Psychopathology Scale (CAPPS) for assessment of patients on hemodialysis and used interdialysis weight gain as a compliance measure. They found that chronic anxiety and depression plus "chronic characterological problems of dependence, anger, excitability, and impulsiveness" (p. 1241) significantly identified the noncompliers. De-Nour and Czaczkes (1972), too, found that the personality characteristics of low tolerance for frustration and sick role gains, both primary and secondary, were distinguishing factors between two groups designated as compliers and noncompliers. The noncompliers had lower frustration tolerance and tended to accept the sick role. De-Nour and Czaczkes (1972) also found that although "acting out" (i.e., the expression of unconscious aggression and hostility) was common to both groups, it was more common in the noncompliers. Eight of the ten patients who died during the study were noncompliers.

A group of 60 hemodialysis patients aged 60 and above were compared by McKevitt, Jones, and Marion (1986) to a group of 60 patients 59 and under; they were matched according to gender, race, and treatment modality. The elderly were more compliant with fluid restriction than were the comparison group, and the elderly living with other persons were more compliant than were the elderly living alone. Based on the Beck Depression Inventory (BDI), Mckevitt et al. (1986) found that 62% demonstrated some level of depression. In another study of adjustment of older patients, Schultz and Powers (1987) found that in their sample of patients 55 and older, the elderly experienced less interdialysis weight gain and spent significantly less time on dialysis, indicating more compliance with fluid and diet restrictions, although they ranked fluid restriction as a great stressor.

In a 20-month study, Gonsalves-Ebrahim, Sterin, Gulledge, Gipson, and Rodgers (1987), used a structured interview by a social worker, an unstructured psychiatric interview, and self-administered psychological tests. They found that 88% of the younger (ages 19-34) patients were noncompliant with the medical regimen. In addition, the younger patients had more financial difficulty although they were more often employed, were less likely to be married and more likely to live with parents, had more anger and tendency to act out, had more difficulty with restrictions, and exhibited less frustration tolerance and lower self-esteem.

Using two structured interviews, one in the beginning and one at the end of 3 years, O'Brien (1980) studied 64 patients to determine how attitudes and behaviors of significant others influenced compliance on a continuing basis. She found a statistically significant relationship between compliance and the patients' expectations of significant others in both primary (family and friends) and secondary (hemodialysis center personnel) support systems. At the second interview, the lowest level of compliance was reported by unskilled workers and those living alone, while the highest level of compliance was reported by professionals and those living with significant others. Patients who had never been married scored lowest on compliance. O'Brien found that at the time of the second interview, the patients' expectations of caregivers had a stronger correlation with compliance than the expectations of both primary and secondary support groups. Somer and Tucker (1988) found a relationship between the attitudes of spouses and compliance. They sent questionnaires to 68 spouses of patients on hemodialysis to determine the relationship between compliance and social, vocational, recreational activities, and marital adjustment. They found higher marital adjustment and engagement in life activities were significantly correlated with dietary compliance by the patient.

Hilbert (1985) found that higher levels of social support were associated with compliance. She administered the Inventory of Socially Supportive Behaviors (ISSB) to 26 subjects and collected self-report data on compliance. The directive guidance subscale of the ISSB was associated with higher levels of compliance. In another study Hilbert (1989) found no statistically significant relationship existed between social support and compliance. After administering a social support instrument, the Hemodialysis Stressor Scale (HSS), and collecting self-report data on adherence from 56 subjects, Hilbert concluded that problems with the measurement of social support may have contributed to the non-significant relationship.

In order to look at compliance without any possible intervention or patient contact that could be viewed as intervention, Ferraro et al. (1986) examined 98 patient records. Weight gain between dialysis treatments and serum levels of potassium, phosphorus, blood urea nitrogen (BUN), creatinine, and sodium were evaluated. These are measures of physiological compliance that are used to evaluate diet, fluid, and medication compliance with the medical regimen. The researchers found that more compliant patients were older white individuals who had been on dialysis for a short periods of time and had lost kidney function due to hypertension.

In summary, a relationship appears to exist between personality variables and compliance, with anxiety and depression adversely affecting compliance. The relationship between social support and compliance is not definitive and findings are sometimes contradictory. However, people who feel that they have more control tend to comply at a higher level than those who feel a lack of control. Identification of the variables that affect compliance can facilitate planning interventions.

#### Interventions with Patients on Hemodialysis

A majority of the hemodialysis research has been on personality characteristics, psychological consequences of hemodialysis, compliance, and adjustment. In contrast, there has been little research on counseling interventions to facilitate psychosocial adjustment and compliance for patients on hemodialysis.

Interventions for compliance based on the Health Belief Model were used by K. Parker et al. (1985) to help patients identify barriers and benefits of compliance and set goals. Physiological measures of weight. potassium, phosphorus, blood urea nitrogen, and blood pressure were used to measure adherence. The intervention consisted of eight nurse-patient sessions over a four week period. Physiological data were collected for a three month period of time before the intervention, during the four week intervention, and for a two month period of time after the intervention. The interventions consisted of helping patients identify problems in adherence to medical regimen, set goals, identify barriers to and strategies for adherence, and termination. K. Parker et al. (1985) found a significant drop in systolic and diastolic blood pressure during the intervention, but this was not maintained at the two-month evaluation. There was no change in the other physiological indicators of weight, potassium or phosphorous during or after the intervention. In spite of these findings, the subjects reported great interest and enthusiasm for the study. Further research was recommended to evaluate the effects of this intervention on psychological reactions such as anxiety, depression, body image, self-esteem, and locus of control.

Newton and Bohnengel (1978) studied the spouses of predialysis patients with ESRD using an experimental "psychoeducational" group, a control group with conventional group treatment, and a control group with no treatment. The psychoeducational interventions included information on stress, styles of coping, typical conflicts and affects that spouses experience, and the psychological stages that patients experience. The authors found that the predialysis group tended to be non responsive and did not show up for the meetings. These researchers concluded that although they supported prophylactic psychoeducation, this approach appeared inappropriate for spouses before hemodialysis actually began. They suggested that a better time for psychological intervention is when the patient is using less denial and significant others are experiencing anger.

Using a behavioral-ecological model which requires researchers and consultants to form a treatment partnership with the members of a community, Tucker et al. (1982) developed a treatment program for hemodialysis patients. This program consisted of four phases: (a) preassessment, (b) direct and indirect treatment, (c) peer facilitation training, and (d) post-assessment. Although the program seemed feasible, only eight subjects agreed to participate in the post-assessment data collection. Other evaluation data were collected from patients, nurses, and doctors about observed behavioral changes. The data suggested that the intervention resulted in positive psychosocial consequences for the patients and nurses who participated. Other outcomes of the interventions were increased patient morale, development of a social support system, and a positive social and physical environment.

In another study of group counseling at the same dialysis center (Tucker et al., 1986), 15 patients on hemodialysis completed an assessmentof-concerns inventory and identified adjustment difficulties caused by dependency; depression related to self-esteem and body image changes; stress related to concerns about death, sexual adequacy, and financial security; family relationships; and interpersonal difficulties. Based on these concerns, a program of group counseling was designed with five topics; (a) anxiety reduction, (b) marital happiness, (c) sexual enrichment, (d) personal happiness, and (e) self improvement. Patients were told about the format of the sessions and informed that they could attend sessions with no advanced notice and could participate or just listen. Ninety-five percent of the 55 participants thought the counseling sessions were very helpful; 80% reported improvement with anxiety and depression, 60% reported feeling better about themselves, 72% reported that the program had increased communication of feelings with family, and 5% reported no benefits.

In another group approach, Friend, Singletary, Mendell, and Nurse (1986) divided all ESRD patients at Harlem Hospital Center, New York City, into those who participated in a patient support group and those who elected not to participate. Before the intervention, the two groups of patients were similar on psychosocial and physiological measures. Those who participated survived substantially longer than those who had not participated. Absence of a record of patients' attendance at the sessions, however, is a weakness of this study, making it impossible to assess the relationship between frequency of attendance and longevity. Although education, age, religion, and marital status were not related to survival, the group members were similar in that all were black and were being dialyzed at an urban center.

In a study based on the Health Belief Model to improve compliance with the medical regimens of ambulatory hemodialysis patients, Cummings et a. (1981), divided 116 subjects into four groups: (a) a behavioral contracting group with a significant other, (b) a behavioral contracting group without a significant other, (c) weekly telephone contracting group, and (d) a control group. Data were collected before treatment, after a sixweek intervention, and three months after completion of the study. Dietary compliance was measured by mean serum potassium level and mean weight gain between dialysis treatments. Although the groups that received the interventions achieved a higher level of compliance, health beliefs were not predictive, nor did the effects continue through the three- month evaluation. These findings strongly suggest a need for long-term interventions.

Eleven dialysis patients, who had been referred for psychiatric consultations, completed a 10-session group therapy intervention in a study by Campbell and Sinha (1980). The sessions were one and one-half hours every week and were conducted while the patients were on the hemodialysis machine. The goals of the therapy were to produce cognitive and affective changes in relation to the illness and to change illness perception to a perception of challenge. Denial of illness and fear of death were the primary concerns of the group members; depression and apathy were also of concern. The outcome criteria used for evaluation included diet and fluid control, improved interpersonal communication, changes in attitudes and behavior, and decreased somatic complaints. The ratings were done, independently, by the psychiatrist and two nurses, for a total of 30 ratings per patient. At the end of 10 therapy sessions, 64% of the patients (N=7) were rated as good while the other four were equally divided between ratings of fair and poor. The authors concluded that group therapy while patients are on the machine provides direct confrontation of the physical disability and makes denial more difficult.

In summary, it seems that patients on hemodialysis respond to group interactions with positive psychosocial outcomes. It may be that the interpersonal support during the process of the intervention is helpful since behavioral interventions appeared to improve compliance. However, the effects on compliance did not continue through the two- and three-month evaluation.

#### <u>Summary</u>

Patients on hemodialysis appear to experience an adjustment process consisting of an initial period of disruption and a middle period of working through the problems before reaching some level of adaptation. Anxiety and depression are common experiences for most patients on hemodialysis. Control issues have been found to affect both depression and compliance with the hemodialysis medical regimen. Dependence-independence issues, too, have been found to influence adjustment to and compliance with hemodialysis. Although the research on social support is ambiguous, the consensus seems to be that social support is important to the adjustment process and compliance for hemodialysis patients.

Compliance appears to be affected by the psychosocial reactions of anxiety, depression, and psychosocial adjustment to illness along with issues of control and social support. Interventions to support adjustment and compliance for patients on hemodialysis have been mainly in the form of group interventions. The responses to the groups have indicated a decrease in anxiety and depression and an improvement in patient morale and social support but there was little support for long term compliance.

### Stress as a Transaction

The conceptualization of stress used in this study has evolved from models of stress as a response, a stimulus, and a transaction. Selye (1956, 1974) defined stress as a generalized physiological response to life events. Physiological responses are adaptive because they prepare people for "fight or flight," but they become maladaptive when they are prolonged; they can then lead to psychophysiological illness. In the stimulus model, stress occurs as the result of an environmental factor (i.e., professional stress, raising children, lack of money, war, famine, and hemodialysis), and the person responds to this event with strain and/or tension (Matheny, Aycock, Pugh, Curlette, & Cannella, 1986). From stress as a response to stress as a stimulus to stress as a transaction between a person and the environment is a logical conceptual progression.

In the transactional model, stress resides in the transaction between the situation and the person rather than in the situation or the person. The experience of stress is dependent on cognitive appraisal and occurs when demands are appraised as greater than coping responses to meet them (Lazarus, 1966, 1974). The person-environment relationship, therefore, is viewed as mutually reciprocal, dynamic, and bidirectional (Folkman et al., 1986). Stress is a complex emotion that includes subjective aspects (i.e., affect and cognition), behavioral aspects (i.e., action impulses), and physiological changes (Lazarus, 1974). The two processes that act as stress mediators are appraisal and coping, resources and strategies (Folkman et al., 1986).

# **Appraisal**

Appraisal is used to assess the fit between demands and personal coping strategies and resources available to meet the demands. This section will discuss demands and cognitive appraisal (i.e., primary appraisal, secondary appraisal, and reappraisal).

<u>Demands</u>. Demands result from internal, external, or physiological stimuli that require a response. Internal demands are self-generated and include ambition, control of emotional responses, responsibility for others, values, goals, and beliefs. External demands originate outside the individual in the environment and include life events like the death of a loved one, loss of a job or health, hemodialysis, and accidents (Matheny et al., 1986). Physiological demands occur as a reflex via the autonomic nervous system when the body experiences a trauma (e.g., a large burn or surgery) or malfunction of a body system (e.g., myocardial infarction, renal failure) (Clarke, 1984). Environmental demands are based on learning, both social and cultural.

The patient on hemodialysis experiences demands in all three domains; internal, external, and physiological. Hemodialysis creates internal demands because goals become impossible to achieve and valued role relationships are affected; it results in external demands since maintaining a job becomes difficult. Hemodialysis also creates physiological demands through changes in body systems and functions. Although the physiological demands are constant, the internal and external demands are based on cognitive appraisal.

<u>Cognitive Appraisal</u>. Cognitive appraisal is the process of evaluating the significance of transactions between persons and the environment (Folkman et al., 1986; Pollack 1984). Lazarus (1974, 1980) described three possible appraisal judgments: the transaction is irrelevant; the transaction is benign or positive; and the transaction is stressful. The latter are transactions that are threatening, harmful, or challenging (Folkman et at., 1986; Lazarus, 1974, 1980). Obviously, hemodialysis cannot be appraised as irrelevant or benign so it must, therefore, be appraised as stressful. The types of cognitive appraisal are primary and secondary appraisal, and reappraisal.

Primary appraisal evaluates the potential for harm or benefit (Folkman et al., 1986). The intensity and quality of a person's emotional response are determined by the primary appraisal, which is influenced by both internal and external factors (Lazarus, 1974, 1980). Appraisal is filtered through internal factors such as knowledge base, values, beliefs, goals, commitments, expectations, and resources (Folkman, Schaefer, & Lazarus, 1979). External factors include stressful environmental circumstances such as chronic life strains and negative life events, or persistent conditions requiring daily readjustments that interfere with roles (Pearlin, 1985; Thoits, 1986). Hemodialysis is both a negative life event and a persistent condition that requires daily adjustment and interferes with roles. Primary cognitive appraisal of hemodialysis, then, tends to be overwhelming as people become aware of the losses and changes that are required. Stressful primary appraisal is followed by secondary appraisal. Secondary appraisal follows a primary appraisal of harm and evaluates what can be done to decrease the threat or harm and improve the situation (Folkman et al., 1986). The processes of primary and secondary appraisal are interdependent and seem to occur almost simultaneously. The difference between the two processes is determined by the content of the appraisal (Lazarus, 1980). The patient on hemodialysis is challenged to identify anything that can be done to decrease the harm or to improve the situation. Therefore, both primary and secondary appraisals can lead to a feeling of loss of control and stress. Primary and secondary appraisal are followed by reappraisal.

Reappraisal is feedback from and reflection on changes in the person and the environment as the transaction proceeds (Lazarus, 1980). Reappraisal evaluates the on-going match between demands and coping resources. With a high number or set of environmental demands, some people will experience helplessness, anxiety, and/or depression while others react with rage or anger (Lazarus, 1974). Personality factors affect the appraisal of demands, provide coping resources, and influence the choice of coping processes (Lazarus, 1974). Even with reappraisal, patients on hemodialysis continue to have difficulty identifying ways to decrease the harm so that the reappraisal tends to be reinforcement of the original appraisals. This process can lead to helplessness and hopelessness. Thus, depression is a major problem for many patients on hemodialysis.

In summary, primary appraisal determines the significance of demands or environmental events. Secondary appraisal determines the availability of resources to meet the demands. Reappraisal is an on-going process that evaluates the match between demands and coping responses. <u>Coping</u>

Coping, which is a response to internal or external demands, is appraised as being successful or unsuccessful (Clarke, 1984) and protects people from harm (Pearlin & Schooler, 1978). It is both cognitive and behavioral and involves thoughts and actions used to control, manage, reduce, master, or tolerate demands evaluated as taxing (Folkman et al., 1986). Stress coping involves multidimensional behaviors, cognitions, and perceptions and functions on multiple levels (Pearlin & Schooler, 1978). It is influenced by personal characteristics and occurs on a continuum from not meeting challenges to meeting them at a very high level. Coping is a dynamic process (Roth & Cohen, 1986) because challenges are constantly arising. Coping is ever-changing as new strategies are developed to meet both old and new demands. A circular relationship exists between demand and coping since successful coping reduces demand and unsuccessful coping increases demand (Hobfoll, 1989). Some demands are met at higher levels than others and on some days more than on other days. Coping, then, can best be defined as "any effort, healthy or unhealthy, conscious or unconscious, to prevent, eliminate, or weaken stressors, or to tolerate their effects in the least hurtful manner" (Matheny et al., 1986, p. 509). Coping resources and coping strategies determine the process of coping. <u>Coping Resources</u>

Resources are those assets that are available to people to help them develop coping repertoires (Pearlin & Schooler, 1978). Coping resources act as buffers and include social support, cognitive skills, sense of control, and life skills such as assertiveness, energy, and previous successful experiences (Matheny et al., 1986). Coping resources include not only what people do but also what is available to them in order to tolerate, master, reduce, or minimize a threat, problem, or demand (Turk, 1979). Resources for coping fall into physical, psychological, and social domains.

Physical resources can be divided into personal physical, physiological, and environmental resources. Personal physical resources include general health status, age, intelligence level, developmental stage, (Turk, 1979), energy, and stamina (Matheny et al., 1986). Physiological resources include a healthy, functioning immune system, normal hemoglobin, and serum electrolytes (e.g., sodium, potassium, chloride) within normal limits. Environmental resources include housing, socioeconomic factors, and social support systems, both personal and community support (Turk, 1979). Physical and physiological resources for the patient on hemodialysis are compromised by low hemoglobin, fatigue, insomnia, and anorexia and this makes them more vulnerable. Socioeconomic resources, too, are frequently not available since most patients on hemodialysis are unable to continue working (Ferrans & Powers, 1985). Community resources, however, are available since the medical costs of dialysis are covered and disability monies are available. Because physical resources are so limited, it is important to focus on psychological resources.

Psychological resources include available personality characteristics which reside within the self, resist stress, and represent what people are independent of roles (Pearlin & Schooler, 1978). They are both personal characteristics and interpersonal relationships. One's personality, total life experiences, family constellations, and current behavior and motivation are individual resources that can aid or hinder coping.

Personal characteristic resources include a positive attitude toward oneself (Pearlin & Schooler, 1978) and a sense of control. Control is experienced when an individual perceives that the ability to cope is greater than the demand; when demand is perceived as being greater than the ability to cope, an individual may experience helplessness (Clarke, 1984). Likewise, an individual's appraisal of an aversive situation is less threatening when there is some control over the aversive stimulus (Meichenbaum, 1975). Lack of personal control can lead to learned helplessness, powerlessness, and depression. Therefore, the concept of personal control is important for understanding the management of harmful or threatening demands.

Personal control is particularly important in chronic disease since perceived control may make the difference between living with the chronic disease with equanimity or simply surviving with discouragement, invalidism, and despair (Diamond & Jones, 1983). The ability to control or manage the environment and the condition is necessary to maintain the quality of life (Lubkin, 1986). A sense of personal control over health interacts with other contributing factors such as the severity of the disease process, motivation to maintain health, social support systems, attitudes toward and experiences with health professionals, costs and benefits, and demographic factors such as race and social class (Wallston, Wallston, & DeVellis, 1978). Information about personal control can be used to plan individualized care since externally oriented patients may need a more directive approach (Shillinger, 1983). Personal control may be cognitive, behavioral, or decisional (Averill, 1973). Cognitive control is the way that an event is appraised or interpreted. Behavioral control includes responses which affect, influence, or modify the demand directly. Decisional control is the ability to choose a course of action from several choices (Averill, 1973).

Personal characteristic resources are enhanced when patients can identify their personal control, be in charge of aspects of treatment, and make choices. Since patients on hemodialysis have lost control over many aspects of life, it is important to provide control wherever and whenever possible. Personal characteristic resources and interpersonal relationship resources are both needed to enhance psychosocial adjustment to hemodialysis.

Interpersonal relationships are important in adjustment to health outcomes (Wills, 1985) and are a coping resource. Pearlin (1985) suggested that it is important, even necessary, to conceptualize support in terms of interpersonal relationships; it is the relationship rather than the actions of separate individuals that determines support. Thoits (1986) noted that empathic understanding is a "crucial condition" for both seeking and accepting coping help. Interpersonal coping resources, then, are dependent not only on the social availability of others but also on individual relationships and an ability to communicate. Interpersonal relationships are a part of the individual's social resources.

Social resources for coping include interpersonal networks of family, friends, colleagues, neighbors, and voluntary or community organizations (Pearlin & Schooler, 1978). The structure of social resources includes the existence of relationships, while the function of social resources is based on the extent to which the relationships provide resources (Cohen & Wills, 1985). Social networks, therefore, refer to the number of relationships while social support is the perception of the supportive care of social interactions (Schaefer, Coyne, & Lazarus, 1981).

Social support involves the participation of others in the coping process. Social support persons have both positive and negative aspects. Too many support persons can lead to overload; the receiver feels responsibility for the support persons causing additional stressors and increasing demands. Another problem is that dysfunctional support persons apply pressure in nonhelpful ways. Overly involved, overly protective, intrusive, indulgent, and self-sacrificing support persons can impede rather than facilitate the assumption of responsibility for self (Coyne & DeLongis, 1986).

There are several typologies of social support. Cobb (1982) identifies four kinds of support: social support including emotional, esteem, and network support; instrumental or counseling support; active support; and material support. Social support includes information that a person is "cared for and loved," "esteemed and valued," and "belongs to a network of communication and mutual obligation" (Cobb, 1976, p. 300). Instrumental support or counseling involves guiding to the highest level of autonomy, coping, and adaptation. The third type of support, active or mothering support, includes the services performed by mothers and/or nurses and can lead to dependency. The fourth type of support is providing goods and services.

Schaefer et. al (1981) identified three types of social support: tangible support, which involves direct aid or direct services for the patient including loans and gifts; emotional support, which is intimacy, attachment, and reassurance of having a confidant; and informational support, which involves giving advice and providing feedback about problems.

Thoits (1986) uses a slightly different typology of social support. Instrumental aid involves actions and/or materials that help people fulfill their normal roles. Socioemotional aid includes assertions of love and caring and provides s sense of belonging to a group. Informational aid includes providing information, giving advice, and reacting to and giving feedback.

Tangible or instrumental social support for the patient on hemodialysis might include transportation to and from the dialysis center and could be provided by friends, family, or community resources. Informational social support, on the other hand, would be provided by professional health care workers. Emotional support resources include family, friends, church, professionals, clubs, and other relationships that increase self-esteem, such as a personal support person. Cobb (1976, 1982) identified counseling as a support to help patients develop autonomy; hence, all forms of social support can be resources including counseling which assists patients develop and/or maintain a sense of competence and self-worth.

When adjustment includes an unalterable situation, coping involves acceptance of the situation or condition and maintenance of a sense of meaning in life (Horowitz, 1982). During the adjustment period it is important to maintain available relationships and it may be crucial to develop new relationships to facilitate coping processes (Horowitz, 1982). Coping is enhanced by coping strategies.

### **Coping Strategies**

Coping strategies include overt and covert behaviors used to change or control a situation appraised as threatening or harmful (Turk, 1979). Coping strategies may be conscious and/or unconscious (Turk, 1979). The purposes of coping strategies are to control the situation, control the meaning of the situation, or control the stress of the situation (Pearlin & Schooler, 1978). Coping can involve both direct actions and palliative or indirect actions (Lazarus, 1974).

Direct coping actions include those actions taken to control or decrease the demand (Clarke, 1984). Direct action occurs when a person tries to alter, demolish, avoid, and/or flee the harmful situation or to prepare to meet the threat (i.e., preparing for an exam) (Lazarus, 1974). Other direct actions may include jogging, taking medication, expressing anger, seeking revenge, fleeing the situation, and/or suicide. Direct action is aimed at the environment or at the self, both are potentially changeable (Lazarus, 1980). Direct coping actions may be problem-focused.

Problem-focused coping involves direct action to remove or alter circumstances appraised as threatening (Thoits, 1986). This type of coping involves changing the situation by changing one's offending action (focus on self) or by changing the environment that is damaging (Lazarus, 1980). Problem-focused coping seeks to modify or eliminate the source of stress by seeking advice or information, learning new skills, using problem solving techniques to develop alternative plans, negotiating, and compromising. Other problem-focused coping strategies include developing alternative rewards, new social relationships, developing autonomy and independence, or substituting other pursuits such as religion or volunteer work (Moos & Billings, 1982). When direct action is not a viable choice, indirect action can alter the experience of the demands.

Indirect coping actions include alteration of the experience of the demand though the demand itself does not change (Clarke, 1984). Indirect actions include both inhibition of action and personal characteristic modes of action (Lazarus, 1980). Inhibition of action involves holding back harmful action impulses that may exacerbate the situation. This requires the ability to control action impulses in the presence of more important values. Personal characteristic modes of action include reinterpretation or reconceptualization of the event. This process can foster denial, which can be an effective defense mechanism in some circumstances. Other forms of indirect actions include palliative coping focused on reducing affective and motor disturbances. Examples include ego-defense mechanisms, alcohol and/or drugs, or biofeedback interventions like relaxation (Lazarus, 1974). Indirect actions are emotion-focused coping.

Emotion-focused coping involves actions or thoughts to manage undesirable feelings (Lazarus, 1980; Thoits, 1986). Lazarus (1980) called these emotion regulatory actions that keep emotions under control so that they do not damage morale or social function. With emotion-focused coping, the primary emphasis is on feelings in order to maintain affective control (Moos & Billings, 1982; Thoits, 1986).

Moos and Billings (1982) described emotion-focused coping as including affective regulation (i.e., controlling feelings by consciously not thinking about demands, keeping a "stiff upper lip", and tolerating ambiguity), resigned acceptance (i.e., waiting for time to remedy the problem, expecting the worse, and submission to fate), and emotional discharge (i.e., crying, smoking, overeating, and impulsive acting out). When coping cannot change the situation, responses to change the meaning of the problem can buffer the threat (Pearlin & Schooler, 1978).

Thoits (1986) combined problem- and emotion-focused coping into: behavioral problem-focused coping (i.e., altering, avoiding, leaving, or replacing the situation); cognitive problem-focused coping (i.e., reinterpretation of demands and/or keeping busy to distract); behavioral emotion-focused coping (i.e., acting out desirable feelings and/or using stimulants, depressants, coffee, and cigarettes); and cognitive emotionfocused coping (i.e., controlling physiological sensations with biofeedback). Both problem-focused and emotion-focused coping are used to manage demands that are appraised as threatening or harmful.

When circumstances cannot be changed and a person must live with a reality, the impact of the situation can be buffered by responses that help to control the meaning of the situation. Perception focused management is a cognitive attempt to alter the meaning of situational difficulties in order to render them less threatening (Thoits, 1986). This process may include, for example, "selective ignoring" when a person searches for a positive attribute or "something good" in the situation and concentrates on this (Pearlin & Schooler, 1978). Lazarus (1980) wrote that preservation of uncertainty can maintain hope and improve morale and involvement with living. This can help people tolerate the intolerable, relieve emotional distress, decrease pain, and continue living.

Appraisal-focused coping incorporates aspects of both problem-focused and emotion-focused coping and includes logical analysis, cognitive redefinition, and cognitive avoidance (Moos & Billings, 1982). In appraisal-focused coping, attempts are made to define the meaning of what is happening. Logical analysis includes identification of the problem, attending to one aspect of the problem at the time, using past experiences as resources, and mental rehearsal of actions and consequences. Cognitive redefinition, on the other hand, includes acceptance of reality but attempts to redefine it in order to identify something favorable. For example, thinking that things could be worse or that others have more difficult situations and one is well off, are forms of cognitive redefinition. Cognitive avoidance is the use of defense mechanisms to deny fear and/or anxiety, by trying to forget or refusing to believe, and using wishful fantasies instead of realistic thinking (Moos & Billings, 1982).

In summary, coping involves a variety of behaviors, cognitions, and perceptions (Pearlin & Schooler, 1978). It can be adaptive or maladaptive; it can reduce or worsen stress. Social outcomes of coping involve maintaining interpersonal relationships and fulfilling social roles (Cohen, 1984). This is important for patients on hemodialysis since they have a tendency to withdraw due to the time constraints of hemodialysis, depression, fatigue, and anxiety. Cognitive, behavioral, and decisional control need to be combined with affective control as patients use indirect, emotion-focused coping strategies. Appraisal and coping interventions may reduce the stress experienced by some patients on hemodialysis. Stress inoculation education is a cognitive behavioral intervention that might facilitate psychosocial adjustment for patients on hemodialysis. Summary

The conceptualization of stress as a transaction between an individual and the environment allows for individual differences in the physical, psychological, and social domains, making adjustment to illness an individualized and unique experience. One person may perceive a demand in a situation where another would not experience a demand. Likewise, coping actions seen by one person as satisfactory may be seen by another as unsatisfactory and may add internally generated demands to external demands. Coping can affect psychological reactions and an individual's general sense of well-being in terms of depression and anxiety, as well as the individual's performance on tasks and in interpersonal relationships (Cohen, 1984).

Resources for coping include cognitive skills for manipulating symbols, social support for meeting emotional needs, a sense of control over demands, and life skills such as assertiveness (Matheny et al., 1986). Physical and psychological resources can enhance coping and the lack of physical and psychological resources can render coping more difficult. It is vital to build on available coping resources and to develop new coping resources when possible.

# CHAPTER III METHODOLOGY

This chapter describes the methods followed in studying the effects of SIE and counseling on the psychosocial reactions of anxiety, depression, psychosocial adjustment to illness, and perceived hemodialysis stressors, and on adherence to the medical regimen by patients on hemodialysis. The chapter includes the research questions and hypotheses, subjects, descriptions of the instruments, procedures, and analyses of data.

**Research Questions and Hypotheses** 

The following specific questions were addressed by the study: What are the effects of Stress Inoculation Education (SIE) and counseling on (a) the psychosocial reactions of anxiety, depression, psychosocial adjustment to illness, and perception of hemodialysis stressors, and (b) adherence to the medical regimen of a patient on hemodialysis? What is the relationship of psychosocial reactions and adherence to the medical regimen to physiological responses while on dialysis?

While the research design and sample size precluded formal hypothesis testing, seven tentative hypotheses were developed to answer the research questions and examine the effects of the intervening variables of interpersonal support and control. The following hypotheses were developed:

- 1. Subjects who participate in SIE and counseling will demonstrate decreased levels of anxiety and depression.
- 2. Subjects who participate in SIE and counseling, will experience increased levels of psychosocial adjustment to illness.
- 3. Subjects who participate in SIE and counseling will experience a decreased perception of hemodialysis stressors.
- 4. Subjects who participate in SIE and counseling will demonstrate increased levels of adherence in terms of medications, diet, and fluid restrictions.

- 5. Subjects who exhibit a higher level of adherence will experience fewer episodes of nausea, vomiting, hypotension, and leg cramps, while being dialyzed.
- 6. Subjects who can identify a person(s) with whom they actually talk about their thoughts and feelings and perceive it as helpful will exhibit lower levels of anxiety and depression and higher levels of adherence and psychosocial adjustment to illness.
- 7. Subjects who perceive that they have some control over their lives will exhibit lower levels of anxiety and depression and higher levels of adherence and psychosocial adjustment to illness.

### Subjects

The six subjects, patients with ESRD who were being dialyzed at one of two outpatient Kidney Centers in a mid-size city in North Carolina, are presented in Table 1. The subjects were (a) between the ages of 30 and 47; (b) two male and four female; (c) five black (1 male and 4 female) and one white (male); (d) three (female) with children; (e) not currently married; (f) two male and one female working parttime; (g) all high school graduates; and (h) two with some college work. According to the <u>United States Renal Data System</u> (1990) the ESRD incidence rates for the black population are approximately 3 to 4 times greater than for the white population for those over 19. Therefore, the sample is fairly representative of the population.

All subjects were (a) alert, oriented, and without psychiatric problems; (b) on hemodialysis at least six weeks but no more than three months prior to beginning the study; (c) able to read; (d) not diabetic; (e) not on any type of peritoneal dialysis; and (f) not recipients of a kidney transplant. One subject was lost to the study when he required emergency open heart surgery so a seventh subject was included for a total of six. Subjects, included without regard to gender, marital status, race, educational level or occupation, entered the study as they were identified and met the criteria.

	Subject							
Category	1	2	3	4	5	6		
Chronological age	38	47	40	35	30	30		
Gender	Μ	Μ	F	F	F	F		
Race	W	В	В	В	В	В		
Marital status	D	S	S	S	S	S		
Number of children	0	0	1	0	2	2		
Education in years	12	13	12	12	16	12		
Employment Status	PT	РТ	No	РТ	No	No		

Chronological Age, Gender, Race, Marital Status, Number of Children, Education in Years, and Employment Status

Note. PT=part-time.

Table 1

## Intervention

SIE and counseling were based on the cognitive behavioral intervention of stress inoculation training described by Michenbaum (1975; 1985). It is based on stress as a transaction between the person and the evivonment. The intervention began with a semi-structured psychosocial interview. The purposes of the interview were to establish a collaborative and therapeutic relationship with the subject and to collect information about the subject. The interview focused on the thoughts, feelings, and actions of the subject. At the second session the subject watched a video about the conceptualization of stress as a transaction and participated in a relaxation technique. An audiotape of the relaxation exercise and a tape recorder were given to each subject. Sessions 3, 4, and 5 focused on medications, diet, and fluid restrictions. The order of these sessions was based on the fact that fluid restriction has been identified as the most difficult problem for patients on hemodialysis. The final session focused on termination. At this session the subject received the PAIS-SR, GCS, CAS, HSS, and the Evaluation Form to complete and return at the next dialysis. The Stress Inoculation and Education Manual is in Appendix D.

Instruments for Data Collection

Several instruments were used for data collection to measure anxiety, depression, psychosocial adjustment to illness, and hemodialysis stressors. Their purposes and psychometric properties are described below. Additional forms were developed by the researcher to assess a subject's perception of: (a) daily adherence to diet, fluids, and medications; (b) daily feelings and life events; (c) problems while on hemodialysis; (d) feelings before and after each session; and (e) the experience of participating in SIE and counseling. The physiological data form was developed to collect information from the medical record.

In preparation for the study, a pilot study was conducted with three subjects. As a result of the pilot study the Self Assessment Form, the Hemodialysis Experience form, and the Evaluation Form were added. <u>Clinical Anxiety Scale (CAS).</u>

The Clinical Anxiety Scale (Corcoran & Fischer, 1987) as presented in Appendix C is designed to measure amount, degree, severity, and changes in the level of anxiety. It consists of 25 simply worded and easily understood items with a five-choice Likert scale ranging from 1=rarely or none of the time, to 5=most or all of the time. Eight items are positively worded and 17 are negatively worded to reduce the effects of response-set bias (Westhuis & Thyer, 1986). Eight of the items are reverse scored (items 1, 6, 7, 9, 13, 15-17). The items are totaled and the total is subtracted by 25 for a range from 0 to 100; higher scores indicate higher anxiety. Thirty is the clinical cut-off score for anxiety on the CAS (Corcoran & Fischer, 1987). Reliability studies have shown a coefficient alpha of .94. The mean standard error of measurement is 4.2 (Corcoran & Fischer, 1987) indicating that the respondent's score will fall within 8.4 points of the true score 95% of the time. The phi coefficient of .81 demonstrates high discriminant validity (Westhuis & Thyer, 1986), indicating that the CAS effectively differentiates among criterion groups known to be experiencing anxiety.

Generalized Contentment Scale (GCS)

The Generalized Contentment Scale (Hudson & Proctor, 1977) presented in Appendix E, is a measure of nonpsychotic depression, and has been used to monitor and evaluate the effects of treatment in single-subject research. The 25 items on the instrument are scored on a 5-point scale with half the items positively worded and scored in reverse order (items 5, 8, 9, 11, 12, 13, 15, 16, 21-24) in order to reduce bias (Wetzel, 1984). Test-retest and split-half reliabilities range from .887 to .963 with a mean of .930 (Hudson & Proctor, 1977) and a standard error measurement of 4.56 (Corcoran & Fischer, 1987). Two-hour test-retest correlation was .94 (Corcoran & Fischer, 1987). Concurrent validity was .85 and .76 with two samples using the Beck Depression Inventory and .92 and .81 with two samples using the Zung Depression Inventory (Corcoran & Fischer, 1987). A score of 30 or above indicates the presence of depression and a score of 70 indicates a suicidal risk (Wetzel, 1984). A change of eight or more points indicates a significant change in the degree of depression (Hudson & Proctor, 1977). The item "I do not sleep well at night" is the only item that might give confounding information since this symptom is common to people who are on hemodialysis and those who are depressed. Hemodialysis Stressor Scale (HSS)

The Hemodialysis Stressor Scale (Baldree et al., 1982), see Appendix F, was designed especially for patients on hemodialysis, to assess the type and severity of stressors perceived by the patient. The original scale of 29 items using a 5-point scale with descriptors only at the endpoints has been changed to a 4-point scale; three items relating to dialysis equipment, treatment discomfort, and boredom (items 26, 30, 31) have also been added (Bihl, Ferrans, & Powers, 1988). A total stressor score is obtained by summing responses. The higher the score, the higher the level of stress experienced by the patient. An extensive review of the literature and a panel of experts were used to assess content validity. The test-retest reliability correlation is .71 (Baldree et al., 1982). Cronbach's alpha coefficients are .89, .69, and .88, respectively, for the total scale, the

physiological and psychosocial subscales. The low physiologic coefficient may be due to the small number of physiological stressor items (Murphy et al., 1985).

### Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR)

The Psychosocial Adjustment to Illness Scale (Derogatis & Lopez, 1983), designed for populations with chronic or prolonged conditions, evaluates seven principal domains of psychosocial adjustment: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress (Deragotis & Lopez, 1983; Morrow, Chiarello, & Derogatis, 1978). The two forms of the PAIS are a semi-structured interview form and a self-report (PAIS-SR) form. The PAIS-SR is a 46 item instrument that can be completed in approximately 20 minutes; items are rated on a 4-point scale from 0 to 3. Under vocational and domestic environment, 14 items measure adjustment to role function; under extended family and social environment, 11 items measure social support; under the psychological distress domain, 6 items measure intrapsychic function. Lower ratings indicate higher levels of psychosocial adjustment to illness. There are norms for the PAIS for four groups (renal dialysis, acute burn, essential hypertension, and lung cancer patients) and the PAIS-SR for two groups (cardiac bypass and a heterogeneous group of cancer patients). The average domain intercorrelation is 0.28 for the PAIS-SR (Deragotis, 1986). Reliability coefficients alpha for the PAIS with renal patients range from 0.63 to 0.87 (Derogatis, 1986). The PAIS-SR is located in Appendix H.

## Self Assessment Form

The Self Assessment Form in Appendix A was designed to assess daily level of adherence and intensity of feelings perceived by the subject. The subject was instructed to place a check each day by (1) the statement that best described his/her evaluation of adherence to diet, fluid, and medication regimen and (2) the number that best described his/her feelings. Space was provided to describe any unusual daily occurrences.

### Hemodialysis Experience

The Hemodialysis Experience form was designed to determine the number of episodes of hypotension, leg cramps, nausea and vomiting while on hemodialysis. The subject was asked to check a box each time he/she experienced a symptom of nausea, vomiting, hypotension, and/or leg cramps while on hemodialysis. Space was provided for the subject to identify other problems while on hemodialysis. This form is located in Appendix G.

### Evaluation Form

This form, see Appendix I, provided information for a summative evaluation of the experience with SIE and counseling as perceived by the subject. The purpose was to provide the subject with an opportunity to rate the experience. The subject was asked to answer four yes/no questions and to rate the experience by choosing a number on a continuum. <u>Psychosocial Interview</u>

A psychosocial interview instrument, located in the manual in Appendix D, was designed to establish rapport and develop a collaborative relationhsip with the subject, assess lifestyle and affect of hemodialysis on lifestyle, and collect data needed on perceptions of interpersonal support and control. Four experts read the psychosocial interview instrument to evaluate content validity. No major problems were identified and only editorial suggestions were made. In addition, the psychosocial interview was used during the pilot study and found to meet the goals and provide assessment data.

### State Evaluation Form

The "feeling thermometer" was developed to identify the subject's perception of feeling before and after the SIE and counseling session. The subject was asked to circle the number that best described level of feeling. It is found in Appendix J.

### Physiological Data Form

One additional form, see Appendix B, was developed to collect data from the medical record of the subject. This form was a work sheet on physiological data, including the average weekly interdialysis weight gain and serum values of phosphorus and calcium. Since interdialysis weight gain is a function of residual renal function and fluid restriction, variation in the interdialysis weight gain is a more appropriate measure of self-care (Lee et al., 1978).

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### Procedure

In order to control for individual differences among subjects (Pedhazur, 1982) and to demonstrate changes over time (Tracey, 1983), a single-subject experimental design with multiple, repeated measures was employed (Barlow, Hayes, & Nelson, 1984). Baseline data were collected across behaviors and individuals for four weeks. By using the same design and same treatment across six subjects, it was possible to determine whether the treatment produced the same effects in similar circumstances (Tracey, 1983).

Procedural changes resulting from the pilot study included: (a) a longer period of baseline data collection, (b) a videotape presentation of the SIE, and (c) conduct of the intervention in a place that was private. <u>Data Collection</u>

The study was introduced by a Kidney Center staff person and explained to each subject by the researcher. The consent form was signed while the subject was on hemodialysis. At this time the subject received the initial baseline data collection booklet, containing the PAIS-SR, GCS, CAS, and HSS, and was instructed to return the booklet at the next hemodialysis session.

With return of the initial booklet, the subject received the booklet containing the daily Self Assessment Form, Hemodialysis Experience Form, and CAS and GCS. These booklets were collected weekly during both the baseline and intervention phases of the study. The subjects were instructed to fill out the forms after the evening meal. During the baseline data collection period, the booklets were collected and new booklets presented by a staff person at the Kidney Center to all subjects but one. At one Kidney Center, it was necessary for the researcher to collect the booklet each week. During the intervention phase, the subject brought the completed booklet and received a new one at each session. The Physiological Data Form, completed by the researcher, was used to collect information from the medical record.

#### Analyses of Data

A variety of data analyses techniques were used to answer the first part of the first research question: what are the effects of SIE and counseling on the psychosocial reactions of anxiety, depression, psychosocial adjustment to illness, and perception of hemodialysis stressors? In addition to initial and final scores for anxiety and depression, baseline and intervention plot graphs were examined to identify changes in direction and level and two standard deviation rule graphs to identify trends and data points of significance (M. J. Miller, 1985). Graphs of the feeling self-report were examined to determine subject self-awareness and change between baseline and intervention periods. Initial and final scores for the PAIS-SR and HSS were compared to identify changes.

The second part of the first research question addressed the effects of SIE and counseling on adherence to the medical regimen. Adherence was measured by laboratory data on phosphorus and calcium, average weekly interdialysis weight gain, and self report. The laboratory data, which are routinely collected monthly, were collected for four months beginning with the time nearest the initial assessment. Criteria for adherence included phosphorus and calcium levels within normal limits three out of the four months. Average weekly interdialysis weight gains were collected for both baseline and intervention periods. Criteria for adherence included no more than one average weekly interdialysis weight gain greater than five pounds during baseline or intervention periods. Criteria for adherence on the self-report were subject-identified adherence to diet, fluids, and medications for 21 days in the baseline phase and 28 days in the intervention phase.

Research question two addressed the relationship of psychosocial reactions and adherence to physiological responses while on dialysis. To answer this question, the findings on the first and second parts of question one were examined in relation to the number of physiological problems identified by the subjects while on hemodialysis.

Perceptions of the two intervening variables, interpersonal support and control, were identified using information from the psychosocial interview and were examined along with adherence and psychosocial data.

#### Summary

This chapter described the research questions and hypotheses, subject selection, descriptions of the instruments, procedures, analyses of data, and limitations of the study. A repeated-measures, single-subject experimental design was used to answer the research questions. A cognitive behavioral intervention and counseling over a 6-week period was used with six subjects on hemodialysis. Anxiety, depression, psychosocial adjustment to illness, and perception of hemodialysis stressors were measured with specific instruments; self report and laboratory data were used to determine adherence, and self report was used to determine perception of feelings; a psychosocial interview was used to determine perceptions of interpersonal support and control.

# CHAPTER IV RESULTS OF THE STUDY

This chapter reports the results of the analyzed data concerning the effects of SIE and counseling on (a) the psychosocial reactions of anxiety, depression, psychosocial adjustment to illness, and perception of hemodialysis stressors (hypotheses one, two, and three), and on (b) adherence to the medical regimen of a patient on hemodialysis (hypothesis four) and the relationship of psychosocial reactions and medical regimen adherence to physiological responses while on dialysis (hypothesis five). Hypotheses six and seven relate to the intervening variables of interpersonal support and control.

This chapter is divided into two parts. Part One reports the quantitative data analyses for the six subjects, and Part Two reports a qualitative subject summary from interview data gathered during the intervention phase. In part one, the results of the study are organized by hypotheses.

#### Quantitative Data Analyses

#### Hypothesis One

Hypothesis one stated that subjects who participate in SIE and counseling will demonstrate decreased levels of anxiety and depression. Anxiety and depression scores and slope and two standard deviation graph data are presented.

Anxiety. At the end of each intervention session the subject received a new booklet. The scores are from the booklet following the intervention sessions. The anxiety scores are presented in Table 2. The final anxiety score was lower than the initial score of all six subjects. Examination of the anxiety slopes of the intervention phase in Figure 1 reveals descending slopes for three subjects (1, 4, 6), indicating that their level of anxiety was decreasing. The anxiety slopes of two subjects (2, 5) indicated a low level and steady state of anxiety. The anxiety slope of Subject 3 appeared to be

ascending slightly although all of the scores indicated a lower level and steady state of anxiety.

# Table 2

		Weel	kly S	cores	5			Mean	SD
Subject	1	2	3	4	5	<u>6</u> a	Range		
Subject 1									
Baseline	17	14	22	21	19		14-22	18.6	3.21
Intervention	23	29	16	27	17	14	14-29	21.0	6.23
Subject 2									
Baseline	12	19	11	14	13		11-19	13.5	3.11
Intervention	10	10	8	10	10	6	6-10	9.0	1.67
Subject 3									
Baseline	14	26	14	12	23		12-23	17.8	6.26
Intervention	8	2	9	10	8	8	2-10	7.5	2.81
Subject 4									
Baseline	36	63	37	32	28		28-63	39.2	13.77
Intervention		26	38	19	23	23	19-38	25.8	7.26
Subject 5									
Baseline	9	12	7	7	13		7-13	9.6	2.79
Intervention	8	7	6	8	7	8	6-8	7.3	.82
Subject 6									
Baseline	32	24	26	24	24		24-32	26.0	3.46
Intervention	30	29	19	18	23	19	18-30	23.0	5.33

Baseline and Intervention Scores on Clinical Anxiety Scale With Range. Mean, and Standard Deviation for all Subjects

<sup>a</sup>The dash indicates that no data were collected.

<u>Note</u>. Possible scores ranged from 0 to 100, with a clinical cutting score of 30.



Figure 1. Plot of initial, weekly baseline and intervention, and final scores on the Clinical Anxiety Scale for each subject.

The two standard deviation graphs of anxiety in Figure 2 showed lower levels of anxiety in the intervention phase for all six subjects. Subject 1 had lower anxiety scores during the baseline phase; however, he had more data points below the mean during the intervention phase, indicating that he was improving. In summary, all subjects demonstrated lower or decreasing levels of anxiety during the intervention phase. The results of the study, thus, support the hypothesis that those who participate in SIE and counseling will demonstrate lower levels of anxiety.

Depression. The depression scores are presented in Table 3. For four subjects (1, 3, 4, 6), the final depression score was lower than the initial score. As reported in plot graphs in Figure 3, three subjects (1, 3, 6) reveal a rise in depression between the end of the baseline phase and the beginning of the intervention phase. The intervention scores followed the psychosocial interview session. The descending depression slopes of these subjects (1, 3, 6) during the intervention phase suggest that depression levels were improving. One subject (4) had a fairly straight line during the intervention phase indicating little change; however, intervention scores were lower than baseline scores. The ascending slopes of two subjects (2, 5) indicated a slight rise in depression level during the intervention. Examination of the two standard deviation graphs for depression in Figure 4 shows that three subjects (3, 4, 6) had more data points below the mean during the intervention phase, indicating lower levels of depression. Two subjects (2, 5) had data points above the mean and outside the two standard deviations, indicating a rising level of depression during the intervention phase. One subject (1) had an equal number of data points below the mean, even with an outlier. In summary, three subjects (3, 4, 6) experienced lower depression levels and one subject (1) experienced a decreasing depression level during the intervention. The study results partially support the hypothesis that those who participate in SIE and counseling will exhibit lower levels of depression.

#### Hypothesis Two

Hypothesis two stated that subjects who participate in SIE and counseling will experience increased levels of psychosocial adjustment to illness.



<u>Figure 2</u>. Standard deviation graph of initial, weekly baseline and intervention and final scores on the Clinical Anxiety Scale for each subject.

Table 3

Baseline and Intervention Scores on the Generalized Contentment Scale With Range, Mean, and Standard Deviation

Subjects			Sco	ores					SD
	1	2	3	4	5	<u>6</u> a	Range	Mean	
Subject 1									;. <u>_</u> ,
Baseline	43	31	33	39	38		31-43	36.8	4.82
Intervention	43	73	41	45	37	35	37-73	45.6	13.89
Subject 2									
Baseline	10	8	4	10	9		4-10	08.2	2.49
Intervention	11	12	12	15	16	18	11-18	14.0	2.76
Subject 3									
Baseline	14	23	20	2	3		2-23	12.4	9.61
Intervention	11	15	10	3	5	6	3-15	8.3	4.46
Subject 4									
Baseline	53	59	53	45	37		37-59	49.4	8.53
Intervention		37	47	37	41	37	37-47	39.8	4.38
Subject 5									
Baseline	19	19	13	14	20		13-20	17.8	3.24
Intervention	18	17	14	25	20	21	14-25	19.1	3.72
Subject 6									
Baseline	29	39	35	23	35		23-39	32.2	6.26
Intervention	43	33	23	23	18	16	16-43	26.0	10.20

<sup>a</sup>The dash indicates that no data were collected.

<u>Note</u>. Possible scores ranged from 0 to 100, with a clinical cutting score of 30.

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Figure 3. Plot of initial, weekly baseline and intervention, and final scores on the Generalized Contentment Scale for each subject.


Figure 4. Standard deviation graph of initial, weekly baseline and intervention and final scores on the Generalized Contentment Scale for each subject.

Presented in Table 4 are the scores on the PAIS-SR which indicate that four subjects (1, 2, 4, 6) experienced a higher level of psychosocial adjustment to illness at the end of the intervention phase. Two subjects (3, 5) demonstrated a higher level of psychosocial distress; however, the change in level of psychosocial adjustment to illness for one of these subjects (5) was quite small. In summary, four subjects experienced a higher level of psychosocial adjustment to illness and two subjects experienced a lower level. There is partial support for the hypothesis that those who participate in SIE and counseling will experience increased levels of psychosocial adjustment to illness.

# Table 4

Initial and Final	Scores for the	<b>Psychosocial</b>	Adjustment to	<b>Illness Scale-</b>
Self Report and	the Hemodialy	sis Stressor Se	<u>cale</u>	

Instrument	Subject							
	1	2	3	4	5	6		
PAIS-SR <sup>a</sup>						·····		
Initial	42	25	35	81	37	59		
Final	35	9	44	47	38	34		
HSSb		····-						
Initial	27	23	25	69	34	67		
Final	41	31	4	45	41	35		

<sup>a</sup>Lower scores indicate higher levels of psychosocial adjustment to illness. <sup>b</sup>Lower scores indicate lower levels of stressor perception.

# Hypothesis Three

Hypothesis three stated that subjects who participate in SIE and counseling will experience a decreased perception of hemodialysis stressors. The scores on the HSS in Table 4 demonstrate that three subjects (3, 4, 6) identified fewer hemodialysis stressors at the end of the intervention and three subjects (1, 2, 5) identified more hemodialysis stressors. Two subjects (2, 5) indicated 8 and 7 more stressors at the conclusion of the intervention, while one subject (1) indicated 27 more stressors at the end of the intervention. In summary, three subjects identified more and three fewer perceived hemodialysis stressors; therefore, there is only partial support for the hypothesis that those who participate in SIE and counseling will experience a decreased perception of hemodialysis stressors.

# Hypothesis Four

Hypothesis four stated that subjects who participate in SIE and counseling will demonstrate increased levels of adherence. Adherence was measured by phosphorus and calcium laboratory data, interdialysis weight gain, and self-report.

Laboratory data. Examination of phosphorus and calcium laboratory values in Table 5 shows that no subject was adherent in all areas. All subjects had abnormal levels of phosphorus indicating nonadherence to diet and/or medications. Three subjects (2, 3, 5) had three or more calcium values within the normal range and one subject (6) had no calcium values within the normal range. Two subjects (1, 4) had three abnormal levels of calcium. Thus, subjects 2, 3, and 5 had calcium values that met the criteria for adherence.

Average weekly interdialysis weight gain. Examination of the average weekly interdialysis weight gain in Table 5 shows that one subject (1) had a high average weekly interdialysis weight gain every week during both the baseline and intervention phases. Two subjects (2, 6) had elevated weight gains every week during baseline and for three of the five weeks of the intervention phase, showing improved adherence to the fluid regimen. One subject (5) exhibited adherence to the fluid regimen during baseline and intervention phases. One subject (3) had one elevated average

Table 5

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Four Month Phosphorus and Calcium Levels and Weekly Baseline and Intervention Interdialysis Weight Gain

			5	Subjects		
Variable	1	2	3	4	5	6
Monthly phosphorus <sup>a</sup>			mg	/100cc		
1	3.5	7.0	5.7	5.9	5.6	4.1
2	7.0	6.8	7.0	8.7	5.4	7.1
3	9.3	6.6	5.3	8.5	7.1	4.6
4	6.5	7.0	7.4	12.1	5.7	10.6
Monthly calcium <sup>b</sup>						
1	11.9	10.2	9.5	8.5	8.7	7.9
2	13.3	10.3	9.9	9.2	9.4	6.8
3	10.3	10.3	9.9	8.9	9.3	7.1
4	11.4	10.1	9.3	8.7	9.8	8.8
Weekly Baseline	Weight Gain in Pounds					
1	6.7	6.7	4.5	6.2	4.8	5.2
2	7.5	8.1	2.4	5.4	3.9	6.1
3	7.5	5.7	4.4	4.7	5.4	7.9
4	9.6	7.2	4.0	5.9	4.7	5.8
Weekly Intervention						
1	9.0	4.4	7.5	4.3	3.1	6.3
2	9.1	7.5	1.5	6.5	2.7	10.0
3	6.2	10.0	2.3	8.2	3.0	1.6
4	6.9	7.5	3.3	4.8	1.7	4.2
5	5.6	4.7	4.8	4.9	2.8	6.1

a(normal range=2.4-4.5 mg/100cc). b(normal range=9-11 mg/100cc). interdialysis weight gain during the baseline and intervention periods. One subject (4) demonstrated nonadherence at three of four weeks during baseline and at two of five weeks during intervention, demonstrating some improvement. Thus, only subjects 3 and 5 met the criteria for adherence to interdialysis weight gain during baseline and intervention and three subjects (2, 4, 6) demonstrated improvement during the intervention phase.

<u>Self-report.</u> According to self-report for adherence in Table 6, three subjects (2, 3, 6) reported adherence to diet, fluids, and medication during the baseline phases. However, the self report of two of these subjects (2, 3) was considered invalid since they checked all answers. Both subjects (2, 3) reported adherence during the intervention phase. The remaining subjects (1, 4, 5) reported at least one low adherence in both baseline and intervention phases.

	Subjects						
Variable	1	2	3	4	5	6	
Baseline				<u></u>	···		
Medications	High	High	High	High	High	High	
Diet	Low	High	High	Low	Low	High	
Fluids	Low	High	High	Low	Low	High	
Intervention		U	0			U	
Medications	High	High	High	High	Low	Low	
Diet	High	High	High	Low	Low	High	
Fluids	Low	High	High	Low	High	Low	
Average number		8	0				
Baseline	2.5	12.0	7.5	2.5	4.3	3.0	
Intervention	3.6	12.0	5.4	2.4	.4	3.8	

# Table 6Baseline and Intervention Self-Report on Adherence and Average ofHemodialysis Problems

In summary, none of the subjects exhibited three or more normal phosphorus values but three subjects (2, 3, 5) demonstrated three or more normal calcium values. Two subjects (3, 5) exhibited adherence to fluid restriction during baseline and intervention, and three subjects (2, 4, 6) demonstrated improvement during the intervention phase as measured by the average weekly interdialysis weight gain. The results of this study, therefore, partially support the hypothesis that those who participate in SIE and counseling will demonstrate increased levels of adherence. Hypothesis Five

Hypothesis five stated that subjects who exhibit a higher level of adherence will experience fewer episodes of nausea, vomiting, hypotension, and leg cramps while on dialysis. The self-report data indicated which problems the subject had, but not the number of times that a problem occurred. The hemodialysis medical records indicated a higher number of problems than the self-report. As reported in Table 6, two subjects (2, 3) indicated an average of more than five problems a week while on dialysis. Of these, one subject (2) demonstrated nonadherence to fluids as seen in Table 5 and one (3) demonstrated average interdialysis weight gains under five pounds. Four subjects (1, 4, 5, 6) indicated an average of less than five problems a week. Of these, one (1) demonstrated nonadherence to the fluid restrictions during baseline and intervention, two (4, 6) showed slight improvement in adherence to fluid restrictions during the intervention, and one (5) demonstrated adherence to fluid intake. Subject 5, the only subject with an interdialysis weight gain within five pounds during both baseline and intervention, reported the fewest problems during the intervention period. In summary, subjects demonstrating an interdialysis weight gain greater than five pounds identified both low (subjects 1,4) numbers of problems and high (subject 2) numbers of problems. The subject (5) with an interdialysis weight gain less than five pounds reported the fewest problems. Therefore, based on this data, there is only a little support for a relationship between adherence to the medical regimen and the number of physiological problems while on hemodialysis.

# Hypothesis Six

Hypothesis six stated that subjects who can identify a person(s) with whom they talk about their thoughts and feelings and perceive it as helpful will exhibit lower levels of anxiety and depression and higher levels of adherence and psychological adjustment to illness. As reported in Table 7, four subjects (2, 3, 4, 6) could identify a special person with whom they had talked about being on hemodialysis. Of these four, two subjects (2, 3) had low anxiety and depression scores and high levels of psychosocial adjustment to illness; and one (3) also adhered to the medical regimen. Two subjects (4, 6) identified a person with whom they had discussed feelings about being on hemodialysis but exhibited high levels of depression, low psychosocial adjustment to illness, and nonadherence. Two

		•••••••••••••••••••••••••••••••••••••••				
Question	1	2	3	4	5	6
Do you talk about your problems and concerns with other people?	Some times	Some times	No	Only with boy friend	No	No
Is there a special person you talk to when you have a problem?	No	Yes	Yes	Yes	Yes but don't	Yes
Is there anyone with whom you can talk about your feeling about being on dialysis?	No	Yes	Yes	Yes	No	Yes

Table 7Answers to Psychosocial Interview Questions Concerning InterpersonalSupport

subjects (1, 5) stated that there was no one with whom they had discussed feelings about being on hemodialysis. Of these two, one (1) had high depression levels and was nonadherent; the other (5) had low anxiety and depression levels, high psychosocial adjustment to illness, and was adherent to the fluid regimen. In summary, two subjects (2, 3) who could identify a person with whom they had discussed their feelings about being on hemodialysis had low levels of anxiety and depression and high levels of psychosocial adjustment to illness. One subject (1) who had not discussed his feelings had high depression and low psychosocial adjustment to illness. Therefore, this study provided partial evidence to support the hypothesis that subjects who can identify a person(s) with whom they talk about their thoughts and feelings and perceive this as helpful will exhibit lower levels of anxiety and depression and higher levels of adherence and psychosocial adjustment to illness.

# Hypothesis Seven

Hypothesis seven states that subjects who feel they have some control over life events will exhibit higher levels of adherence. As reported in Table 8, five of the subjects (1, 2, 3, 5, 6) indicated that they had a great deal of control over their lives before going on hemodialysis. Four subjects (2, 4, 5, 6) indicated that they felt some control over their lives since going on hemodialysis. One subject (1) indicated that he felt a little control since being on hemodialysis; this subject identified the lowest level of control and the greatest change in control of any of the subjects. One subject (4) indicated that she felt no control before going on hemodialysis and some control since being on hemodialysis. One (3) indicated that she felt no change in control. Subject 3 indicated the highest levels of control before and after hemodialysis and also the highest level of adherence. In summary, four subjects (1, 2, 5, 6) felt that they had less control since hemodialysis. The only subject (3) who identified no change in control had the highest level of adherence. There is, thus, support for this hypothesis that those who feel that they have some control over life events exhibit higher levels of adherence.

Table 8

Answers to Psychosocial Interview Ouestions Concerning Control

	Subject						
Question	1	2	3	4	5	6	
How dependent on others do you think dialysis has made you? <sup>a</sup>	Not at all	Some what	Some what	Little	Little	Very	
Before going on dialysis, how much control do you feel you had over your life? <sup>b</sup>	Great deal	Great deal	Great deal	No control	Great deal	Great deal	
How much control do you feel that you have over your life since going on dialysis? <sup>b</sup>	Little	Some	Great deal	Some	Some	Some	

aThe scale ranged from very dependent, somewhat dependent, only a little dependent, not at all dependent.

<sup>b</sup>The scale ranged from great deal of control, some control, only a little control, no control.

The subjects, in general, evaluated the experience in a positive manner as seen in Table 9. All but one indicated that they would participate again and recommend it to a friend. The written comments of Subject 5 suggest that she was confused about what she was to evaluate. The state evaluation of Subjects 2 and 3 demonstrate no change; each identified a level of 100 before the session and after the session. There were no negative differences.

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Table 9Summative Evaluation of Experience and State Evaluation DifferenceScores

	Subjects							
Indicator	1	2	3	4	5	6		
	Final Questionnaire <sup>a</sup>							
I had a chance to say what was on my mind.	Yes	Yes	Yes	Yes	Yes	Yes		
I have used the skill I learned.	Yes/N	loYes	Yes	Yes	Yes	Yes		
I would participate again.	Yes/	NoYes	Yes	Yes/No	No	Yes		
I would recommend to a friend.	Yes	Yes	Yes	Yes	No	Yes		
I found this experience to be:								
Easy	6	4	4	4	2	4		
Valuable	4	3	0	4	8	4		
Positive	6	6	0	2	4	6		
Helpful	6	8	8	6	6	6		
Session	State Evaluation <sup>b</sup>							
One	0	0	0	5	0			
Two	5	0	0	20	5			
Three	5	0	0	25	10			
Four	_	0	0	15	0			
Five	10	0	0	5	0			
Six	10	0	0	10	0			

Note. \_\_= Insufficient data.

aQuantitative measuring weights: 0=not at all to 8=extremely. bNumber of points between before and after scores.

#### Summary of Quantitative Data Analyses

Of the six subjects who participated in SIE and counseling, all experienced some lessening of anxiety; four experienced lower levels of depression and higher levels of psychosocial adjustment to illness; and three perceived fewer hemodialysis stressors. Based on this data there is no evidence that SIE and counseling affects adherence to the medical regimen since the level of adherence was low. Nor does this data support a relationship between adherence and the number of physiological problems identified by subjects while on hemodialysis. There is partial support for the hypothesis that those subjects who can identify a person(s) with whom they talk about thoughts and feelings and perceive it as helpful exhibit lower levels of anxiety and depression and higher levels of adherence and psychosocial adjustment to illness. Finally, there is support for the hypothesis that those who feel that they have some control over life events exhibit higher levels of adherence.

## Qualitative Data Analyses

The qualitative analyses provides a summary of the interview data from the intervention phase. These data include a description of affect and information from the intervention sessions; the subject's perception of interpersonal support and control; how subject anxiety and depression levels were related; results of the feeling self-report; and subject's perception of hemodialysis stressors and psychosocial adjustment to illness based on the HSS and PAIS-SR. Additional data about lifestyle, employment, medical history, support systems, and problems occurring during the intervention phase are included. Graphs of the self assessment of feelings for each subject are presented and discussed. <u>Subject 1</u>

Throughout the study, Subject 1 appeared depressed with a flat affect, slow, monotone speech, and slow movement. He was cooperative during the study and completed the booklets on schedule. The only time that he was unable to meet for the intervention session, he asked the nurse to call. He identified multiple losses: (a) his divorce occurred at the time of his first experience with renal pathology, six to seven years before beginning hemodialysis, and he believed it was caused by his renal problems; (b) he was able to work only parttime, wanted to work more, and was concerned about maintaining his health insurance; (c) he was unable to maintain separate living quarters or contribute to housing expenses; and (d) he indicated that he had lost control since being on hemodialysis. At the first session his biggest worry was how to pay his bills. At the second session he stated that the hospital was calling him about his unpaid hospital bill. This was the time of the highest scores on both anxiety and depression scales. At this session he appeared and sounded so depressed that a suicide assessment was done. He denied suicidal ideation.

He stated that only "sometimes" did he discuss problems and concerns with others. He denied having a special person with whom he talked about problems, nor had he discussed feelings about being on hemodialysis with anyone. He indicated that hemodialysis had not made him dependent on others, yet he was unable to maintain separate living conditions. He stated emphatically that "I don't ask for help." Subject 1 indicated that he had a great deal of control over his life before going on hemodialysis and only a little control since being on hemodialysis. He identified the largest loss of control of any of the six subjects.

His scores on the CAS and GCS indicated that this subject had moderate levels of anxiety but clinical levels of depression during baseline and intervention phases. The highest anxiety and depression scores occurred at the time of calls from the hospital. The graphs of anxiety and depression indicate that both were decreasing during the intervention phase. Interestingly, this subject's self-report in Figure 5 indicated low levels of anxiety and no feelings of sadness during baseline phase. He rated himself as feeling more anxious, slightly more sadness, more peeved, slightly more active, more worn out, and less able to concentrate during the intervention. His rating for feeling friendly was in the middle range.

Final HSS and PAIS-SR scores indicated that he was more aware of hemodialysis stressors but, at the same time, was experiencing a higher level of psychosocial adjustment to illness. On both the initial and final PAIS-SR he did not respond to the section on sexual relationships. He identified that he did not adhere to the medical regimen and the objective data supported this. It is interesting that this subject became "Patient of the



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Month" following the study indicating that he was adherent to diet, fluids, and medications.

# Subject 2

Subject 2 appeared unconcerned and uninvolved with the environment, but his comments and questions indicated that he was observant and aware. His clothes, though clean, looked as if he had slept in them. He was cooperative during the study, completed the booklets on time, and was willing to return the next day (a nondialysis day) for the one session that he forgot. He answered questions thoughtfully and asked questions appropriately, although some of his questions indicated a lack of knowledge. The main lifestyle change of Subject 2 was the time commitment needed to be on hemodialysis. He described himself as unemployed with no plans to return to work; however, he continued his small "junk" business which allowed him to work when he was able. He lived alone in a rented house but identified a stable relationship with his girlfriend.

He indicated that he talked about problems and concerns "every now and then." He identified a special person with whom he talked when he had problems and another with whom he had talked about his feelings about hemodialysis. He also stated that this was very helpful. He indicated that hemodialysis had made him "somewhat dependent" on other people. Before going on hemodialysis, he felt that he had "a great deal of control" over his life. Since being on hemodialysis, he felt that he had "some control" over his life. He indicated that he made his own decisions.

Both his anxiety and depression scores were low. However, his anxiety scores were higher than his depression scores during baseline and lower than depression scores during the intervention phase. Decreasing anxiety levels during the intervention were documented with a slightly descending slope and all data points below the mean on the two standard deviation graph. Depression levels were rising during the intervention phase; all intervention data points on the two standard deviation graph were above the mean, with three outside two standard deviations, indicating a significantly higher level of depression. However, the scores were still considerably below the cutoff for clinical depression. As evidenced in Figure 6, the subject rated himself higher on feeling anxious, sad, and peeved, more active, slightly less worn out, and slightly less able to concentrate, but friendlier during the intervention.

At the end of the intervention he indicated greater awareness of hemodialysis stressors but also a higher level of psychosocial adjustment to illness. His self-report data on adherence was contradictory since he checked "yes" for most items. Laboratory data indicated nonadherence. All of the hemodialysis complications were checked for every hemodialysis experience. The hemodialysis record indicated numerous episodes of low and high blood pressure, nausea, and cramps. Subject 2 described episodes of hypotension and stated that he was afraid to sleep on hemodialysis for fear that no one would notice his blood pressure drop. He also reported that he sometimes had to call the nurse when he observed another patient in trouble while on hemodialysis.

# Subject 3

Subject 3 responded to people in a positive and out-going way. Cooperative during the study, she completed the booklets on time and all intervention sessions were on schedule. She indicated that she participated actively in church activities, was a member of a bowling team, played soft ball, and visited frequently with the people in her neighborhood. She was observed talking and encouraging other patients in the waiting room. She was able to maintain an apartment and lived with her son. She had been employed in the past, was not employed now, and had no plans to return to work.

Subject 3 indicated that she did not talk about problems and concerns with other people. However, she identified a person to whom she could talk when she had a problem. She also indicated that she had talked about her feelings about being on hemodialysis and had found this to be "very helpful." She felt that she had "a great deal of control" over her life before going on hemodialysis and that this had not changed since being on hemodialysis. Yet, she felt that hemodialysis had made her "somewhat dependent" on others.

Her scores on the CAS and GCS indicated low levels of both anxiety and depression. She had a lower anxiety score at the end of the





intervention phase, with none of the intervention scores as high as the baseline scores. There was a similar pattern for depression scores. The slopes of both baseline and intervention indicated a lessening of depression as seen in Figure 3. The self-report on feelings in Figure 7 was consistent and, for the most part, the same for baseline and intervention. With the exception of two scores early in the baseline phase, Subject 3 rated herself as neither anxious, sad, nor peeved. Levels of activity, feeling friendly, and being able to concentrate did not change, although she indicated that she was less worn out during the intervention.

Final HSS score indicated a lower perception of hemodialysis stressors but final PAIS-SR score indicated a lower level of psychosocial adjustment to illness. This subject met the adherence criteria for this study. It is interesting that she experienced improvements in anxiety, depression, and perception of hemodialysis stressors, but also a lower level of psychosocial adjustment to illness.

#### Subject 4

At the initial meeting, Subject 4 appeared depressed, distant, and angry with a flat affect and slow responses. The researcher delivered and picked up the baseline booklets. Subject 4 agreed to participate in the study and the process was explained. She completed the initial booklet but had difficulty completing the booklets for the next two weeks. The directions were explained again and she completed the next four booklets without difficulty. It is interesting that she did not complete the CAS and GCS after the initial

session and the psychosocial interview. The remaining booklets were completed without problems.

She was reluctant to discuss hemodialysis, her perceptions, or her lifestyle during the intervention but did not miss a session. The researcher took her home since she would miss her ride by participating in the study. She talked more freely during the ride than when the tape recorder was on. She lived in a rented a room and had a parttime job.

Subject 4 indicated that she did talk about problems and concerns but only sometimes with her boyfriend. She stated that she had talked to her boyfriend about her feelings about being on hemodialysis. Her relationship





Baseline

Intervention

with her boyfriend began shortly before she started on hemodialysis. Interestingly, she had not told with her family that she was on hemodialysis although she stated that she communicated with them on a fairly regular basis. She was quite reticent during this part of the psychosocial interview. She indicated that before going on hemodialysis she had "no control" and since being on hemodialysis felt that she had "some control," stating that she was "on drugs" before going on hemodialysis. Now that she was not "doing drugs" she felt more in control.

Baseline levels of anxiety and depression and levels of depression during the intervention were all above 30 indicating clinical levels of anxiety and depression. The two standard deviation anxiety graph showed all intervention data points below the mean, indicating a lower level. With one exception, the baseline levels of anxiety were above 30 and during the intervention they were below 30, demonstrating less anxiety. All of the depression scores were above 30 indicating a clinical level of depression. The two standard deviation graph showed four of the five data points, including the final three, below the mean during the intervention phase, indicating decreasing depression. Examination of the self-report graphs in Figure 8 indicated that this subject felt less anxious, less sad, less peeved, less worn out, and more active, more able to concentrate, and friendlier during the intervention.

Final HSS and PAIS-SR scores indicated lower perception of hemodialysis stressors and higher psychosocial adjustment to illness. She indicated on self-report that she did not adhere to diet or fluid restrictions. Her laboratory data support this. She identified problems while on hemodialysis and the medical record corroborated multiple problems. During the intervention she stated that she did not "appreciate" the way that she was treated by the staff. She indicated several areas of disagreement. One especially sensitive area was being at the Kidney Center on time. She indicated that they were upset and not understanding when she was late for hemodialysis.

# Subject 5

Subject 5 was quite talkative and cooperative. She completed the baseline data without difficulty and each session was held on schedule. She





talked freely and openly about her experiences with hemodialysis. She stated that she had known since she was fifteen that she would eventually need dialysis, began hemodialysis before she got sick, and was still having difficulty believing that she must continue hemodialysis. She stated that she was not sure that she needed to be on hemodialysis because "I never fell out like a lot of them." She expressed concern about being "grumpy" and having a short temper and no tolerance since being on hemodialysis. She talked about a number of neighborhood friends and church activities in which she was involved. She grew up in the church but had not been a regular member until recently. She was not employed but planning to return to work.

She stated that she did not talk about problems and concerns with other people. She identified a special person with whom to talk but stated, "I just don't." She also indicated that she had not discussed her feelings about hemodialysis with anyone. Subject 5 indicated that she had "a great deal of control" over her life before going on dialysis and "some control" over her life since being on hemodialysis. She lived in an apartment with her two young sons and was involved with church, family, and friends. She felt that she was "a little dependent" on others since being on hemodialysis.

Subject 5 began the study with lower anxiety scores than depression scores although both were relatively low. Anxiety scores were lower during the intervention. In contrast, baseline depression scores were slightly lower than intervention depression scores. The outlier during the intervention phase occurred at the time of the death of a neighborhood child, who was killed by a random bullet. Even without the outlier, however, this subject had a slightly higher level of depression during the intervention phase. Her self-report data, as reported in Figure 9, indicated that she identified a higher level of feeling anxious, sad, and peeved during the intervention phase but also was more active, less worn out, better able to concentrate, and friendlier during the intervention phase.

Final scores on the HSS and PAIS-SR indicated that she had a higher perception of hemodialysis stressors and a very slightly lower level of psychosocial adjustment to illness. She met the criteria for adherence with fluid restrictions. Self report data indicated that she did not adhere to diet





in baseline or intervention phases and did not follow the medication regimen during the intervention but this was not supported by the laboratory data. Hemodialysis problems included low blood pressure, leg cramps, and nausea. During one dialysis she experienced "cramps all over," and after one dialysis she experienced low blood pressure after returning home.

## Subject 6

Subject 6 was cooperative and seemed quite interested in participating in the study. The researcher agreed to drive her home after the session since this would be a problem for her. When she signed the consent form, she stated that she would be having "gall bladder" surgery but did not know the date of the surgery. She completed the initial and first four baseline booklets on time; session one followed the baseline data collection. At this time, she and her two sons lived with her boyfriend in a duplex. She was unemployed and identified being unable to work as the most difficult change that she had had to make since being on hemodialysis. She was planning to return to work. She stated that "partying and drinking" were the activities she did for fun.

She was cooperative during the psychosocial interview. She stated that she did not talk to others about problems and concerns, but had talked to boyfriend about her feelings about being on hemodialysis. She felt that hemodialysis had make her "very dependent" and that this was difficult for her. She identified some loss of control since being on hemodialysis. She "hates" the fluid restriction and had "over stepped a lot lately."

At the next scheduled session, she asked to postpone the session since she was "not feeling well." It was obvious that she had been drinking. Session two was held the following week. At this time she stated that she would be having surgery but might be out of the hospital in a week. Session 3 was canceled since she had hemodialysis in the hospital before going home. Session 3 was held the following week; she was alert, cooperative, and interested in viewing the video. The next three weeks the subject was either ill or did not show up for hemodialysis. In addition to surgery, she experienced multiple physical problems (clotted graph twice) and psychosocial difficulties (boyfriend unable to support her) during this time. It was necessary that she and her two sons move in to live with her parents. She did, however, continue to complete the booklets. The final three sessions were held on schedule.

Initial anxiety score and baseline anxiety scores tended to be higher than intervention scores. The two standard deviation anxiety graph indicates more data points below the mean during the intervention. Three of the baseline depression scores were above 30 indicating a clinical level of depression. During the intervention there are two scores outside the two standard deviations indicating a significant improvement in depression. Her self-report of feelings in the intervention phase in Figure 10 demonstrated that she felt more anxious and sad, more peeved and worn out, had more difficulty concentrating but also friendlier. At the end of the study, she identified fewer hemodialysis stressors on the HSS and a higher level of psychosocial adjustment to illness on the PAIS-SR. She reported that she did not adhere to the medical regimen and this was supported with the laboratory and average interdialysis weight gain data.





# CHAPTER FIVE CONCLUSIONS

#### Summary

Hemodialysis requires radical lifestyle changes. The physical and physiological demands of hemodialysis are universal, but psychosocial responses to these demands are based on "the personal significance of demands" (Haberman, Woods, Packard, 1990, p. 34). Not only is psychosocial adjustment a developmental process, but crisis events and complications can reinstitute the process (Ulrich, 1987). The difficult lifestyle changes required by hemodialysis and the resulting anxiety and depression experienced by many patients suggest a need for interventions to support patients throughout the adjustment process and alleviate the psychosocial distress that accompanies hemodialysis.

The primary objectives of the present study were to (a) investigate the effects of SIE and counseling on anxiety, depression, psychosocial adjustment to illness, perception of hemodialysis stressors, and adherence to the medical regimen, and (b) examine the relationship of psychosocial reactions and adherence to physiological problems while on hemodialysis. Also, two intervening variables, interpersonal support and control, were examined to determine their influence on adherence and anxiety, depression, psychosocial adjustment to illness, and perception of hemodialysis stressors.

SIE and counseling, based on a cognitive behavioral intervention, consisted of six sessions, each with a specific focus. The intervention began with a psychosocial interview to establish a collaborative relationship. This was followed by presentation of the conceptualization of stress as a transaction and cognitive behavioral skills acquisition. The next three sessions focused on rehearsal and application of skills and the final session focused on termination. Baseline data, collected for four weeks, were compared to data collected during and after the intervention to determine the effectiveness of the intervention. Six subjects, who had been on hemodialysis between 6 weeks and 3 months, participated in the study.

Conclusions

The findings suggested that, overall, the intervention was effective in reducing some problems for all of the subjects. There was evidence that the six SIE and counseling sessions were effective in decreasing anxiety, depression, and perception of hemodialysis stressors, and in increasing psychosocial adjustment to illness. Slight evidence existed that the sessions improved adherence to the medical regimen. The salient findings of this study are presented for each variable examined. Anxiety

Although anxiety scores tended to be fairly low for this group of subjects, all experienced lower or decreasing levels of anxiety at the end of the intervention. This finding suggests that the opportunity to talk about the process of hemodialysis and express thoughts and feelings about what is happening may decrease anxiety. The view that a psychosocial interview or assessment constitutes an intervention is supported by DeVellis, Blalock, Hahn, DeVellis, and Hochbaum (1988) and Simonds (1983). That is, someone listening to a patient provides an important source of support (Kasch, 1984; Collier, 1990) and increases patient satisfaction (Yoos, 1981). Also, as patients relate their personal experiences, they get "in touch with the meaning and context of the illness experience" and thus experience caring and healing (Collier, 1990, p. 7). Depression

Subjects with high depression scores tended to be without a wide base of social support. One had experienced multiple losses and was unable to maintain separate living arrangements or to work fulltime. Another, who was able to maintain a rented room, seemed to communicate only with her boyfriend, to have few friends, and to have difficulty sharing with her family. One had lost a significant relationship and had to move in with her parents. None tended to talk freely to others about feelings. Subjects with lower levels of depression maintained an active interest in life, and were active in church, shared experiences with other people, and maintained independent living arrangements. These findings suggest that depression

may be influenced by social support systems, interpersonal relationships, and independence or control.

Anxiety is frequently associated with depression. Two of the subjects with low initial levels of anxiety and depression experienced a rising level of depression during the intervention. For one, the rising levels of depression may have been due to environmental problems that had nothing to do with hemodialysis. Or, it may be that anxiety was a defense mechanism against depression since as anxiety levels decreased depression levels rose. Another possibility is that denial may have been used to cope with stress and this defense could not be maintained when discussing techniques for maintaining diet, fluid, and medication regimens. It is important to note that, although the depression levels were rising, these two subjects were still well below the cutoff for clinical depression so the rise may have been due to normal fluctuations of feelings. Psychosocial Adjustment to Illness

Four subjects experienced higher levels of psychosocial adjustment to illness at the conclusion of the intervention. For three of these, the intervention may have provided a support system since they had lost significant relationships, were experiencing additional stresses, surgery and/or financial problems, or did not communicate well with friends or family. The intervention provided an opportunity to discuss their situations or problems in order to resolve some of the difficulties they were experiencing.

An interesting relationship existed between depression and psychosocial adjustment to illness. The three subjects with the lowest initial depression scores had the highest initial levels of psychosocial adjustment to illness. Conversely, the three subjects demonstrating the highest initial depression scores had the lowest initial levels of psychosocial adjustment to illness. The relationship was similar at the end of the intervention; i.e., lower depression scores were accompanied by a higher level of psychosocial adjustment to illness. Thus, there is some support for the view that decreasing depression may also increase psychosocial adjustment to illness. A higher level of psychosocial adjustment to illness might allow the patients to participate more fully in self-care and also enhance adherence to the medical regimen.

# Hemodialysis Stressors

There appeared to be a relationship between levels of depression and perception of hemodialysis stressors. Two of the subjects with high initial levels of depression also had the highest perception of hemodialysis stressors. With a decrease in depression, there was also a decrease in perceived hemodialysis stressors. The two subjects who experienced higher final depression scores also perceived higher final levels of hemodialysis stressors. This suggests that depressed patients perceive more hemodialysis stressors, as all problems tend to be magnified. <u>Interpersonal Support</u>

Levels of depression, psychosocial adjustment to illness, and perception of hemodialysis stressors were related to interpersonal support. Four subjects stated that they did not talk about problems and concerns or did not have a person with whom to talk. Two of these exhibited high initial depression scores, two had high perception of hemodialysis stressors, and three had low levels of psychosocial adjustment to illness. After the intervention, two had a lower level of depression, three had a higher level of psychosocial adjustment to illness, and three indicated a decrease in perceived hemodialysis stressors. These findings suggest that patients who are unable to identify interpersonal support can benefit from counseling and may, in fact, need counseling more than those who have competent support systems. Certainly, one focus of counseling should be on helping patients develop support systems, since they may decrease levels of depression.

#### <u>Control</u>

Hemodialysis results in a loss of control over many aspects of life. All but one of the subjects identified some change in control since being on hemodialysis. The one who identified no loss of control lived independently, maintained an acceptable and active lifestyle, and had low depression scores. Some control is lost because patients on hemodialysis are frequently unable to work full time. Only two subjects had no plans or desire to return to work and both lived independently and were able to maintain apartments and acceptable lifestyles. The other subjects had plans or wanted to return to full time employment.

The relationships among depression, psychosocial adjustment to illness, and perception of hemodialysis stressors, control, and interpersonal support strongly suggest that interventions to help patients maintain control and develop support systems may decrease anxiety, depression, perception of hemodialysis stressors, and increase psychosocial adjustment to illness. <u>Adherence</u>

In this study, there was was only slight evidence that SIE and counseling were effective in increasing adherence to the medical regimen for patients on hemodialysis. Three subjects demonstrated improvement in fluid restriction during the intervention. Two of these also demonstrated lower depression levels during the intervention. It may be that a cognitive behavioral intervention is not helpful in promoting adherence for patients on hemodialysis until depression, anxiety, and other adjustment problems are resolved, or the subjects selected for this study may have had limited skills in problem solving, cognitive restructuring, and physiological control such as relaxation. Since high levels of anxiety and depression may prohibit learning new information and skills, interventions to decrease anxiety and depression before presenting new information might increase the learning of these new skills. Also, a longer intervention period and/or more frequent intervention sessions might be needed, especially for patients with difficult adjustment problems.

#### Implications for Practice

There are a number of implications for counselors based on the results of this study. First, since all subjects experienced benefits in some area, it appears that counselors can assist and provide support for patients on hemodialysis. Second, since subjects with significant others who were unable to deal with hemodialysis, had higher levels of depression, it appears that counselors should work with the personal network systems such as family members, friends, and neighbors (Rounds & Israel, 1985) to enable them to support the patient on hemodialysis. Third, because subjects who were active, involved, and maintained independent living arrangements demonstrated less depression it seems appropriate for counselors to help patients increase or develop activities. Fourth, because control is an issue for patients on hemodialysis, counselors might help patients identify and develop other areas in their lives where they can maintain control. Also counselors might work with the dialysis center personnel to help them determine ways to give more control to patients. Finally, since patients spend more than 10 hours a week being dialyzed, counselors could assist personnel to increase psychosocial assessment and communication skills and develop effective interventions. These interventions which could be incorporated into the health care plan, should have a positive impact on outcome behaviors of patients on hemodialysis, and would surely improve the quality of life for patient and family and possibly patient productivity.

# Limitations of the Study

The limitations of this study included the following. The sample of patients in this study involved one group of physicians, which increased control but limited generalizability. Participants in the study also included volunteer hemodialysis patients who had no other chronic conditions, could read, and did not have severe psychiatric problems. The collection of baseline data may have had the effect of an intervention and thus influenced responses since the extra attention provided by weekly communication of a staff person or the researcher could be influential (DeVellis et al, 1988; Simonds, 1983). An effect also may have existed due to the possibility of maturation (i.e., a subject might change due to time on hemodialysis) and instrumentation (i.e., a subject might answer without reading the statements or questions) (Bausell, 1986). Confounding data on the Self Report for adherence and problems while on hemodialysis limit the usefulness of this data since some subjects checked all answers. Also, complications such as a clotted graph, surgery for an unrelated condition, financial difficulties, and loss of personal relationships may have affected the dependent variables. Finally, six weeks was a short period of time to effect behavior change in persons undergoing such massive lifestyle changes.

# Recommendations

The costs of hemodialysis are rising and resources are diminishing. Therefore, it is imperative that health care professionals develop efficient and cost effective interventions for patients on hemodialysis. A number of recommendations exist for further research based on this study. First, it is recommended that a follow-up study be conducted to determine whether there are lasting effects for the intervention. Second, there is a need for a study with more subjects and a longer intervention period to investigate further the relationships among depression, anxiety, psychosocial adjustment to illness, control, and interpersonal support to adherence. A larger sample would include patients with additional problems such as diabetes, lupus, and other chronic illnesses. Third, research is needed to determine the effects of employment on psychosocial adjustment, control, and adherence of hemodialysis patients since there appeared to be a relationship among these variables.

Since depression levels appeared to affect psychosocial adjustment to illness, perception of hemodialysis stressors, and adherence, research is needed to determine the best methods for identifying those patients who are most vulnerable to depression. Finally, research is needed to identify costeffective and efficient interventions to assist hemodialysis patients once problems are identified.

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APPENDIX A

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# SELF ASSESSMENT FORM

Place a check by the statement that best describes your evaluation of how well you followed your diet, fluid restriction, and medication instructions.

# DIET

All the food I ate today was on my diet.	Yes	No
Most of the food I ate today was on my diet.	Yes	No
Some of the food I ate today was on my diet.	Yes	No
None of the food I ate today was on my diet.	Yes	No
FLUID		
I stayed within my fluid restriction today.	Yes	No
I drank less than my fluid allowance today.	Yes	No
I drank more than my fluid allowance today.	Yes	No
MEDICATIONS		
I took all of my medications today.	Yes	No
I took most of my medications today.	Yes	No
I took some of my medications today.	Yes	No
I took none of my medications today.	Yes	No

This list of adjectives is to describe how you have been feeling during each day. Please circle a number by each adjective that describes how you have felt today. Use any number between 0 and 8.

0=not at all	2=a little	4=quite a bit	6=very much	8=extremely
Anxious 0	2	4	6	8
Sad				
0	2	4	6_	8
Peeved				
0	2	4	6	8
Active				
0	2	4	6_	8
Worn out 0	2	4	6	8
Unable to co	ncentrate			
0	2	4	6_	8
Friendly			_	
0	2	4	6_	8
Has anything	g happened	to you today to	o make you feel p	articularly good or

Yes \_\_\_\_\_ No\_\_\_\_\_ bad?

If you answered yes, please write a few words to say what happened.

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APPENDIX B

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# PHYSIOLOGICAL DATA FORM

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Week	Weight	<u>B/P</u>	K	Phos
FIRST				
DAY				
SECOND				
DAY				
THIRD				
DAY				
Week II				
FIRST				
DAY				
SECOND				
DAY				
THIRD				
DAY				
Week III				
FIRST				
DAY				
SECOND				
DAY				
THIRD				
DAY				

Week IV FIRST	•			
SECOND DAY		 		
THIRD DAY		 		
<b>Week V</b> FIRST DAY		 	۰ 	
SECOND DAY		 		
THIRD DAY		 		
Week VI FIRST DAY		 		
SECOND DAY		 		
THIRD DAY		 		<del>,</del>
Week VII FIRST DAY		 		
SECOND DAY		 		
THIRD DAY				

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Week VIII FIRST DAY
SECOND DAY
THIRD DAY
Week IX FIRST DAY
SECOND DAY
THIRD DAY
Week X FIRST DAY
SECOND DAY
THIRD DAY
Week XI FIRST DAY
SECOND DAY
THIRD DAY

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Week FIRST DAY_	XII	 	 
SECONE	ס		 
THIRD DAY		 	 

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APPENDIX C

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#### PLEASE NOTE

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APPENDIX D

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# STRESS INOCULATION EDUCATION

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## AND COUNSELING

## FOR

# PATIENTS ON HEMODIALYSIS

## TREATMENT MANUAL

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## Nancy Fleming Courts 717 Dover Road Greensboro, North Carolina 27408

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#### STRESS INOCULATION EDUCATION

Stress inoculation training (SIT) is a cognitive, behavioral intervention with both treatment and prevention components (Meichenbaum, 1985). Stress inoculation education (SIE) and counseling incorporate some of the basic skills of SIT. SIE and counseling is not a specific technique with prescribed interventions for all situations; rather, it is a generic paradigm flexible enough to meet the needs of a variety of clients and/or groups (Meichenbaum, 1985). Based on the transaction model, stress is defined as the result of "demands that tax or exceed the resources of the system or,... demands to which there are no readily available or automatic adaptive responses" (Lazarus & Cohen, 1977, p. 109). Demands are events that are appraised as requiring a response. Appraisal, primary and secondary, determines the importance of the demands.

Primary cognitive appraisal of an event as threat or challenge leads to the secondary appraisal of available coping responses. Coping responses involve direct action or cognitive restructuring (Meichenbaum, Turk, & Burstein, 1975). The response, then, is adequate or inadequate. Adequate responses tend to decrease threat or challenge while inadequate response leads to reappraisal. Hence, cognitive appraisals and coping responses determine the level of threat or challenge (Cameron & Meichenbaum, 1982) and form the basis of this process model.

SIE and counseling link transactional and cognitive-behavioral coping models and include the psychosocial responses to stress. A basic assumption is that "most human functioning involves a complex integration of cognitive, affective, and behavioral processes" (Cameron & Meichenbaum, 1982, p. 697). Since persons with the same problem may have very different coping methods and/or deficits and require different interventions, SIE and counseling is designed to build on effective coping skills and to teach and develop new ones. These include skills to replace negative self-talk with positive self-talk, to define stress and stressful events in terms of problems to be solved, and to control physical and physiological reactions. The techniques used in skill development are flexible, dependent on the client or group, and exist throughout all sessions.

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SIE and counseling begin with the psychosocial interview and assessment. SIE consists of three phases: (1) conceptualization phase, (2) skills acquisition and rehearsal phase, and (3) application and followthrough phase. The final session is focused on termination. Each phase has specific goals, client objectives, and techniques. SIE builds "psychological antibodies" or coping skills that protect an individual psychologically in much the same way that measles antibodies protect an individual physiologically. Both counselor and client are involved in a collaborative effort throughout the process.

Client participation in SIE and counseling is essential. Meichenbaum and Cameron (1983) have identified a number of variables that pertain to client participation. An inviting, warm, genuine, and empathic counselor creates an atmosphere that fosters client feelings of acceptance. This is needed in order for the client to disclose the cognitions and affect necessary for successful SIE and counseling. When explaining the treatment protocol, the counselor must be careful not to promise unrealistic results since some failures and setbacks are probably inevitable. Failure provides the counselor an opportunity to role model adaptive responses, teaches the client to expect setbacks, and includes plans for positive responses. SIE and counseling can involve not only the client but also significant persons in the life of the client.

Personal network systems such as family members, friends, and neighbors (Round & Israel, 1985) are an influence on and resource for the client and can make a contribution to the treatment plan. A separate interview with members of the personal network system may be done to get additional information to clarify the problem(s), determine the responses to the situation, and elicit cooperation in the treatment process. The personal network system can be a support and reinforcer resource for clients as they attempt to incorporate the principles of SIE, practice the techniques, and meet the goals of each phase.

The goals of the first session, assessment and psychosocial interview, are to (a) develop a therapeutic, collaborative relationship and (b) begin the assessment and data collection. The second session provides a conceptual framework to understand stress as a transaction between the client and the environment (Meichenbaum et al., 1975). The basis of the collaborative relationship, the therapeutic alliance, encourages free exchange of information and this implies that both client and counselor participate in the formulation of the problem, the plan of action, and evaluation after implementation (Meichenbaum & Cameron, 1983). Establishment of the relationship, assessment and therapy are so closely kin that they cannot be separated (Meichenbaum & Cameron, 1983). Assessment and reassessment continue throughout the process of SIE and counseling. The objectives of the beginning assessment include identifying the client's thoughts, feelings, behaviors, and resources in the physical and physiological, psychosocial, and spiritual domains.

The conceptual framework of SIE, presented in a didactic, discussion format, is designed to help the client understand stress in a framework that provides some control. The clients learn how primary and secondary appraisals affect stress outcome, how the body reacts to stress, and the points at which they can control outcome (see "Conceptualization of Stress" on p. 130). It is important for the client to understand the role that cognitions (thoughts) and affect (feelings) play in engendering and potentiating stress (Meichenbaum & Cameron, 1983,) and how they affect behavior (doing). A variety of techniques are available to help client learn to pay attention to self-talk in order to identify and control it.

Techniques used to reconceptualize problems in order that newly acquired problem-solving skills can be tried include free discussion of what makes the problem worse or better, what the client has tried, what has worked, and what has not worked. Another technique that may be helpful is to ask the client to do an image based reconstruction; that is, to relate an incident with specific and exact descriptions of what took place, what thoughts they had during the incident, and what self-statements they made. The self-monitoring that results from this process is another skill that will help clients develop awareness of cognitions, affects, and behaviors(Meichenbaum & Cameron, 1983). A check list or open ended diary is still another technique that encourages clients to keep a record and practice self-monitoring. The client is encouraged to discuss any problems anticipated in implementation so that the counselor and client together can generate solutions. This is an added tool as the counselor role models the problem-solving process and provides the client an opportunity to practice these skills. If feasible and/or necessary, direct behavioral assessments where the counselor goes into the environment and observes the client can be helpful. The conceptualization phase lays the foundation as clients learn new approaches and techniques so that new skills can be learned in the second phase.

The main goal of the second phase, skills acquisition and rehearsal, is to make sure that the clients learn to execute effective coping responses (Meichenbaum & Cameron, 1983). Ensuring that the client can integrate and execute new skills involves rehearsal. Skill development is designed to teach new skills and help the client develop intrapersonal and interpersonal coping skills. This content is based on the needs of the client and should never be undertaken without a careful analysis and identification of the problem (Meichenbaum, 1985; Meichenbaum & Cameron, 1983). Again, it is important to know how the client views the problem and what is and is not helpful.

Coping skill acquisition occurs in the cognitive, affective, and behavioral domains. Cognitive coping skills include cognitive restructuring with substitution of positive self-statements for negative selfstatements and self monitoring of thoughts, feelings, and behaviors that cause difficulty. Affective coping skills utilize both cognitive and behavioral skills to deal with and control feelings. Behavioral coping skills include muscle relaxation (Horan, Hackett, Buchanan, Stone, & Demchik-Stone, 1977; Hussian & Lawrence, 1978), deep breathing, biofeedback, mental imagery, and exercise.

Coping techniques are based on problem-focused and emotion-focused strategies (Folkman, Lazarus, Gruen, & DeLongis, 1986). For problem focused coping, the client learns to define the event as a problem to be solved. This approach communicates that a solution is possible. The client is assisted to set realistic goals so that success is possible. Problem solving skills involve identification of the problem in specific terms and descriptions, generating information about the problem with possible solutions, selection of specific solutions or interventions, practice of the

solutions or interventions, implementation, and evaluation of the interventions. In each step discussion centers around the thoughts, feelings, and behaviors that are facilitative and/or disruptive. The client is "coached" in each problem-solving step, helped to postpone judgment during idea generation, encouraged to seek needed information, aided to anticipate consequences of interventions, and given an opportunity to rehearse. It may be helpful to have clients anticipate failure so that they can picture regaining control and mastery (Meichenbaum et al., 1975). Throughout this process, the counselor models problem-solving skills (Meichenbaum, 1985).

Emotion-focused coping, on the other hand, is used in aversive situations that cannot be resolved, altered or avoided (Meichenbaum, 1985; Meichenbaum & Cameron, 1983). When events cannot be controlled, people can derive some sense of control by choosing their responses to the event (Stensrud & Stensrud, 1983). The goal, in this instance, is to relieve the distress as much as possible (Meichenbaum & Cameron, 1983). There are a variety of techniques that support or foster emotion-focused coping. One technique is perspective taking which encourages the client to find sources of satisfaction in other areas of life. This must be handled with sensitivity so that it is not interpreted as a "pollyanna" approach. A role model with the same condition who has successfully handled the problems may be helpful to the client (Meichenbaum & Cameron, 1983). Another technique is attention diversion which seeks to focus attention on areas that have brought a sense of well-being in the past (Turk, 1978). Encouraging expressions of affect, including ventilation of feelings and "getting things off one's chest" can be helpful and adaptive when people experience events they are unable to control (Meichenbaum & Cameron, 1983; Moos & Billings, 1982). Finally, when coping strategies are unsuccessful, "responses that function to control the meaning (author italics) of the problem" can buffer the stress (Pearlin & Schooler, 1978, p.6). Examples of this type of coping strategy include positive comparisons, selective ignoring, identifying some positive attribute, and substitution of rewards (Pearlin & Schooler, 1978).

The third phase, application and follow-through, is when the client actually uses the newly-learned skills in the real world, testing them in actual stress situations. The two main goals of this phase are to have the client incorporate the newly learned skills into daily living and to increase the probability that the changes will last (Meichenbaum & Cameron, 1983). The counselor nurtures the client's confidence in skill utilization (Meichenbaum & Cameron, 1983). Relapses are handled in a matter-offact way that acknowledges that failure is a part of the process. Clients are helped to evaluate the situation, incorporate the resulting new data into a new plan, and anticipate success. Behavior change is a process and requires time to incorporate new habits. It is important that the counselor understand and communicate this to the client. As the client gains skill and confidence termination is appropriate.

It is helpful to have a transition period between concentrated interventions and termination (Meichenbaum & Cameron, 1983). This provides a structure for the client which promotes a sense of security. As problems are solved, new problems arise. Although the basic skills can be applied to other specific problems, clients may need to discuss their thoughts, feelings, and behaviors as they learn to manage stress.

SIT has been successfully used with a variety of populations. Selected examples include: (a) speech anxious individuals (Altmaier, Ross, Leary, & Thornbrough, 1982; Jaremko, 1980); (b) test-anxious students, (Hussian & Lawrence, 1978); (c) athletes (Mace & Carroll, 1986; Mace, Eastman, & Carroll, 1986); and (d) individuals having difficulty managing anger (Novaco, 1977; Schlichter & Horan, 1981). SIT has also demonstrated effectiveness with individuals with medical problems. Selected examples include: (a) cancer patients (Moore & Altmaier, 1981); (b) burned patients (Wernick, Jaremko, & Taylor, 1981); (c) a rehabilitation patient (Coburn & Manderino, (1986); (d) patients experiencing presurgical anxiety and postsurgical pain (Wells, Howard, Nowlin & Vargas, 1986); (e) patients with multiple sclerosis (Foley, Bedell, LaRocca, Scheinberg, Reznikoff, 1987); and (f) psychiatric patients (Holcomb, 1986; Kaminer & Shahar, 1987). In summary, the goals of treatment with SIE and counseling are to provide an opportunity for clients to incorporate changes into their lifestyles, reduce the frequency and/or eliminate maladaptive cognitions (catastrophic anticipations, distorted interpretations), and facilitate adaptive thinking and behaviors. Disruptive behavior is an intervention focus since a change in behavior will change transactions. Both change in cognitions and behaviors will foster fewer disruptive feelings (Meichenbaum & Cameron, 1983).

## **SESSION I**

# Session I Assessment and Psychosocial Interview

## Equipment and environment

- 1. Audiotape recorder.
- 2. Private room.

## Session I Goals

- 1. Establish rapport and develop a collaborative relationship with the subject/family.
- 2. Data collection or assessment (Psychosocial Interview)

## Session I Objectives

At the end of the session the counselor will be able to describe the:

- 1. meaning of the illness to the subject.
- 2. perception of the subject about how dialysis affects lifestyle.
- 3. adequacy of the subject's behavioral repertoire (Meichenbaum, 1985).
- 4. variety of available coping responses (Meichenbaum, 1985).
- 5. knowledge and expectations of the subject (Meichenbaum, 1985).
- 6. self-statements that support escalation of the stress response.

The Psychosocial Interview is an outline. It is not meant to be followed verbatim. Some of the questions may be inappropriate for some. The session is conducted like a counseling session. When questions are underlined, this means that the information is very important. It does not mean that the questions are asked in that fashion. Frequently, the subjects will provide answers to the questions without being asked. The information in the parens is the rationale for the questions. It is there to provide information for the counselor. When probing for answers, probe gently. Much of the information will come as the client begins to understand the process.

#### PSYCHOSOCIAL INTERVIEW

## I. DEMOGRAPHICS

Current Address	Date of birth:/
<u></u>	Date of 1st Dialysis:
	Times of Dialysis:
Current phone	
Code Silently: Sex: Male Race: 1 2 3	(2) Female(1) 
Level of education: 8-12 college	(number of years)
Marital status: SM	DSEPNo of years
Describe person: (appearance etc.)	, affect, psychomotor activity, grooming,

#### II. PROBLEM DEFINITION

(It is important to have a definition of the problem from the perspective of the patient (Meichenbaum, 1985). Probe for cognitions, behaviors, affect, situational problems, and physiological effects. Give the subject an opportunity to express him/herself before asking specific questions. Ask the specific questions only as necessary to collect data.)

"Losing kidney function and having to go on dialysis is a very upsetting (stressful) event in a person's life. Tell me about your illness. How has it been for you?"

(The perception of the patient to personal loss and what it means to him/her is important in determining how he/she will adjust to the illness.)

"What are your thoughts about your illness/experience?"

"What are your feelings about your illness/experience?"

"What do you **do** (behaviors) to handle these thoughts and feelings?" (cry, eat, drink)

"What has changed most in your life since you found out about your kidney disease? Dialysis? How has your life changed? Or, how do you anticipate your life changing?"

## If indicated:

"Of all of the changes you have had to make in your daily activities, which ones are/were the most difficult for you?"

If indicated: "What is important for you to stay the same?"

"What is the most bothersome thing about this for you? What is your biggest worry? What bothers you the most?"

#### III. SOCIAL SUPPORT

(The subject's perceptions of his/her social support systems determines the usefulness of the support systems to him/her.) "Who are the important people in your life?"

# A. FAMILY CONSTELLATION

#### RELATIONSHIPI WHERE LIVE | SAME TOWN | IN STATE | OUT OF STATE! Spouse

spouse		
child(ren)		
grandchild(ren)	 	
parent(s)		
siblings		
relatives		
friends	 	
others		

#### If indicated:

"How has your role/position/ situation in your family changed since you started on dialysis?"

#### If indicated:

"How has your dialysis affected others in your family?"

#### If indicated:

"Of all the changes in your family, which one(s) bother you the most?"

# B. OTHERS

"Do you talk about your problems and concerns with other people?

No\_\_\_\_\_ Yes\_\_\_\_\_

"Is (are) there a special person(s) you talk to when you have a problem?

No\_\_\_\_\_ Yes\_\_\_\_\_

"With whom have you discussed your condition?" Identify relationship: 1=spouse 2=child(ren) 3=parents 4=sibling 5=other relatives 6=friends 7=doctor 8=nurse(s) 9=other

"Is there anyone with whom you can talk about your feelings about being on dialysis?"

	Identify person:	1=spouse
No_		2=child(ren)
Yes_		3=parents
		4=sibling
		5=other relatives
		6=friends
		7=doctor
		8=nurse(s)
		9=other

. -

.....

. . . .

"How helpful is it to talk to them?"

1=very helpful 2=somewhat helpful 3=only a little helpful 4=not at all helpful

"Is there anyone who has been especially **helpful** to you in the past?"

No\_\_\_\_\_ Yes\_\_\_\_\_ Identify person(s): 1=spouse 2=child(ren) 3=parents 4=sibling 5=other relatives 6=friends 7=doctor 8=nurse(s) 9=other

"What kind(s) of help are your family/children/friends especially good at giving?"

"What kind(s) of help is it hard for you to ask for? Is it easy for you to ask for?"

"Do you think that dialysis affects the way people act toward you?" No\_\_\_\_\_ Yes\_\_\_\_\_ If yes:

In what ways?

"<u>Do you know anyone else who is on dialysis?</u>" No\_\_\_\_\_ Yes\_\_\_\_\_

If yes: Who would that be?\_\_\_\_\_ Do you talk to them about dialysis and dialysis problems?

If yes: "Is this helpful?" 1=very helpful 2=somewhat helpful 3=only a little helpful 4=not at all helpful

"How **understanding** is your spouse/children/significant other/ identified person/to you in relation to your condition?"

(Get a rating for each person that is discussed by the subject.)

1=very understanding 2=somewhat understanding 3=only a little understanding 4=not at all understanding

"How supportive or helpful is your spouse/ children/significant other/ identified person/ to you in relation to your condition?

1=very supportive 2=somewhat supportive 3= only a little supportive 4=not at all supportive

"How attentive is your spouse/children/significant other/identified person to you?

1=very attentive 2=somewhat attentive 3= only a little attentive 4=not at all attentive "How dependent on others do you think your dialysis has made you?"

1=very dependent 2=somewhat dependent 3=only a little dependent 4=not at all dependent

## "Before going on dialysis, how much control (influence, power.decision making ability, ability to manage) do you feel that you had over your life?"

1=a great deal of control2=some control3=only a little control4=no control

"How much control do you feel that you have over your life since going on dialysis?"

1=a great deal of control2=some control3=only a little control4=no control

"Of all of the changes that you have experienced in your family (with others) which ones bother you a lot? are the most important?"

"Often people who experience medical problems feel like asking "why me?" Have you asked this question?"

No\_\_\_\_\_ Yes\_\_\_\_

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*If yes:* How have you answered this question?

# IV. ACTIVITIES (Base line information)

··· ··· ·

A. <u>WORK</u> "Which of these describes what you are doing now?" 1=working (how many hours per day or week) 2=student 3=temporarily not working 4=unemployed 5=retired 6=disabled 7=homemaker 8=other (describe)\_\_\_\_\_

"What kinds of work have you done? How long?"

If indicated: "Have you had to make changes due to dialysis?" No\_\_\_\_\_ Yes\_\_\_\_ Identify changes?

If indicated: "When did you stop working? month year

If appropriate: "Are you planning to go back to work?" No\_\_\_\_\_ Yes\_\_\_\_\_

"Tell about your plans."

#### B. DAILY LIVING

"What are some of the changes you have had to make in your daily activities, like work, play, hobbies?"
## "Of all the changes that you have had to make in your daily activities, which one(s) really bother you a lot? Tell me more about that."

# "What kinds of things did you do before dialysis that you can no longer do?"

"Of all the things that we have talked about so far, what do you miss being unable to do the most?"

## C. LEISURE

.....

## "What are the things that you do for fun?"

## "Of the things that you did for fun, what can you still do? cannot do?

#### If indicated:

"Of all the changes that you have had to make in your leisure time, which ones bother you the most?"

## If appropriate:

"What activities have you found to occupy yourself/time?"

"Describe a typical day when you do not go to dialysis." (Probe for specifics.)

## V. LEVEL OF SELF-CARE

"Tell me about your medication regimen? How difficult/easy is it for you to manage? (Probe to find out if subject thinks that the medication regimen is important to well-being: what would happen if he/she no longer took the medications. skipped a dose. forgot. etc).

"What are your thoughts about your medication regimen?

"What are your feelings about your medication regimen?"

"What are do you do (behavior) about your medication regimen?"

"What is the most difficult thing about your medication regimen?"

"What do you say to yourself about your medication regimen?" (Probe for self-talk.)

"Tell me about your diet. How do you manage? How difficult/easy is it for you to manage? (Probe to find out if the subject believes that diet is important to well-being).

"What are your thoughts about your diet?"

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\_\_\_\_\_

"What are your feelings about your diet?"

"What do you do (behavior) about your diet?"

"What is the most difficult part of your diet for you?"

"What do you say to yourself about your diet?" (Probe for self-talk.)

"Tell me about your fluid restriction? How difficult/easy is it for you to manage? (Probe to find out if subject believes that fluid restriction is important to well-being.)

"What are your thoughts about your fluid restriction?"

"What are you feelings about your fluid restriction?"

"What do you do (behavior) about your fluid restriction?"

"What is the most difficult thing about your fluid restriction?"

\_\_\_\_\_

# "What do you say to yourself about your fluid restriction?" (Probe for self-talk.)

"Tell me about 'going on the machine'. How is that for your?" (Probe for specifics).

"What are your thoughts when you think about it?" (What do you think when you arrive at the Kidney Center? What do you think as the nurse connects you to the machine?)

"What are your **feelings** about going on the machine?" (What are your feelings when you think about going on the machine?)

"What do you do (behaviors) when you think about it?"

"What do you say to yourself about "going on the machine"? (Probe for self-talk).

VI. IDENTIFICAITON OF COPING MECHANISMS

"When you have problems, what do you do? What do you do (behaviors, chemicals, activities, defense mechanisms) that helps you when you have a problem? when you feel stress?"

Probe for specifics. Ask for examples.

"What are your thoughts when things are not working out well?"

"What are you feelings when things are not working out well?"

"What do you do (behavior) when things are not working out well?

"What is the most difficult part of dialysis for you?"

"What do you say to yourself about dialysis?" (Probe for self-talk.)

(The patient's expectations of the future determine, to some extent, his/her ability to deal with the present in a hopeful and productive manner.) "Think about six months from now, what do you think that you will be doing? How do you think that you will feel about dialysis? How will life be for you then?"

"Is there anything the	at we have not t	talked about th	hat worries	vou such as
sexual concerns?"				
NT				

No\_\_\_\_\_ Yes

If yes: "Tell me more about your concerns."

"Is there anything else that you would like for me to know? Any questions that you would like to ask?

"Thank you for sharing your thoughts and feelings with me." Tell client exactly when you will meet again.

## **SESSION II**

## Session II Conceptualization of Stress as a Transaction Acquisition of Relaxation Skills

### Equipment and environment

- 1. Videotape on conceptualization of stress.
- 2. Audiotape recorder and relaxation tape.
- 3. Private room.

## Session II Goals

talk.

- 1. Provide an opportunity for the subject to discuss anything from the previous session and/or anything that has happened during the week.
- 2. Present conceptual model of stress, appraisal, reappraisal, selfetc.
- 3. Problem confirmation. (Present the identified problem to subjects in an open-ended way so that they are free to agree or disagree. Encourage the subject to add to the list of statements and to the list of problems.)
- 4. Begin to replace negative self-statements with positive self-statements.
- 5. Experience the relaxation process.

## Session II Objectives

At the end of the session the subject will have:

- 1. an understanding of how stress affects people.
- 2. participated in the process of identification of self-talk.
- 3. practiced substituting positive self-statements for negative.
- 4. participated in relaxation exercise.

## CONCEPTUALIZATON OF STRESS

Losing kidney function and having to go on hemodialysis can be a stressful process. There are many ways to handle this stress and we have talked about some of the ways that you handle it. This presentation will provide you with what may be a new way for you to handle your stress. Last week we talked about what kinds of things you say to yourself about hemodialysis and how it effects your life. We talk 'in our heads' about the stress event and this is called self-talk. This self-talk is done before. during, and after the stressful episode (Altmaier et al., 1982). What we think, or this self-talk, can affect how we feel in a fairly direct fashion. We influence our feelings by a sort of internal discussion (monologue)--an ongoing series of statements to ourselves----in which we tell ourselves what the event means. This may be an automatic (unconscious) process until we learn to become aware of what we are saying. When we become aware of our self-talk, we can begin to change what we say to ourselves. This self-talk comes from statements that we have incorporated from significant others as we were growing up. Some of the statements are direct quotes from significant authority figures from our childhoods. Others are ones that we interpreted from both verbal and nonverbal messages. Still others are statements that we made up ourselves. Some of our self-talk is positive and helps us in a variety of ways. Self-talk that says that we are smart or good looking, competent, and capable is very helpful self-talk. Some self-talk is negative and is not only not helpful, but also harmful.

A stressor is a word that describes something that we think (perceive) may do us harm. Stressors may threaten or challenge us physically, psychologically, socially/culturally, and/or spiritually. Stressors effect our thoughts, feelings, and actions. Often, the stressors automatically stimulate us to feel anxiety, depression, pain, and/or stress. We then tell ourselves statements that increase feelings of anxiety, depression, pain, and/or stress. At the same time our body begins to tell us that we are 'uptight' because our muscles tighten, our pulse and respiration go up and maybe, too, our blood pressure. There is a panicky feeling in the pit of our stomach. Where do you feel (sense, experience) it? SHOW DIAGRAM

#### STRESSOR

POINT C Cognitive restructuring Rapid heart rate, etc. coping

PHYSIOLOGICAL AROUSAL

POINT A Physical

#### **NEGATIVE SELF STATEMENTS** APPRAISAL

#### "AUTOMATIC

#### **OF SITUATION AS** ANXIETY

POINT B

1. Re-appraisal of stressor -preparation -confrontation -being overwhelmed -self reinforcement 2. Cognitive strategies reappraisal

(Jaremko, 1979, p. 44)

This is a outline (model) of what can happen to us when we perceive something that causes us stress/pain/harm. This is a way that it can work. There is a stressor or something that we perceive is going to cause us harm. Our heart beat becomes rapid, our breathing (respiratory rate) increases, and we interpret these feelings as anxiety and begin to say negative things to ourselves. For example, "I feel just terrible. I know that I am a failure." This makes the physical feelings more intense. This

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becomes a cycle. Fortunately, the cycle can be broken at three places. It can be broken a point A by learning physical coping, like relaxation, biofeedback, mental imagery, etc. At Point B the stressor can be be reevaluated or reappraised. Skills such as problem-solving are helpful. It can be broken at point C by substituting positive self statements for negative self statements (Jaremko, 1979). This is called cognitive restructuring.

An example may help you to understand this process. A young man, with some fear of dating, is around a girl whom he would like to date. He experiences a racing heart and interprets this as anxiety so his automatic thought is"'She may not find me attractive". "She probably has a boyfriend." "I know that she is busy and won't go out with me." He does not ask her out and continues to feel anxious with a rapid heart rate. This keeps the cycle going and he continues to feel fear and anxiety about dating. If these statements make the stress worse, different thoughts and self-talk can be used to reduce and/or avoid the stress. Can you think of other things that he might say to himself?

Another example may be when you have to make a speech in front of 1000 people. As you think about this your heart beats faster, your stomach feels tight and upset, and maybe your hands shake. You feel anxious and nervous. You may say to yourself: "I just know that I will be tongue tied." "I know that I will forget." "I know that I will do poorly." "I really dread this."

This is certainly negative self-talk. How would you change this negative self-talk to positive self-talk? (Use the chart as you explain the examples.)

(Go through the model again with the patient and use some examples from Session I. Instruct the patient in how to substitute positive selfstatements for negative self-statements. Be specific and use the words of the patient. Remember: cognitive restructuring is not Pollyanna talk or only positive thinking; it is specific and involves <u>substituting</u> positive statements for negative ones.)

We have talked about how our muscles get tight, our breathing gets faster, and the feeling in the pit of our stomach. A way that we can have some control over how we feel is through relaxation training. Coping with stress involves physical coping skills, too. such as deep breathing, progressive relaxation, and "mental" relaxation. Have you ever used any of these techniques? ..... How did they work for you? ...... Would you like to try one now?

#### **RELAXATION EXERCISE**

Procedural tips for relaxation teaching:

- 1. It is learning a new skill and takes some time to master.
- 2. You are free to stop at any time. You are in charge. You may choose to close your eyes or you may keep them open.
- 3. Relaxation is not a test so there is no success or failure. It can take time to learn to relax.

As you are learning a relaxation skill, it is important to have a comfortable chair or place to sit or lie down, a time when you will not be interrupted, and a desire to use these skills.

Get into a comfortable position.

First take 3 deep breaths and as you breathe in on the count of 1, 2, 3, think of your body as being filled with oxygen; in your lungs the oxygen enters your blood and the carbon dioxide leaves; pucker your lips and blow the carbon dioxide or used up air out of the body on the count of 4, 5, 6, 7; think of the stress leaving your body with the used up air. Do this 3 times.

The next step is to continue the breathing while contracting and relaxing the muscles, one group at the time. With each exhale, imagine the stress leaving your body. With each inhale, imagine the oxygen entering your body to make you feel good.

Use the following steps:

 Tighten your hands. As you breathe in make a fist and as you breathe out relax your fist and think of the stress as going out of your finger tips.
 Tighten your arm muscles. As you breathe in tighten the muscles in your forearm and upper arm. As you breathe out, relax these muscles and think of the tightness and stress as going out of your arm muscles.

3. Pull your shoulders back as you breathe in and relax them as you breathe out.

4. Turn your head slowly to the right as you breathe in and back to the center with your chin on your chest as you breathe out. Think of the tightness and stress as going out of the body as you exhale.

5. Turn you head slowly to the left as you breathe in and back to the center with your chin on your chest as you breathe out.

6. Open your mouth as possible as you breathe in; pucker your lips as you exhale and think of your stress as being blown out with the used air.

7. Extend your lower legs as you breathe in and relax them back on the floor as you exhale. Think of the stress as going out of your legs.

8. Tighten the muscles in your calves as you breathe in; relax the muscles in your calves as you breathe out. As you relax the calf muscles think of the stress as going out of your legs.

9. Tighten the muscles in your feet and point your toes as you breathe in; relax the muscles in your feet and think of the stress as moving out of your feet.

You are now relaxed. Your body has lots of oxygen and you feel good.

## SESSION III

## Session III Focus on Medications

#### Equipment and environment

- 1. Audiotape recorder.
- 2. Private room.

## Session III Goals

- 1. Provide an opportunity for the subject to discuss anything from the previous session and/or anything that has happened during the week.
- 2. Confirm self-statements about taking the medications.
- 3. Develop positive self-statements about the medication regimen to replace negative self-statements.
- 4. Rehearse cognitive and physical coping skills.

## Session III Objectives

At the end of the sessions the subject will:

- 1. verbalize positive self-statements about taking medications
- 2. discuss ways to stop the negative self-talk cycle.
- 3. demonstrate the relaxation technique.

## **SESSION IV**

## Session IV Focus on Diet

#### Equipment and environment

- 1. Audiotape recorder.
- 2. Private room

#### Session IV Goals

- 1. Provide an opportunity for the subject to discuss anything from the previous session and/or anything that has happened during the week.
- 2. Evaluate the effectiveness of strategies identified in session
- 3. Confirm and/or identify problems with staying on the diet.
- 4. Develop strategies to enhance dietary adherence.
- 5. Rehearse dietary adherence strategies.
- 6. Rehearse cognitive and physical coping skills.

#### Session IV Objectives

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At the end of the session the subject will:

- 1. verbalize strategies and positive self-statements about dietary adherence.
- 2. demonstrate positive self-talk about dietary adherence.
- 3. demonstrate the relaxation technique (if needed).

#### SESSION V

## Session V Focus on Fluid Restriction

## Equipment and environment

- 1. Audiotape recorder.
- 2. Private room.

#### Session V Goals

- 1. Provide an opportunity for the subject to discuss anything from the previous session and/or anything that has happened during the week.
- 2. Evaluate the effectiveness of strategies identified in previous sessions.
- 3. Confirm and/or identify problems with fluid restriction.
- 4. Develop strategies to enhance fluid restriction.
- 5. Rehearse strategies.
- 6. Rehearse coping skills as needed (cognitive and physical).

## Session V Objectives

At the end of the session the subject will:

- 1. verbalize strategies and positive self-statements about maintaining fluid restrictions.
- 2. demonstrate positive self-talk about fluid restriction.
- 3. review any strategies that need rehearsal.

### **SESSION VI**

## Session VI Termination

## Equipment and environment

- 1. Audiotape recorder.
- 2. Private room.

#### Session VI Goals

- 1. Evaluate the effectiveness of the intervention.
- 2. Answer any questions about the process.
- 3. Rehearse any skills identified by subject.
- 4. Terminate the relationship.

#### Session VI Objectives

At the end of the session the subject will:

- 1. discuss ways that the skills can continue to be used.
- 2. demonstrate positive self-talk.
- 3. demonstrate the relaxation technique.
- 4. experience closure of the relationship.

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APPENDIX E

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## APPENDIX E

APPENDIX G

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Date\_\_\_\_\_

## HEMODIALYSIS EXPERIENCE

Please check any of the following symptoms each time you experience them <u>while on dialysis</u>.

Low blood pressure	≠	≠	≠	≠	≠	≠	≠
Nausea	≠	¥	≠	≠	¥	≠	≠
Vomiting	≠	≠	¥	¥	≠	¥	≠
Leg cramps	≠	¥	≠	≠	≠	≠	≠

What other problems did you have?

\_\_\_\_\_

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## APPENDIX H

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**APPENDIX I** 

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## **EVALUATION FORM**

Please check the answer that best describes your experience.

1.	I had a chance to say what was on my mind.	Yes	No
2.	I have used the skills I learned.	Yes	No
3.	I would participate in this experience again.	Yes	No
4.	I would recommend this to a friend.	Yes	No

Please circle the number that describes your feelings about this experience.

6. I found the experience to be:

----

O=not at all 2=a little 4=quite a bit 6=very much 8=extremely

easy 0	2	4	6	8
valuable 0	2	4	6	8
positive				
0	2	4	6	8
helpful 0	2	4	6	8

What I liked **best** was:

What I liked least was:

\_\_\_\_\_

Thank you for your participation in this study. Your cooperation has been greatly appreciated. It has been a joy working with you. Best wishes for the future.

## APPENDIX J

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#### STATE EVALUATION FORM

#### FEELING THERMOMETER

This is a feeling thermometer. Zero is the lowest level of feeling indicating that you are feeling very depressed and blue. One hundred is the highest level indicating that you are feeling very happy and glad. Indicate the level of your feeling at this moment by circling the number that best describes your feeling.

