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thesis entitled

PERCEPTIONS OF REHABILITATION
BETWEEN HEMODIALYSIS CLIENTS
AND THEIR SIGNIFICANT OTHERS.

presented by

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has been accepted towards fulfillment
of the requirements for

MASTERS of science degree in NURSING

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Date 2-19-87

ABSTRACT

PERCEPTIONS OF REHABILITATION BETWEEN HEMODIALYSIS CLIENTS AND THEIR SIGNIFICANT OTHERS

By

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Using King's Nursing Model, this study was designed to describe the perceptual congruence between 28 hemodialysis dyads regarding the client's rehabilitative status and their satisfaction with that status. The Sickness Impact Profile (SIP) and a Satisfaction Survey was administered to a convenience sample. Reliability coefficients of the study instruments were assessed to be acceptable. There was a moderate to high degree of perceptual congruency between the dyad members in the clients overall rehabilitation and in the following SIP scales: Sleep/Rest, Home Management, Work and the overall physical dimension. No significant relationship was found between their perceptions in the overall psychosocial dimension or in the SIP Scales; Social Interaction and Eating. The dyads did have similar perceptions of satisfaction with the client's rehabilitation yet, no consistent relationship was found between their perceptions of dysfunction with satisfaction. This information will add to the body of rehabilitation knowledge and offer strategies for nurses working with ESRD dyads.

DEDICATION

This project is dedicated to the 31 hemodialysis clients and their significant others who participated in this study.

ACKNOWLEDGEMENTS

Further acknowledgments are given to the following individuals, who provided continual encouragement and unending support:

Bruce Daniels
Bryan Coyle
Diane White
Marge and Dick Tuinstra

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CHAPTER I

THE PROBLEM

End Stage Renal Disease (ESRD) is a chronic lifelong illness necessitating either a kidney transplantation or a form of dialytic therapy for survival. The treatment options, for dialysis, once limited to only in-center hemodialysis, have been expanded to include: Hemodialysis--both in-center and home, intermittent peritoneal dialysis (IPD), and continuous ambulatory peritoneal dialysis (CAPD). Each of these modalities are designed to mimic the kidney's basic processes of diffusion and osmosis.

Regardless of the treatment modality, ESRD clients and their families are faced with numerous disruptions in their lifestyle. Adjustments to physical limitations, dietary restrictions, time commitments for dialysis, and a host of psychological factors can be dilemmas for any family dealing with ESRD. Unlike an acute illness, ESRD places the client and his/her family in a position which may require family and social role changes. Often these changes are realized by the clients and their families after being discharged to a chronic outpatient treatment modality. Through time, the client and his/her family must redefine role obligations that are not only mutually satisfying but also maximize the client's actual ability (Diamond & Jones, 1983). The ability to cope with the treatment regimen and the accompanying life changes will ultimately affect the client's rehabilitative potential.

Purpose

The purpose of this study was two-fold; to describe the degree of perceptual congruence between an ESRD client and his/her significant other on physical, psychological, and gainful activity dimensions of rehabilitation and their degree of perceived satisfaction with the client's status. Information from this study will provide data for health professionals in promoting the rehabilitation of ESRD clients. Conceptual support is in part provided by Corbin and Strauss (1984). They note the importance of perceptual congruence between clients and their significant others for establishing a new life trajectory that will be mutually satisfying. Incongruent perceptions in respect to physical expectations, and role responsibilities may precipitate a stressful, non-supportive environment impeding rehabilitation. The client and significant other work against each other in this situation expending precious energy fruitlessly. Therefore, the concept of perceptual congruence becomes critical as there is an assumed sharing and working together towards a goal. The goal, with it's associated activity, is the process of rehabilitation.

Finally, the purpose of this study was to raise the consciousness of health care professionals regarding the complex nature of rehabilitation. Interventions must be realistic and geared towards both clients and their support networks if the goal of rehabilitation is to be realized by the ESRD population.

Statement of the Problem

The focus of this study was to examine the concept of rehabilitation in a sample of chronic hemodialysis clients receiving treatment at a large medical center in Southwest Michigan. Data were collected to answer the following major research questions and their associated sub-questions.

I) What is the degree of perceptual congruence between the hemodialysis client and his/her significant other regarding the client's present overall rehabilitation status?

a. What is the degree of perceived congruence between the client and his/her significant other on the physical dimension of rehabilitation?

b. What is the degree of perceived congruence between the client and his/her significant other on the psychosocial dimension of rehabilitation?

c. What is the degree of perceived congruence between the client and his/her significant other on the rehabilitation dimensions of sleep/rest, work, eating, recreation and pastimes, and home management?

The second major research question was:

II. What is the degree of perceptual congruence between the client and his/her significant other regarding their satisfaction with the client's present rehabilitation?

One sub-research question was developed to elaborate further on question II:

a. What is the correlation between perceived congruence on the dimensions of rehabilitation and their degree of perceived satisfaction with the client's rehabilitation status?

Conceptual Definitions

The concepts utilized in this research were defined in the following manner:

End Stage Renal Disease Client

A client who is medically diagnosed as having less than ten percent kidney function thereby requiring dialysis for life survival.

Significant Other

Person living within the same household with the client and is identified by the client as a primary support. The relationship must have been established prior to the client's onset of kidney disease. The term dyad will be used in this paper to refer to the significant other and the client.

Hemodialysis

Technique in which blood is circulated outside the body through a filtration system. The goal is to remove toxic waste products from metabolism, excess water, adjust electrolytes, and correct metabolic acidosis. The hemodialysis process can be performed in a hospital based outpatient unit, or in the client's home.

Rehabilitation

A restorative process through which an individual with chronic renal failure develops and maintains self-sufficient functioning appropriate to his/her environment. The components of rehabilitation will include the following: Sleep and rest, emotional behavior, body care and movement, home management, mobility, social interaction, ambulation, alertness behavior, communication, work, recreation and pastimes, and eating. These components will be measured as perceptions of rehabilitation and interpreted as rehabilitation status.

Perceptual Congruence

King (1981) defines perception as each human being's representation of reality. It is an awareness of persons, objects, and events in relation to how one perceives self, body image, home and space. Congruence is defined by Webster as that which is agreeable or harmonious (1981). In this study perceptual congruence of rehabilitation was defined as the degree to which the client and their significant other have similar perceptions of both the physical, psychological and gainful activity components of rehabilitation.

Satisfaction

Campbell, Converse and Rodgers (1976) conceptually define satisfaction as an affective expression denoting a feeling of well-being. The basis for determining the degree of satisfaction is through the cognitive judgement of a current situation laid against external standards of comparison. The external standard for comparison may be to other people or more private levels of aspiration. Each frame of reference is highly individual and can be expected to differ from person to person. The subjects of this study were not given a particular frame of reference for assessing their satisfaction with the various rehabilitation dimensions. This was purposefully avoided to allow for individual interpretation, since the subjects were expected to be at different points within the life cycle and the disease process itself. Potential differences within the frame of reference will be explored in the interpretation of the data.

Background of the Problem

From inception, the concept of rehabilitation has been recognized as an integral component of the dialysis program. Taylor (1978) cites the initial objectives of dialysis programs was to do more than provide a medical treatment to prolong life. The dialysis process was to be a vehicle for returning the individual to some semblance of his previous lifestyle.

The process of restoring a previous lifestyle is commonly referred to as rehabilitation. Studies conducted to examine rehabilitation have until recently been sparse and inconclusive. In fact, the emphasis placed on rehabilitation was not given much attention until the mid 1970's. Gutman Stead & Robinson (1981), summarizes the

focus of the early research efforts as a time when the actual dialysis process was considered a scientific frontier. Researchers working with the ESRD population focused their attention on evaluating the effectiveness of the actual dialysis process for long-term survival. Certainly one could not criticize the early researchers for their narrow focus on life survival. Rather, their efforts must be viewed as the key to "Pandora's box." Early researchers could not foresee the long-term implications of dialysis, either physically or psychologically. Furthermore, the strong work ethic which prevails within American society fairly well assumes that all individuals will make every attempt to be productive. Quite possible, both the medical and governmental sectors felt that, by providing a reasonable guarantee for survival, dialysis would not interfere with self-attainment of a productive, full life.

Interestingly, one can correlate the enactment of governmental policies and the intent under which they were founded with the direction of the early researchers. When the ESRD program was established by section 2991 of the Social Security Amendment in 1972, the enactment was geared to prevent financial catastrophe for the patients and at the same time provide monies for ESRD research. Virtually all clients who required chronic dialysis or transplantation were eligible for medical coverage and disability. Eligibility was contingent on meeting one of the following

stipulations: the client was currently insured under Social Security at the onset of disease, was a monthly Social Security beneficiary, or the spouse or dependent child of an eligible person.

The ESRD program began operation with approximately 11,000 beneficiaries and paid out benefit payments of about 229 million dollars. By calendar year 1979, there were 42,500 clients on dialysis receiving a total of almost 985 million (H.C.F.A., 1982). Up to this point, there were no incentives for providing cost-effective therapy. The system was designed for retrospective reimbursement with few regulations designed to foster rehabilitation. Clients were provided with not only free or minimal-cost dialysis but also Social Security disability pay.

Clearly, the original intent of the governmental reimbursement policies and the medical researchers was achieved. Families were protected from financial catastrophe, and life survival on dialysis was perfected. By 1978, the H.C.F.A. began enacting amendments to help alleviate the rapidly increasing expenditures. In 1981 the Omnibus Budget Reconciliation Act (P.L. 97-35) required the H.C.F.A. to devise a more efficient method to pay for dialysis. Subsequently, efforts were directed at establishing a prospective system for payment. At this time, 3.8% of the total Medicare benefit payments were allotted to approximately 60,000 clients.

That so much is expended on so few, caused some to question whether the Medicare ESRD program should continue to consume such a large proportion of the health care budget. In order to justify the value of the ESRD program, health care workers and legislators turned to the research for rehabilitation data.

Unfortunately, the research was found to be limited and dated. Gutman et al (1981), reveals that the studies conducted in the 1960's pointed to a high level of debilitation among the ESRD population. He cautioned the readers of these studies to interpret the findings with due respect, for the emphasis at that time was placed more on the dialysis process and the characteristics of the population, excluded older and sicker patients. In addition, several other problems were noted in the studies conducted in the late 1960's and 1970's; They were limited to small sample size, included only home dialysis patients and/or utilized samples from only one institution.

In lieu of the renewed emphasis on rehabilitation Gutman et al (1981) published his own plea for rehabilitation data that encompassed a holistic approach to rehabilitation. Concurrently, a task force was convened by H.C.F.A. to evaluate "model" rehabilitation programs, evaluate disability payments, and structure reimbursement to encourage self-care. One such incentive was to reimburse centers at the same rate for clients who dialyzed either at home or in-center. Home dialysis was viewed as a vehicle to foster independence, increase control over the treatment process, and increase client comfort while at the same time controlling costs. In 1982, 17% of all dialysis treatments were conducted in the home, with an anticipated increase to 30-40% over the next five to seven years (H.C.F.A., 1982).

The need to foster research on rehabilitation in light of the policy changes is of critical importance. The insurgence of home dialysis therapy with its financial incentive for dialysis programs may lead to higher percentage of home clients who are not capable or without adequate support to dialyze at home. The end result may have financial benefits but could severely hamper the quality of life in the dialysis population.

Finally, one can note the conceptual evolution of rehabilitation within the literature in conjunction with the reimbursement policies. Employment status was initially the measure by which patients were evaluated. This measure lent itself easily to the field of research and provided an interpretable yardstick for monitoring a patient's progress. Yet, such a limited definition of rehabilitation is no longer applicable to the total population now served by dialysis. Employment, is not the best indicator of rehabilitation for the individual who lacks a stable employment history, who is at retirement age, or who does not work outside the home, nor is it applicable for the very young (Kutner, 1983). Additionally employment does not provide information about other important variable critical to rehabilitation-personal satisfaction-family involvement, community participation, social or recreational activities and corresponding psychological well-being. Therefore, rehabilitation must be viewed in a holistic manner that encompasses both a physical and psychological component.

Just as the measure of rehabilitation needed to be expanded so do the factors which influence the clients potential. Several authors have speculated on the following intervening factors: The client's physical endurance, restrictions on diet and time, response to psychosocial stress and degree of mutuality regarding the client's capabilities between the client, his family, and the health care team. (Decker, 1979; De Nour, 1981; Levy, 1979; Taylor, 1978; Chyatte, 1979; Hollon, 1979; and O'Brien, 1980). The way a client views himself, as well as how others perceive his situation, can make a difference in the client's overall response to the illness. Previous studies have tended to focus on the <u>health team's perception</u> of client rehabilitation and/or the client and his family's perception of the illness as it affect them (Baldree, Murphy & Powers, 1982; Hatz & Powers, 1980). Equally necessary, and probably foremost, one should look at the perceptions of the client and his significant other regarding the client's present rehabilitative status and his/her degree of satisfaction. From this, mutuality can be incorporated into goal strategies and energies appropriately directed towards maximizing the client's potential.

Scope and Limitations of the Study

The following limitations are recognized as being inherent within this study:

1. The Sickness Impact Profile has not been evaluated for validity or reliability in measuring the perceptions of other individuals regarding the client's rehabilitation status.

2. Due to the small number of participants, the results can not be generalized to a larger population.

3. The participants were not selected via random sampling, but were a convenience sample. This again limits the ability to generalize to a larger population.

4. Results are reflective of the specific dialysis unit from which the participants were obtained. This will limit generalization due to potential philosophical differences that occur between dialysis centers.

5. The study is not longitudinal in design and, therefore, the results will reflect a one-time measure only.

6. Confounding variables such as past history of disease, perception of health care professionals, types of interventions given pre-dialysis to promote rehabilitation and family dynamics will not be addressed.

7. The measurement of perceived satisfaction

based on the criteria components of the SIP will have only a one-time measure of reliability and validity.

Assumptions

For the purpose of this study, the investigator made the following assumptions:

1. The focus of nursing is the interaction of human beings with their environment. The goal of this interaction is to assist the individual to function in various social roles.

2. End Stage Renal Disease is a paradigm for chronic illness. Both physical and psychological stressors exist which affect the client and his/her spouse and ultimately the client's rehabilitation.

3. Perceptions of the client's disability by the client and his spouse will influence their interactions and subsequent transactions.

4. Incongruent perceptions will cause increased personal stress for the dyad and interfere with their growth in the life cycle.

5. The goal for nursing is to facilitate communication between the dyad to identify current perceptions for mutual goal setting toward successful rehabilitation.

6. The revised SIP will be sensitive to the significant other's perceptions of the client's rehabilitation status.

7. The participants will respond honestly and to

the best of their ability.

Overview of Chapters

Presentation of this research project is organized into six chapters. Chapter One is an overall introduction to the problem and questions of interest. Basic definitions, purpose, limitations, and assumptions are outlined.

In Chapter Two the concepts and theories relevant to the study are interrelated. The nursing theorist, which provides a unifying framework for the concepts, is presented. Chapter Three will entail a review of recent literature about the process of rehabilitation within the dialysis population. This review will provide past research findings related to the concepts of interest.

Methodology and procedural steps are outlined in Chapter Four. A description of the sample, setting, data collection procedure, instruments, scoring procedures, and human rights protection are addressed. In Chapter Five an overview of the various statistical measures utilized with the data is presented. In Chapter Six, the data are compared to other research studies and implications for nursing practice, education and research are discussed.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

The diagnosis of End Stage Renal Disease (ESRD) precipitates a life crisis for clients and their significant others. One only needs to examine the typical medical regimen of dietary restrictions, time requirement for treatment, and daily medications to understand the magnitude of changes imposed by chronic renal failure. The major goal of health professionals working with the ESRD population is to aid the client in making a life adaptation to dialysis that will allow continual functioning throughout the life cycle (Hadge, 1983). Unfortunately, there are many impediments to such an adaptation. Individual reaction to the illness will depend on the client's personalized symbolic meaning of the illness, pre-existing adaptations, object relations, intrapsychic conflicts, and available support (Hadge, 1983).

The goal of this research study was to elucidate further on the dimension of support from which implications for nursing practice can be suggested. The following research questions were developed based upon the study's goal:

I. What is the degree of perceptual congruence between the hemodialysis client and his/her significant other regarding the client's present rehabilitation status?

- a) What is the degree of perceived congruence between the client and his/her significant other on the physical dimension of rehabilitation?
- b) What is the degree of perceived congruence between the client and his/her significant other on the psychosocial dimension of rehabilitation?
- c) What is the degree of perceived congruence between the client and his/her significant other on the rehabilitation dimensions of sleep/rest, work, eating, recreation and pastimes, and home management?

and

II. What is the degree of perceptual congruence between the client and his/her significant other regarding their satisfaction with the client's present rehabilitation?

- a) What is the correlation between perceived congruence on the dimensions of rehabilitation and their degree of perceived satisfaction with the client's rehabilitation status?

The following concepts found within the study questions will be explored both separately and as they relate to each other: End Stage Renal Disease,

Rehabilitation, Perceptions, and Satisfaction. Imogene King's theory of the dynamic interacting system was used to provide further guidance in explicating the interrelationship of the concepts.

End Stage Renal Disease Pathophysiology of ESRD

A brief overview of the pathophysiology, clinical manifestations and medical management of ESRD is provided. The purpose is to assist the reader in gaining a better perspective of the numerous challenges imposed upon the client. The chronicity of the physical problems along with the client's coping abilities will determine his/her overall rehabilitation.

End Stage Renal Disease is a condition with multiple etiologies. A variety of pathological processes are involved in renal failure: Congenital anomalies, genetic abnormalities, immunologic processes, infection, toxic reaction, obstruction, vascular changes, neoplastic growth, and metabolic changes. Each of these processes have different physical presentations with medical management individualized accordingly. Initially, the treatment goals of ESRD are to preserve kidney function through dietary and pharmaceutical measures. Once conservative management is no longer effective, the sequel of problems associated with dialysis become universal within the ESRD population.

Bauers (1983), characterizes' ESRD "as the state in which the function of the kidney is impaired to the degree that life is threatened and the impairment is not reversible" (p. 17). At this point, the kidneys have ceased to remove metabolic wastes and excess water from the blood. The degree of impairment determines the need for dialytic therapy and, in most cases, 80% of the nephrons may be lost before the client is ever diagnosed with ESRD. Typically, when there is less than ten percent functional renal tissue, dialysis therapy becomes imperative for life survival (Brundage, 1980).

Clinical Manifestations of ESRD

End State Renal Disease is often an insidious disease. The client may be asymptomatic for years and diagnosed only through a routine physical. When considerable renal tissue is lost the client begins to experience a cluster of symptoms attributed to the uremic syndrome. Brundage (1980) describes this syndrome as a complex of symptoms, physical findings, and biochemical changes caused by the retention of the products of nitrogen metabolism and associated changes in water, electrolyte, and acid-base balance.

Client assessment will result in identifying the altered internal homeostasis. The typical physical findings upon examination include: generalized edema, hypertension, cardiac irregularities, dyspnea, depressed neurological reflexes, depressed sensorium, and changes in the skin integrity (Brundage, 1980).

These physical alterations are a result of the high serum concentration of nonprotein nitrogens, especially urea, and other urinary retention products such as creatinine, uric acid, phenols, guanidine bases, sulfates, phosphates, and potassium (Guyton, 1981). Several other metabolic processes altered in ESRD also contribute to the physical symptoms experienced by the clients. Changes in calcium metabolism as a result of the kidneys inability to activate vitamin D causes a progressive osteoporosis. The result of this alteration leads to fractures of the ribs, long bones and vertebrae. Equally distressing is the chronic anemia due to the decreased production of erythropoietin by the kidney. Resulting from this deficiency is the chronic fatigue frequently cited by the clients (Friedrich, 1980).

In addition to the physical problems noted above, are several other changes experienced by many clients. One of the most distressing is a reduction in their sexual activity. The exact etiology of this dysfunction is unclear, although the retention of metabolic by-products has been implicated. The accumulation of these toxic substances has also been cited as the cause of anorexia, nausea, vomiting and an altered taste sensation (Brundage, 1980).

Many of these problems will occur before the actual need for dialysis exists. Once the renal function is no longer compatible with life, dialysis must be initiated.

In severe cases of complete renal shutdown, death will ensue in 8 to 14 days if left untreated.

Clinical Management of ESRD

Since 1960, the technology of dialysis has literally blossomed. The ESRD population at that time had at least one option available for long-term survival--hemodialysis. Now, 24 years later, the client is given several choices for treating his/her disease. Chronic hemodialysis, chronic ambulatory peritonital dialysis, and transplantation. Hemodialysis continues to be the first mode of therapy prescribed for most patients, and often the preferred choice by many.

The basic principle of dialysis is the differential diffusion of solute through a semipermeable membrane separating two solutions. Hemodialysis involves circulating the client's blood through a filter that is semipermeable and surrounded by a dialysate solution in a so-called artificial kidney (Brundage, 1980). The forces of osmosis and diffusion undergird the dialysis process. Hemodialysis is required anywhere from three to four times a week, four to six hours per treatment. Even under the best of conditions hemodialysis, due to its intermittent nature, is unable to completely eradicate the physical ramifications of ESRD. At best, the symptoms can be controlled when hemodialysis is combined with dietary restrictions and medications.

The objective of dietary management is to assist the hemodialysis treatments by reducing the amounts of urea, fluid, and electrolytes (especially potassium, sodium, and phosphate) that must be filtered. Abuse of dietary restrictions can result in a buildup of toxic fluids and metabolic end products in the bloodstream. These may in turn result in nausea, weakness, cardiovascular problems, and even death. Medications are prescribed for phosphate binding, prevention of vitamin deficiencies and at times hypertension. Thus, successful treatment of ESRD depends not only on the efficiency of the dialysis treatments, but on the client's adherence to a comprehensive treatment plan.

REHABILITATION

Introduction

The treatment regimen as previously described requires the individual and his/her significant other to make conscious adjustments to their daily and future plans. "This catastrophic illness imposes enormous losses and narcissistic insults on patients and their coping abilities" (Hadge, 1983, p. 51). The client is placed in a dependent position within the medical system as well as his/her family. In addition, the client finds him/herself reliant on various community services such as transportation services, availability of dialysis services and emergency support systems. Furthermore, the client finds his/her financial situation dependent on the federal and state welfare system. These dependency issues only serve to compound the clients difficulties in adjusting to the physical functional losses.

When Medicare was extended to victims of renal failure in 1973, the purpose was not only to save lives, there was an equal expectation that clients would be able to successfully incorporate the regimen into their daily lives, and thereby said to be rehabilitated. Unfortunately, much of the recent evidence of rehabilitation points to a debilitated population (Lundin & Lundin, 1983). The following paragraphs will explore not only the concept of rehabilitation as it relates to End Stage Renal Disease, but also the relationship between the sick role and rehabilitation.

The Concept of Rehabilitation

Several authors have identified three major components of rehabilitation: Physical status, gainful activity, and psychosocial adjustment (Czaczkes & De-Nour, 1978; Kutner, 1980; Matthews, 1980). Each of these components are impacted in several ways, one of which is the meaning and value placed on the sick role by the client and significant other.

The hemodialysis dyad are challenged throughout the course of ESRD by numerous role changes. The first role presented to the client is the sick role paradigm as outlined by Parsons (1951). He/she is placed in a dependent position with the medical system and is relinquished of responsibilities associated with both job

and family. The client is often too sick as well as being awed by the technology of dialysis to object to this dependent position.

Once the client is medically stabilized and discharged to a chronic dialysis regime, the sick role no longer provides guidelines for hemodialysis clients and their significant others in adjusting to the chronicity of ESRD. Medical personnel assign the term "disabled" to the client as though this clearly differentiates the client from one who is acutely sick (Safilios & Rothschild, 1970). Unfortunately, this new role brings considerable confusion to the client and significant other. The dyad begins to deal with the notion of perpetual treatment without cure in absence of a set of acceptable guidelines from society or the health team (Landsman, 1979). This ultimately places the client in a precarious position by both the significant other and the health team. Landsman (1979) describes this position as that of a "marginal man," living in both the sick and well worlds. On one hand, the client is reminded of his dependence on dialysis and its associated restrictions, yet is told to resume previous life responsibilities by not fixating on the disease.

In this situation, the client is subject to normal expectations for functioning despite the limitations imposed by the disease process. Clients who are unable to meet these expectations may respond by proving they are indeed sick. In this case, the client disables him/herself in an attempt to obtain social validation for the illness.

Coupled with the notion of being a "marginal man" are the problems exposed by Falvo, Allen, and Maki (1982). They have applied the concept of having an invisible disability with impediments towards rehabilitation in the ESRD population. Since kidney failure may not provide an atypical appearance or a readily observable functional limitation to those interacting with the individual, there are no cues emitted--causing others to alter behavior or expectations. The individual's overall rehabilitation may be intertwined with his/her perception or misperception of the reactions of others. The absence of readily observable disabilities may not expose the client to the environmental feedback system that creates for the client the reality of the condition. This lack of feedback may limit the clients own awareness of his/her situation thereby creating confusion for both the client and his/her significant other (Landsman, 1979).

The ability of the client and his/her significant other to satisfactorily alter their usual role responsibilities is dependent upon congruent expectations of the disabled role. Furthermore, the dynamics found within the client support networks prior to the onset of a chronic disease will also affect the client's ability to renegotiate role responsibilities.

Diamond et al (1983) asserts that families respond to the sick role based on the extent to which the individual is integrated within the family, degree of isolation from their extended family, and their linkages within society. For the most part, families are able to readjust their activities to accommodate the sick role. The readjustment of family power and roles is usually underscored by a belief that the family will soon return to their normal state; chronic illness disrupts this belief. Both the degree of perceived disruption within the family unit and their perceptions of the clients physical dysfunction, will effect the family's adjustment. The family may respond by either perpetuation or total relinquishment of the sick role. In either situation, the client's environment will serve to be more frustrating than supportive in promoting rehabilitation. Levy (1979) postulates that clients become discouraged by the disparity of expectations between themselves, their families and the medical team. Ultimately, medical complications may be aggravated by an inability to live comfortably with an appropriate and viable self-image.

Another problem which may arise involves the impact of role changes to the family structure. Role reversal is common, with the partner assuming new responsibilities in addition to ones previously assumed. The client may no longer identify him/herself within the family structure as being useful or needed. The significant other, by not expecting the client to assume usual activities, fosters his/her feelings of uselessness. This may not be a conscious act; but rather, is their way of trying to make life easier for the client. Unfortunately, certain things may be made too easy. For instance, the client may be relinquished from the breadwinner role, household chores, maintenance, childrearing responsibilities, companion to his/her spouse, and attendance at social functions.

The issues surrounding role readjustment ultimately affect the way in which the client's self-image is reshaped. Compounding the problems of carving out a new social role arrangement is the perceived dependency and anxiety associated with the dialysis procedure. "Only very few other forms of medical treatment place the patient in so abject a situation of dependency on equipment, procedure, and personnel" (Levy, 1979, p. 60). Anxiety may occur in response to being away from the dialyzing apparatus, or emerge as a result of being kept on the artificial kidney for extended periods of time. These two reactions can be viewed as opposite sides of the dependency spectrum: The former as over dependency, and the latter as "over independency" on the dialysis procedure. De-Nour, and Czaczkes (1975) describe the highly dependent clients as ones who "enjoy" dialysis and find it difficult to be rehabilitated because of their need to continue in a highly dependent relationship with their illness and the procedure. These clients may regress and assume a childlike position of being cared for, thus making them less productive than the expectation of staff, family, and even the emotionally healthier side of themselves.

Paradoxically, the highly independent client has equal difficulty. The independence may serve the client defensively as a method of disowning his/her dependency. Faced with the necessity to tolerate dependence upon a machine, these clients may respond with anxiety, depression, and uncooperativeness, including dietary indiscretion (Levy, 1979). Ideally, the dialysis client should come to terms with the reality of his/her abject dependency upon the procedure while maintaining sufficient independence. The goal should be to engage in the highest degree of work, family, and other activities within the limitations of his/her illness and its treatment.

The components of rehabilitation; physical, psychosocial and gainful activity, will now be discussed. The order of presentation is not meant to depict order of importance.

Physical Dimension of Rehabilitation

The dialysis process itself can be a major roadblock in the way of returning to a more normal life. "Just as the large accumulation of wastes and fluid make the patient ill, a rapid reduction in the accumulation of waste products which occurs during hemodialysis is also stressful" (Friedrich, 1980, p. 252). A condition known as "dialysis disequilibrium syndrome" may result from the shifting of water, pH, and osmolarity. Consequently, the client may experience nausea, vomiting, and headaches.

This syndrome is only one of the myriad of physical complications associated with chronic hemodialysis. The following list of common complications has been identified as being pertinent to the rehabilitation process:

1. Blindness or diminished visual acuity.

2. Muscle cramping which may persist, after dialysis thereby interfering with mobility.

3. Fatigue--a subjective symptom which can be the result of or the cause of limited activity levels.

4. Hepatitis--even a positive hepatitis antigen titer can interfere with rehabilitation efforts such clients who elect to travel will have difficulty being accepted for transient dialysis.

5. Digestive disturbances--a variety of problems may occur from intermittent constipation and diarrhea, nausea, frequent belching and flatus, to gastrointestinal bleeding.

6. Osteodystrophy--may range from bone pain to overt deformity interfering with motor performance.

7. Peripheral neuropathy--sensory and/or motor loss is frequently reported. Problems occur at rest in which the client feels he/she cannot keep his/her feet still. Additionally, the client may also have a burning paresthesia of the soles of the feet (Chyatte, 1979).

The efficiency of the dialysis treatment is a major factor in the number and severity of the complications. Dialysis therapy has a wide range of possible outcomes, from those in which uremic signs and symptoms are absent to

those in which the recurrences of uremic complications are fairly frequent (Lundin & Lundin, 1983). Such variables as rate of blood flow, dialyzer surface area, time spent dialyzing, and adherence to dietary restrictions are directly proportional to the physical complications. The presence of other major medical conditions also predisposes the client to complications.

Certainly, a client who rarely feels well is unlikely to be rehabilitated (Lundin & Lundin, 1983). The client is apt to be overwhelmed by the constant barrage of physical ailments to consider the possibility of a normal existence. Functional losses as a result of physical impediments may be assessed through examination of both measurable, objective data and subjective data from the client regarding his/her mobility, activities of daily living, and activity schedule (Chyatte, 1979). Both of these measurements can elucidate on the degree of dysfunction but do not unequivocally point to physical complications as the sole responsible factor for the degree of dysfunction. This is demonstrated by those individuals who, despite severe physical impediments, continue to participate in the aspects of life involving vocation, family avocations, and the community involvement. Others do poorly in these areas despite being in better physical condition (Hatz & Powers, 1980).

One potential explanation for the differences noted between clients relates to the amount of social validation the client receives for the physical changes (Landsman, 1979) A client who receives negative feedback regarding valid symptoms may be inclined to ignore the problems, feel hopeless and frustrated, and ultimately find him/herself without adequate support in adjusting to the new physical state. Diamond et al (1980) asserts that successful rehabilitation for the chronically ill is partially dependent on the recognition and reorganization of responsibilities based on the physical limitations. She contends that the element of social validation will also influence the client's adherence to therapy which is intrinsically tied to rehabilitation. Additionally, the role adjustments and expectations which must be redefined between the dyad hinge on congruency of the perceived physical changes and subsequent functioning. The degree of satisfaction with the perceived degree of physical functioning could be a stimulus for setting goals towards a more satisfying level of rehabilitation.

The following SIP criteria components will be utilized to measure the degree of physical functioning: Body care and movement, mobility, and ambulation. These components will help identify the degree of perceived physical dysfunction by the client and his/her significant other.

Gainful Activity: A Dimension of Rehabilitation

Rehabilitation has often been equated with gainful employment. Previously vocational counselors focused on facilitating the client in securing a job within the scope of his/her capabilities. The underlying principle being that employment gave the client a sense of self-worth and purpose. Employment status also provided government regulatory agencies and health care workers with some distinct measurement of the efficacy of the treatment in restoring the client to a productive lifestyle. Certainly the value placed by society on the productive individual influenced the equation of rehabilitation and employment.

Although gainful employment is important, it is not the sole component in successful rehabilitation; nor is it the most appropriate measurement of rehabilitation, especially within the hemodialysis population. The dialysis population has changed since its inception as a viable mode of therapy for chronic renal failure. The early clients were often young, "breadwinning" heads of families who had few, if any, other medical complications (Lundin & Lundin, 1983). Today the typical profile of a client would be of an older and often sicker individual. A growing number of clients are retired or eligible for retirement, as well as many clients who have additional disabilities such as diabetes, heart and lung disease. The overall demographic characteristics have also changed. No longer is the typical client a white, middle-class, well educated American. Rather, a percentage of clients are from the lower socioeconomic strata; who may lack job skills and never experienced gainful employment.

These factors are compounded by the inherent managerial and federal regulatory impediments placed upon clients who desire to seek employment (Gutman, et al, 1981). Therefore, paid employment cannot be the sole determinant of rehabilitation. Expecting clients to maintain full-time employment while undergoing chronic hemodialysis is analogous to expecting them to carry two jobs at once (Brown, 1974).

The occupational issue is one that poses considerable difficulty for the client's self-image. The relationship between what we do and who we are is woven from childhood. The pressures from society, of which the dyad is a part, may criticize him or her for not working (Falvo, et al, 1982). In part, the concept of ESRD clients as having an invisible disability may be a causal factor in the stress associated with job loss. When others do not perceive that there is a disability present which may restrict certain behaviors, the resultant situation may involve frustration of normal expectations, provoking embarrassment or rejection in the extreme. In order to avoid negative reactions, the individual may do one of two things--ignore the limitations to the detriment of the condition <u>or</u> seek to prove his/her disability. In either case, the client ultimately <u>loses</u>.

Other factors which have been found to influence the client's occupational status are reported by Levy (1979). Levy states that previous level of functioning, satisfaction with work, sick role, and client dependency needs all substantially influence the level of vocational rehabilitation. Those who have been marginal in past endeavors may find the stressors of hemodialysis insurmountable obstacles (Levy, 1979).

One crucial factor which will impact the client's adjustment to the disease and treatment process is his/her support system. When family and staff have different expectations for the client's productivity than the client has, frustration and conflict will ensue. Families who treat the client as a limp appendage will probably soon see a self-fulfilling prophecy (Landsman, 1979). The family may not have started with a person severely handicapped, but they will produce one. Potentially the situation could be reversed, with the family setting up unrealistic expectations at the other extreme. The client may soon find himself entangled in self-defeating behavior, which carries him/her deeper into the maze of self-destruction and frustration with a resultant retreat into withdrawal and depression (Landsman, 1979).

The first step in attempting to address this potential problem is by redefining employment. Employment must be defined so to encompass the activities of retirees, housewives, volunteers, and students. The term "gainful activity" more accurately describes those activities assumed by the individual which are goal-directed and aimed toward the production or accomplishment of something.

This component of rehabilitation will be measured by utilizing the SIP criteria: Eating, home management, sleep and rest, work and recreation and pastimes. The criteria included in physical functioning will obviously impact the perceived degree of gainful activity. This association once again illustrates the complexity of rehabilitation.

Psychosocial Dimension

The psychological struggle of the client with chronic renal failure is not a simplistic matter, due to many interrelated variables. One variable felt to be a central stressor is the degree to which the client is struggling with the independency conflict (Levy, 1979; Landsman, 1979). The illness precipitates a loss of the individual's control of him/herself and his/her environment. Initially, the client moves from an active to passive role when initially hospitalized and becomes almost totally dependent on the medical staff, even with regard to the times he/she may eat, sleep, or use the bathroom (Landsman, 1979). In an acute situation, the client may be able to suspend his need for control; but the necessity of dialysis brings with it the ever-clinging albatross of dependence, not only on people but on machinery as well. The frustrations of this newfound passivity are worsened by an awareness of the fact that the controls are now in the hands of strangers (professionals who are assumed medically competent) and the awesome time interval--the rest of his life (Landsman, 1979). This conflict is felt to be the underlying force which can push the client into psychoreactive and regressive states characterized by depression, aggression, or denial. His/her objective dependency can mobilize preexisting, underlying regressive tendencies; and, when coupled with dependent influences exerted by the health team and family, the client is apt to have a lower degree of adaptation to the process itself (Drees & Gallagher, 1981).

The machine seems as a prosthetic device necessary for life, a major source of conflict over control of the client's life. The issue which must be resolved is: Does the client control his/her prosthetic device, or is he/she controlled by the device and its "operating servants"? The element of control over the machine, as noted by Drees and Gallagher (1981), is a strong desire for the client and will influence his/her dependency state. The client often feels like an uncontrolled, depersonalized entity only able to survive as an appendage to the machine and to the sociophysical system in which the machine is housed. The question of control over the process is reinforced by messages received by the client's interpersonal systems (i.e., family, spouse, physician). If the message of reverse dependence is reinforced by the significant other, the line of conflict is enhanced. The client may at this point attempt to exert some control over his situation and find his significant other exerting equal strength in an effort to keep the client in a dependent role. In this manner the significant other is able to control the situation and avoid the underlying issue. This is likely to occur if insecurities exist regarding traditional and expected roles (Drees & Gallagher, 1981).

The degree to which the prosthetic device is under human/self-control and can be taken for granted will determine it's value as an instrument for regaining lost powers and improving the quality of one's life (Levy, 1979; Drees & Gallaher, 1981). Although at this point there are limited alternatives to dependence on dialysis, ways of encouraging the client to regain control have been identified. The concept of self-care dialysis is spreading, which builds in some of the control that has been removed (Landsman, 1979). The issue of control extends into other facets of the client's life, which ultimately relate to dependency and independency. One such variable is the degree to which the marital dyad's roles are perceived to be acceptably altered.

One can easily see the enormous impact on the client's rehabilitation from the discussion on sick-role theory. In addition each of the three dimensions of rehabilitation, physical, psychosocial and gainful activity, presents a unique set of challenges for the client. Together a synergestic relationship is found in that each will be influenced as well as be influenced by the perceptions held by the client and the significant other.

Psychosocial rehabilitation was measured in this study by the following SIP criteria: Communication, alertness behavior, social interaction and emotional behavior. These variables will again be influenced by the other dimensions of rehabilitation as well as the perceived satisfaction held by the client and their significant other. As with all the variables mentioned the SIP will provide only the dysfunction in terms of specific behaviors not the underlying etiology of them. In order to provide a potential linkage between perceived dysfunction and etiology, Kings' (1981) theory of interacting systems was utilized in developing a conceptual framework.

The final two concepts to be explored and included in the conceptual framework are satisfaction and perception.

Perception As A Key Variable

The concept of perception has been alluded to throughout the discussion of rehabilitation. In this study King's (1981) definition of perception, each human being's representation of reality, was used. Perception is an awareness of persons, objects, and events in relation to how one perceives self, body image, time, and space. In other words, perception gives meaning to one's experiences, represents one's image of reality, and influences one's behavior. Although humans share similar experiences, what they select to enter their into perceptual milieu is different. Their perceptions may be distorted by emotional states, an altered nervous system, illness, drugs, alcohol, sensory stimulation/overload/deprivation, use of defense mechanisms, and personality factors. King (1981) identifies the following elements involved in perception:

1. transport of energy from the environment organized by information;
2. transformation of energy;
3. processing of information;
4. storing of information; and
5. export of information in overt behaviors.

These elements influence the behavior of individuals and ultimately influence all human interactions.

This concept was the common thread woven throughout this study. The client's capabilities are directly influenced by how he/she views him/herself in relation to how others view him or her.

Satisfaction

Considerable attention has been directed at determining the impact of ESRD on the client and significant other. This impact has been approached through objective and subjective measurements of the client's present quality of life (Laborde and Powers, 1980). Objective indicators included material possessions that added to the enjoyment of life as well as various social indicators i.e. educational achievement, occupation, income, etc. The problems inherent in these indicators is the lack of universal value and the fact that quality of life is more of a subjective evaluation. Campbell, Converse, and Rodgers (1976) point out that research related to assessing the quality of life has shifted from variables related to possessions to concerns that are essentially psychological. Satisfaction has been identified as an appropriate measure to capture the sense of well being which goes beyond the need for material goods. Based on this fact satisfaction has received recognition as the most apt indicator for quality of life (Cantril, 1965, Campbell et al, 1976).

Satisfaction is defined by Campbell et al (1976) as "the perceived discrepancy between aspiration and achievement, ranging from the perception of fulfillment to that of deprivation" (p. 8). This definition implies a judgmental or cognitive experience which is associated with affective content i.e. disappointment, frustration, success or resignation.

Satisfaction is dependent upon the perception of a particular attribute or domain and the standard against which an individual judges that attribute. The standard of comparison may derive from any or all of the following bases of evaluation: Aspiration levels, expectation levels, equity levels, reference group levels, personal needs, and personal values (Campbell et al, 1976).

The concept of satisfaction has been implicated in the rehabilitation process. The sick role may be perpetuated by the amount of satisfaction obtained by the client from their support network. As previously described, the sick role offers a degree of comfort and security in the relinquishment of usual responsibilities, several authors note the secondary gains obtained as a factor impeding rehabilitation (Evans, Garrison, Manninen & Hart, 1982; Landsman, 1979; De-Nour & Czaczkes, 1975). The benefits of being sick may outweigh the benefits derived from rehabilitation, serving to compound the problems facing the client and family.

Finally, Evans (1982) suggests that the degree of life satisfaction may be readjusted by the client. The ESRD client may revise his/her life expectations and subsequently come to expect less. While this may serve to benefit some by feeling better off then they actually are, it may also be detrimental in assisting the clients in actualizing their rehabilitation potential.

One can easily see the complexity involved in determining a person's level of satisfaction. Yet, it is this complexity which will provide direction to nursing interventions; since human behavior and intentions can be channeled toward maximizing satisfaction. In addition, the level of perceived satisfaction will ultimately impact the motivation level of client's thereby effecting rehabilitation (Anger & Anger, 1974).

Nursing Theoretical Framework

The nursing theoretical framework utilized in this study was King's (1981) theory of dynamic interacting systems. The basic concepts in her theory will be examined and related to the issue of rehabilitation. Specific attention will be on the interrelationship between the following triad: Client, his/her significant other, and a member of the health care team--the nurse.

Nursing as defined by King (1981) is the "process of action, reaction, and interaction whereby nurse and client share information about their perceptions in the nursing situation" (p. 2). Through this process the nurse and client mutually develop goals and explore various options to facilitate the client in maximizing health behaviors and/or restoring health. The nurse-client relationship is derived through the nursing process with the availability of options not limited to what the nurse can directly provide. Rather, the interventions are found in the client's social group as well as other professional disciplines. Therefore, the nurse's responsibility goes beyond the provision of direct care, and expands to the mobilization of all potential health resources to facilitate goal attainment. This concept of nursing implies a relationship between the individuals, each an equal party who brings to the relationship a unique self.

Man, the recipient of nursing care, is an open system capable of reacting with other human beings and having the ability to feel, perceive, think, make decisions, choose alternatives, and set goals (King, 1981). The environment within which man interacts is both internal and external. The internal environment consists of organ systems, cells, hormones, and inner thought processes all in unique interaction. The external environment consists of all things that influence the person from the outside (King, 1981). Both environments are essential for man to function at his optimal level, and define for him, his self-concept.

Environments can be further delineated into three distinct yet "fluid" systems: Personal, interpersonal, and social. Man as an open system comprises one type of system in the environment--a personal system. Through interacting with others, man is also part of an interpersonal system and, on a larger scale, is part of a social system which contains groups with special interests that make up communities and societies. There is a constant exchange occurring between these systems, which is influenced by individually held perceptions. These exchanges determine the behavior of human beings and ultimately lead to transactions.

Figure 1 depicts the interrelationships of these three systems previously described. Transactions, the goal of nursing intervention, involve the exchange between individuals which lead to achievement of mutual goals. The outcome is a reduction of tension or stress in a situation and increased satisfaction (King, 1981). Transactions are dependent upon the quality of interactions between the individuals.

Interactions involve communication between two individuals in which feelings and perceptions are shared.

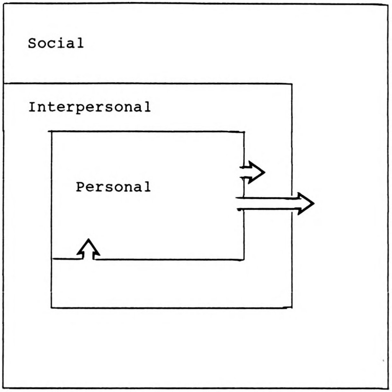

Figure 1. Interacting systems (King, 1981)

The experience of any interaction is unique in that the time, place, circumstances and persons involved can never be repeated. Therefore, interactions are unidirectional, irreversible, dynamic and have a temporal-spatial dimension (King, 1981). Each party of the interaction brings a unique set of variables which influence the interaction: Personal knowledge, needs, goals, expectations, perception, past experiences, and judgments.

Figure 2 depicts the core concepts within Kings' (1981) theory and their interrelationship.

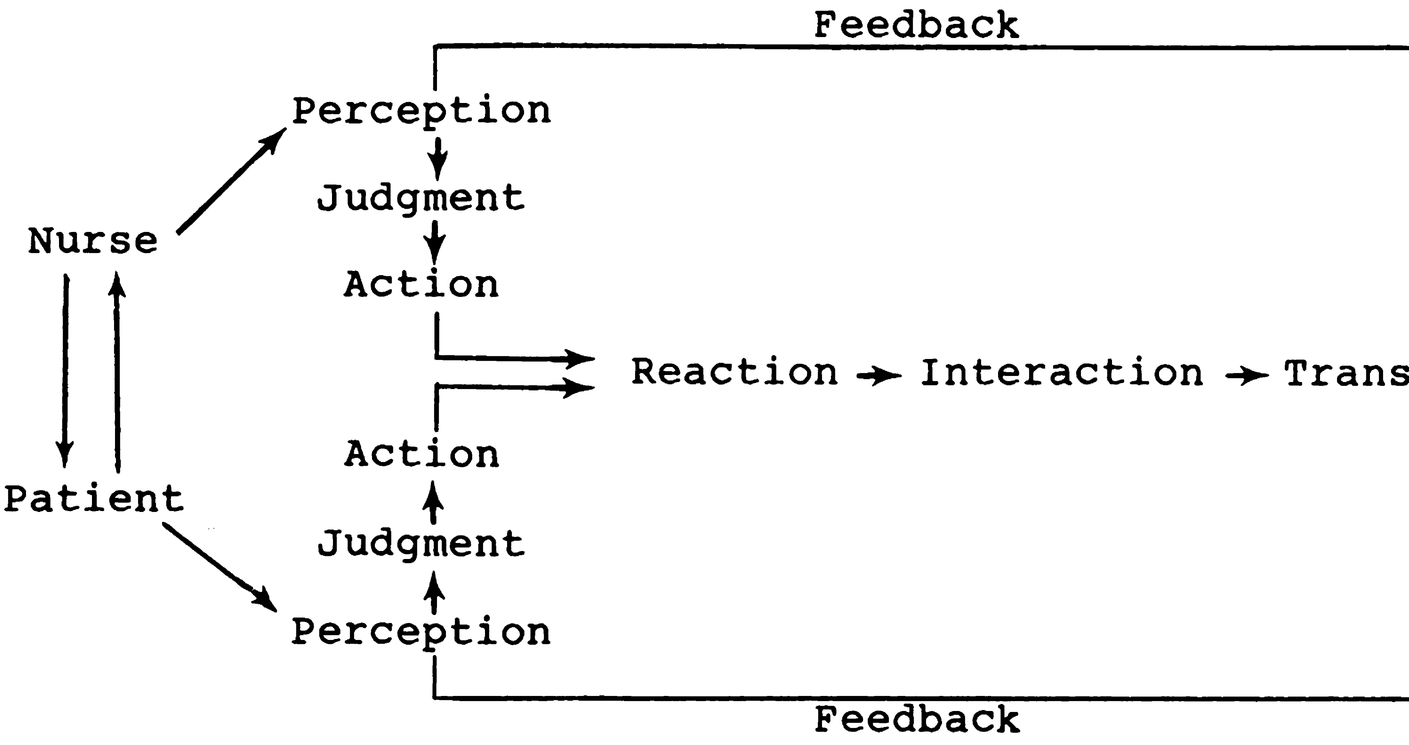

Figure 2. Process of human interactio

The sequence begins with the perceptions held by each
a particular situation or experience. Perceptions are
individually judged in which the situation and the p
involved are evaluated. This process leads to act
both mental and physical. The outcome of this proces
reactions whereby each individual reacts to the ot
perceptions. These four components of the model ar
readily observable. The process of humans' intera
becomes apparent at the point of interaction in K
(1981) model.

The entire process has a feedback system to
perceptual level. Ultimately, transactions sh
influence the perceptions of each individual towa
degree of congruency. The following theoret
propositions are offered by King (1981).

1. If perceptual accuracy is present in nurse-c

interactions, transactions will occur.

2. If nurse and client make transactions, goals will be attained.

3. If goals are attained, satisfactions will occur.

4. If goals are attained, effective nursing care will occur.

5. If transactions are made in nurse-client interactions, growth and development will be enhanced.

6. If role expectations and role performance as perceived by nurse and client are congruent, transactions will occur.

7. If role conflict is experienced by nurse or client or both, stress in nurse-client interactions will occur.

8. If nurses with special knowledge and skills communicate appropriate information to clients, mutual goal setting and goal attainment will occur.

Although nursing is actively involved within each system of the client, their interpersonal system was the focus of this study. The interpersonal system, as previously described, is the interaction of two or more individuals. The process of interactions within an interpersonal system represents a sequence of verbal and nonverbal behaviors that are goal-directed (King, 1981).

In this study the very beginning of the interactional process--perceptions, was investigated. The questions under study--are there perceptual differences both in the area of dysfunction and subsequent satisfaction between the dyad regarding the client's current rehabilitation--lends easily to King's (1981) theory.

The model in Figure 3 is intended to depict the concepts within this study as applied to Kings' (1981) theoretical framework. Each member of the dyad will be influenced by several moderating variables extrapolated from the current literature. The client's perceptions will be influenced by: the number of months/years diagnosed with ESRD and on dialysis, additional comorbidity factors, age and employment status. The time frame since diagnosis and time interval of dialysis have been linked to various adaptation phases of the client (Levy, 1979.) De-Nour, (1981) note that clients experience the losses associated with chronic illness in a cyclical pattern.

Certainly, the number of additional chronic illnesses, will impact the client's rehabilitative outcome. Several authors have clearly noted that such comorbidity factors must be considered as an intervening variable to the clients adaptation (Lundin & Lundin 1983; Evans, 1982; Kutner, 1980). Clients who rarely feel well or are overwhelmed with physical problems will unlikely have energy for rehabilitation.

The final two moderating variables influencing the client's perceptions are age and employment. Both of these factors effect the client's self-image. Older clients may have less difficulty accepting the disability and the alterations in their life trajectory (Stegman, Duncan, Pohren, & Sandstrom 1985). For the most part, they may view losses associated with chronic illness with less disruption in their life goals. Although Matthews (1980) notes that older adults may have more difficulty with adaptation due to additional health problems. Employment status has also been linked throughout the literature as a key variable in the client's self-image. Remaining active in the work world may reduce the client's perceived losses. Unfortunately, employment may also expose the client to numerous mixed messages and expectations (Falvo et al, 1982).

The variables moderating the client's significant other are listed on Figure 3. These may influence their perceptions of the client's present abilities and ultimately their satisfaction with those abilities. Certainly, if the significant other is having to deal with personal health problems, little energy will be available to support the client. Additionally, the number and type of caretaking roles assumed by the significant other will influence the amount of perceived disruption to usual family routines. Round and Israel (1985) couple these variables with the age and employment status of the significant other compounding the overwhelming nature of ESRD. Ultimately, the significant other may respond by perpetuating the dysfunction or minimizing the client's physical limitations.

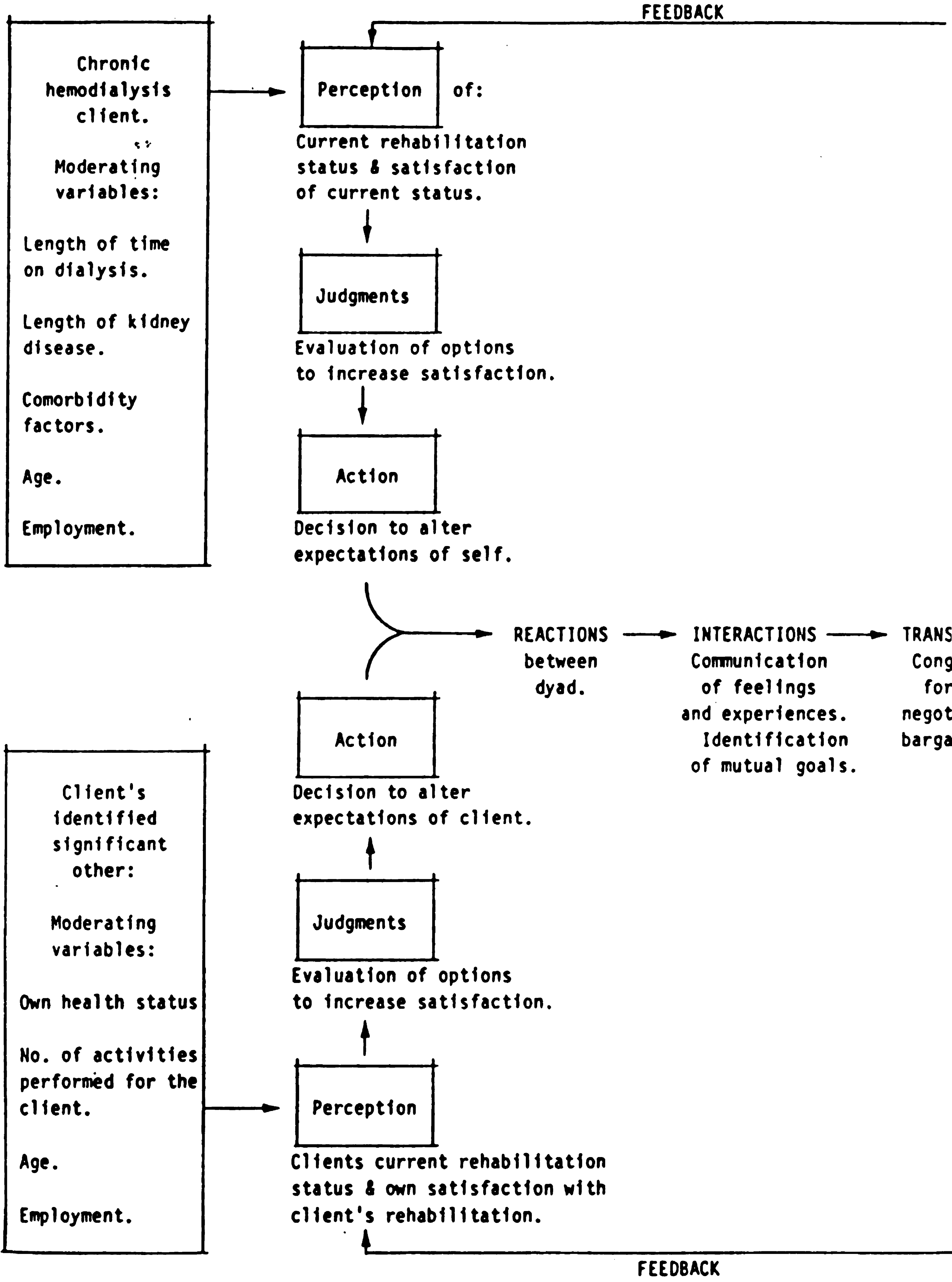

Figure 3. Application of King's Theory to the study concepts

These variables in conjunction with the feedback system will impact the individual perceptions of the client and the significant other. The more harmonious the perceptions within the dyad, subsequent interactions between them will not require as much energy for goal attainment. In this case the feedback from transactions will ultimately increase satisfaction and strengthen the relationship between the client and the significant other.

The transactions which do occur may not necessarily foster optimal rehabilitation. The goal may be to merely increase satisfaction despite a high degree of dysfunction. In this particular example, speculation might exist as to the length of time a dyad will be satisfied with a low level of rehabilitation, as the condition prevails. The dyad may find a status quo existence uncomfortable in our ever changing world. In Chapter six, nursing intervention will be offered to assist the dyad in growth producing transactions. The outcome of incongruent perceptions is depicted in Figure 4. Several concepts are found in figure 4. First is the notable absence of transactions. This is not meant to imply that any amount of incongruence will completely disrupt the dyad's ability for transactions. Rather, when the dyad is unable to identify mutual goals, fostering their own perceptual milieu despite differing opinions, the amount of stress perpetuated will be destructive. Furthermore, as the stress increases between the dyad so does the emotional and possibly physical distance. Ultimately, the dyadic relationship becomes strained leaving the needs of each member unfilled.

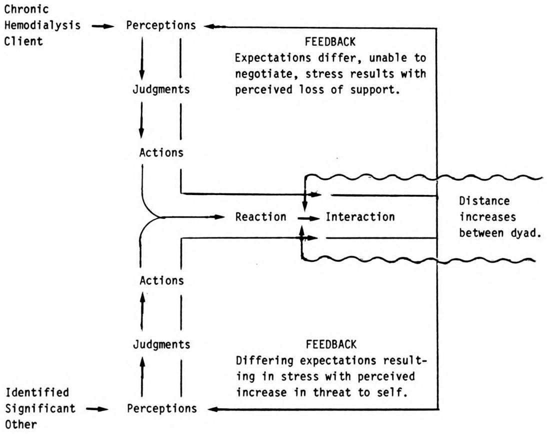

Figure 4. Outcome of Incongruent perceptions

The work involved in a chronic illness for the dyad requires optimal communication. Corbin and Strauss (1984) conceptualize the management of a chronic illness as a "trajectory," due to its movement over several phases. The illness is apt to progress in a zigzag fashion, with ups and downs interspersed with stable periods. Each phase requires various types of work to be performed in its management: Symptom control and monitoring, preventing and handling crises, carrying on regimens, preventing or living with social isolation, modifying routines, maintaining a self-concept, dealing with role changes, handling physical discomfort, maintaining hope, and feeling in control. The client and his/her significant other design a plan to manage one or more of the trajectory movements. The ability to respond is directly related to the dyad's ability to coordinate these tasks and the degree and quality of their outside social support system. Problems with coordination may occur when each have a different trajectory projection and scheme. Here the significant other and the client have different expectations and management plans for the chronic illness. In addition, lack of available outside support, failure to take responsibility--either individually or as a couple--for the organization of the plan, and/or the couple's overriding stress in redesigning their hopes and dreams for the future can impede coordination of the tasks facing the dyad.

Intrinsic within this management plan is congruency and transactions. First and foremost, the dyad must be congruent on how the chronic illness impacts the client's physical and psychological health.

In Chapter six the nursing component of Kings (1981) model will be added. Nursing concerns will be focused on promoting optimal interactions and transactions within the ESRD dyad for rehabilitation. Intrinsic in this concern is a care issue presently in the forefront of shaping ESRD federal policies: What constitutes optimal rehabilitation? Although the final answer to this question is not imminent, nursing research should add to the body of knowledge in formulating the definition. Nurses have been identified as primary providers of care for dialysis clients. They are the professionals who administer dialysis therapy and assist clients with the treatment process on a day to day basis. Logically, these professionals have considerable influence over the client and should be involved in shaping federal policies that address rehabilitation.

Summary

Chapter two provides the reader with the empirical nature of the concepts within this study. King's (1981), nursing theory was utilized for organization of the concepts into a unifying framework. The following review of the recent ESRD research in Chapter 3, will add supporting evidence to the framework's validity for this study.

CHAPTER III

REVIEW OF LITERATURE

Introduction

The following review of literature will include recent research conducted in the area of rehabilitation within the ESRD population. Specific attention will be given to the concepts within the research questions.

> What is the degree of congruence between a hemodialysis client and his/her significant other regarding the client's present overall rehabilitation?

and

> What is the degree of perceived satisfaction regarding the client's rehabilitative status by both the client and his/her significant other?

The discussion will be limited to the subjective measurement of rehabilitation, focusing on the perception of ESRD clients and their significant other. In addition, the Sickness Impact Profile will be presented with data to support its validity and reliability, as well as its usefulness in measuring rehabilitation status.

The Resurgence of Rehabilitation

Gutman, Stead and Robinson (1981) should be credited for their efforts in re-emphasizing the need for research in the area of rehabilitation within the ESRD population.

These researchers found a scarcity of recent data surrounding the physical and occupational rehabilitation of ESRD clients especially in relation to concurrent morbidity factors. They were concerned that federal polices would be formulated on data that did not reflect the current ESRD population. In lieu of this apparent void, Gutman et al (1981) conducted what they considered a preliminary investigation of ESRD clients and the influence of race, age, education, and diabetes on their performance status and morbidity.

Gutman's et al (1981), non-random sample included 2,481 dialysis clients encompassing the range of modalities from 18 dialysis centers. The sample was equally divided between gender and race, with 12% of the total number diagnosed with diabetes mellitus and the average age of the entire sample being 50 years. Gutman et al (1979) employed the services of the individual centers' social workers to provide the research data. These research assistants used their individual and independent judgment in evaluating the physical activity of the clients via the Karnofsky Activity Scale, and a work/employment scale to determine present work status. Clients whose Karnofsky scores ranged between 80 and 100 (able to carry on normal activity at least part of the time) were deemed to have undergone successful physical rehabilitation.

Gutman et al (1981) found the physical activity of nondiabetics considerably greater than that of diabetics

(P < .001). Only 20% of the nondiabetics were judged to be unable to care for themselves completely (Karnofsky score 1-69), in contrast to over 50% of the diabetic clients belonging to this category. The reduced physical activity of the diabetic group was equally reflected in their employment status. Only 18% of the diabetic men as compared to 34% of the nondiabetic men worked outside the home. There was less employment outside the home among diabetic women (6 vs 16 percent, P< 0.001) and a smaller percentage of diabetic women engaged in full-time housework. (18 vs 32 percent P< 0.001).

Gutman et al (1981), found significant differences between black and white clients in their employment status and educational achievement. Around 36 percent of the 740 white males were employed in contrast to the 27 percent of the 541 black males (P< 0.001). Only 11 percent of the black males had received an education beyond the high school level as compared to the 29 percent of the white males (P< 0.001). Clients who were diagnosed with diabetes were not included in the above analysis.

Gutman et al (1981) also correlated the age of the clients to their physical activity. The results showed significant reduction in their ability to do more than self-care with increased age (P< 0.001).

The data from this multicenter survey generated considerable interest among the medical and governmental sectors for several reasons. The apparent level of debilitation was far greater than predicted and appeared pervasive throughout the population sampled. Gutman et al (1981) did caution the readers to interpret the findings in relation to the study's methodological weaknesses. First and foremost, the survey sample had a degree of sampling bias since random sampling was not utilized. Information was not gathered on the location of dialysis--home vs in--center nor the mode of dialysis therapy hemodialysis vs peritoneal. The instruments were not evaluated for their degree of validation and the Karnofsky scale was noted for its weakness in the absence of rigorous observer training. One further weakness not noted by Gutman et al (1981), was the lack of information on the client's social status or psychosocial rehabilitation. Despite these limitations the results did point to the need for further evaluation of ESRD clients and their overall quality of life.

The weaknesses noted within Gutman's et al (1981) study are not unique to the research conducted with ESRD. The problems inherent to the ESRD research include convenience samples, which are often small in size, lack of uniformity in research totals, the failure to obtain data from a variety of non renal populations for comparison and the apparent exclusion of the client's significant other in the research data. Unfortunately, not only is the client frequently the sole subject for data collection but is often the sole recipient of health care. This occurs despite the recognition by numerous authors of the correlation of successful family integration to rehabilitation. (Diamond, 1979; Evans, 1982; Falvo et al. 1982; Friedrich, 1980; Hadge, 1983; Hatz & Powers, 1980; Hutchful, 1980).

Recognition of the Client's Support System for Rehabilitation

The lack of therapeutic integration of the ESRD client's support system by nursing was an interesting side finding in a study conducted by Matthews (1980). The study included a non randomized sample of 347 clients from six teaching hospitals in Metropolitan Toronto and represented each of the five treatment options: In-Center Hemodialysis N = 76, Home Hemodialysis N = 53, Center Peritonal dialysis N = 19, Home Peritonal dialysis N = 51, and Transplant N = 148. The patients ranged in age from 16-70 years with a median age of 45 years. The subjects were found to reflect the general trends in renal treatment with males outnumbering females 2:1, and over 70% of the subjects were married. The goal of the research project was to measure the association of rehabilitation outcome to the hospital environment, patient endowments, demands of the illness and treatment, and formal and informal supports. Matthews (1980) incorporated demographic data, a health team assessment, and a client and family member questionnaire. The health team was composed of all renal unit personnel who had contact with the client and family. Not surprisingly the renal nurses constituted over half of the identified personnel followed by physicians. The health team was asked to, evaluate the client's actual and expected level of functioning; rate the client's personality attitudes; estimate the stress factors affecting the client and identify the type of support provided by the health team members, family, and friends. The client and family questionnaire was geared to information regarding general health and well-being, dialysis, employment, relationships, home activity, social activity, decision-making, and use of voluntary services. Information on reliability or validity was not provided by Matthews (1980) on any of the survey instruments utilized.

A maximum of seven health team members per institution completed a total of 1,174 assessments. A most disturbing finding was the lack of staff contact with the patient's families as well as limited knowledge of the family psychosocial situation. Only about 20% of the health team members reported direct contact with the families. Matthews (1980) indicates from this finding that the patient appears to be the primary focus of health care, rather than the family. Unfortunately, the study statistics were not reported separately for those patients whose family had contact with a health team member. Nor are the statistics clear in the reporting as to which family member was asked to participate in the study, thereby leading the reader to assume that spouses were the most frequently identified family member since marital status was a common variable.

Although Matthews (1980) failed to include some pertinent information for interpretation, the results presented in the perceptions of stress ranked by patients, staff and family were interesting. Discrepancies in ranking order in the perceived stressors were noted between the three groups.

The clients in Matthews (1980) study ranked weakness, having to reduce work, and fluctuating health as the top three stressors, while staff and families chose fluctuating health, weakness, and threat of death. The threat of death was ranked number 13 by clients. Matthews (1980) concludes that the findings tend to substantiate the suggestions for treatment improvement identified by the patients and their families. The top four suggestions were: Improved treatment circumstances 44%, more information on the clients illness 32.3%, more compassion from the staff 28.0%, and support for spouse and family 26.8%. Matthews (1980) study certainly brought forth the exclusion of family members but also shed light on the subsequent problems from poor communication incongruency. The remainder of Matthews (1980) study will be presented elsewhere in this chapter.

Hastings (1982) offers further evidence of the need to include the client's significant other in the rehabilitation process. She emphasizes the need to identify perceptions held by both the client and their significant other as a critical factor in promoting rehabilitation.

Hastings (1982) non-randomized, experimental study included subjects from each treatment modality (CAPD, home hemodialysis and in-center hemodialysis). Together with their significant other, they were randomly assigned to either one of two treatment groups or a control group. A total of 19 couples participated in the program thereby allotting for 6-7 couples in each group. The median age of the participants was 49 with clients reporting varying lengths of time since diagnosis. Hastings (1982) does not report further demographic data on the sample. Therefore, the proportion of subjects from each modality are not readily available.

The overall goal of Hastings (1982) study was to provide an environment conducive to open communication between partners and to teach clients and their significant other new communication techniques. Ultimately, Hastings (1982) aimed to facilitate the couple's adaptation to dialysis. The subjects assigned to the treatment groups met each week for a period of six weeks with the researcher as the group facilitator. The evaluation of the support program was based on a pre-test, post-test control group design. Data was obtained from five different instruments each intended to measure a component of the psychological, social and emotional responses of patients and their partners. The study instruments and their respective reliability follows:

- Demographic survey.
- IPAT Anxiety Scale Questionnaire: This scale is composed of 40 items to measure the trait anxiety. Test-retest reliability of .82 was obtained for the total score and repeated internal consistency scores range from .78 to .92.
- Profile of Mood States: This survey is a self-report rating scale which includes 65 items to assess the impact of renal disease and it's treatment on the patient's and their partners mood state. Internal consistency was reported at .90 and test-retest reliability estimates for a period with a median time of 20 days range from .65 for vigor to .74 for depression.
- The Sickness Impact Profile: Behavioral impact of renal disease and its treatment was evaluated by the administration of the entire SIP. This instrument has established reliability and validity and is discussed in detail later in this chapter.
- Relationship Inventory: This inventory was used to measure the perceived quality of the partner's relationship. Measures of empathic understanding congruence, level of regard, and unconditionality of regard in a relationship are obtained. Hastings (1982) does not report the reliability or validity estimates for this inventory.

These instruments were administered initially, at the end of six weeks, and twelve weeks to the treatment and control groups. All but the Sickness Impact profile was administered to both the clients and his/her significant others. Data analysis was performed in several stages. First, one-way analysis of variance was performed on demographic measures, the IPAT Anxiety Scale, and the other pretest measures to determine whether significant differences were present between the treatment and control groups prior to the program. Next, multivariable profile analyses were performed between pretest subscales of the Profile of Mood States, the Sickness Impact Profile, and the Relationship Inventory. These analyses were used to assess for significant differences between groups prior to the program. Correlated t-tests and a 3 x 3 analysis of variance design with repeated measures at significant level of $P < .05$ were carried out on the pre and post data.

Hastings (1982) found significant improvements for the two treatment groups on the Tension, Depression, Vigor, Fatigue, and Confusion subscales of the Profile of Mood States. Treatment group one which was first to receive the program showed significant improvement on the Overall, the Emotional Behavior, the Alertness Behavior, the Recreation and Pastimes, the Physical and the Psychosocial subscales of the Sickness Impact Profile. The treatment groups improved on all four subscales of the Relationship Inventory, while the control group improved only on the Unconditionality and Congruence subscales. Results of this study were noted by Hasting (1982) to indicate problems with the adjustment of the couple and/or family to dialysis. This was demonstrated by low Empathy and Unconditionality scores on the Relationship Inventory and low Communication scores on the Sickness Impact Profile. Hastings (1982) surmises that clients and their partners may have difficulty interacting, which may result in marital discord and subsequent family functioning.

Although the findings of Hastings (1982) cannot be generalized to the entire population, they do corroborate with the views of Dr. Chyatte (1979), a renal client and professor of rehabilitation medicine. He states that ESRD is a family disease and must be treated as such. The issue must not be <u>client</u> rehabilitation but <u>family</u> rehabilitation.

The research studies thus far reviewed have provided substantiating evidence of the need for client data. The present data reflects a debilitated population whose significant others have not been incorporated into the treatment plan. Further, the lack of communication between the dyads is reflected by incongruent perceptions of the stressors between the dyads. The most striking finding was that of Hastings (1982) who noted an increase in rehabilitation as a result of family vs client interventions.

The dimensions of rehabilitation--physical, gainful activity, and psychosocial--will now be reviewed with respect to both the client and their significant other. For ease of presentation, both physical and gainful activity will be discussed together. Separation of these dimensions is difficult due to their intricate relationship.

Physical Dimension of Rehabilitation:
Physical/Gainful Activity

Measurements of physical rehabilitation have been sought both objectively and subjectively in order to correlate a relationship between physical status and resumption of life activities. A number of interesting approaches have been utilized, some which completely exclude the client in the actual data collection.

Health Team Assessment of Rehabilitation

One such study was conducted by Taylor (1978) who attempted to compare rehabilitation between hemodialysis clients and transplant recipients at one regional center. She defined rehabilitation to include a broad range of activities (i.e., driving a car, socializing, gardening, etc.) in addition to the more traditional activities such as employment. A sample of 92 hemodialysis clients and 85 transplant clients were assessed by the center's physician. A five-level scale for rehabilitation was developed, with level one indicating the patient died during the study period to level five indicating high functioning at essentially pre-illness level. She found that 53.3% of the hemodialysis population functioned at level 4 or 5, compared to 21.9% of the cadaver transplant group and 57.1% of the living donor transplant group. Mean level of rehabilitation for the hemodialysis patients was 3.54, for living donor transplant recipients 3.57 and cadaver transplant recipients 2.31.

Unfortunately, the data obtained by Taylor (1978) was subject to biases, absence of instrument validation, and lack of reported data on the demographics of her sample. She did find a high proportion of dialysis clients active, but offered no explanation for the 47% who were judged to be performing little if any activity.

Utilization of the health team in measuring physical and psychological rehabilitation is one of the most common methods found within the literature. Matthews (1980) study, which was described earlier, incorporated both the health team, the client and a family member in her study on rehabilitation outcome. Recalling that she utilized health team assessments and client/family questionnaires, data was collected on 347 client representing each treatment modality.

Of the health team assessments in Matthews (1980) study 71% of the clients were found to function at the expected rated expected level of functioning as similar, 20% as better than expected, and only 4% as less than expected. However, only 35% of the clients were rated as functioning at full pace or having a normal life; these were predominately transplant clients. Dialysis clients, functioned at less-than-normal pace; and a few were living very restricted lives. Factors given by the staff that adversely affected functioning included the entire range of medical, psychological, educational, employment and social factors.

Matthews (1980) found income to correlate inversely with rehabilitation outcome. Poorer patients (less than $10,000/year) were more likely to have experienced changes in daily life, engaged in fewer household tasks and socialized less. Other variables affecting rehabilitation were age, marital status, treatment modality and length of treatment. In general older patients were found to have poorer adjustment due to multiple health problems and difficulty in role adjustment. This finding is in contrast to that of other researchers who contend that older patients often report higher quality of life. (Stegman, Duncan, Pohren, Sandstrom. 1985)

The married dialysis patient in Matthews (1980) study reported close support from family and friends and continued community involvements. Spouses indicated supportive attitudes but a significant number (figures not provided) commented on the need for more emotional help.

Interestingly, Matthews(1980) found that length of treatment also correlated with rehabilitation. Clients who had been under treatment for a longer time registered a greater degree of rehabilitation. Matthews(1980) infers from this that patients can incorporate ESRD and it's demanding treatment into their lives.

Employment statistics from Matthews (1980) study included: 66% of the clients had paid jobs outside the home, attended school, or were working as housewives. Most of the transplant clients worked full time, while dialysis clients worked part time (percentages not provided). Sixty percent of the housewives on hemodialysis, perceived a reduction in time spent in accomplishing their tasks. A significant relationship (P< .0001) between work and treatment modality was also found. Transplant and home dialysis clients were more likely to work inside and outside the home versus in-center and peritoneal dialysis clients.

The results of Matthews (1980) study are somewhat difficult to interpret. The author fails to define level of functioning and makes no attempt to correlate staff's perception to that of the client and family member. Yet the incorporation of client and family perceptions when determining rehabilitation status opens the field to a wide range of possibilities. Studies in which the health team solely evaluates the client's status are fraught with problems. These problems include: limited contact with the family, personal values of work, perceived difficulties of a chronic illness, and personal definition of rehabilitation. Certainly the team's evaluation is a necessary component of rehabilitation, but it must be integrated with other measurements such as the perceptions of the client and their significant others.

Correlation of Objective to Subjective Indicators of Physical Rehabilitation

A study coordinated by Kutner (1980) incorporated both objective and subjective indicators of physical rehabilitation. A sample of 150 ESRD clients from nine dialysis facilities in the Atlanta metropolitan area were evaluated. The majority of these clients, (91%) were undergoing maintenance dialysis; the remaining clients (9%) had a functional transplant. Subjects ranged in age from 18 to 79 years. with a mean age of 41 years. For each client, the data collected encompassed the client's perception of their current medical, psychosocial, vocational, and family situation as well as a number of objective physical measurements: muscle strength, grip and pinch strength, range of motion, time mobility, and distal sensation, recent blood work recorded and cognitive motor skills. Several psychological measures were also included and will be discussed later in this chapter. In addition the client's satisfaction with various dimensions of his/her life was rated by both the client and a significant other. Kutner (1980) does not provide a detailed description of the study instruments. Report of her findings will be limited to the dialysis population (N = 136).

Kutner (1980) found no differences between long-term clients (> 4 years) and short-term clients (< 4 years) with respect to laboratory values. The average values were within the desired range, indicating dialysis therapy was effective in controlling blood chemistries. Average hematocrits were well below the normal range for both long-term and short-term clients. In terms of the client's subjective complaints, long-term clients were significantly less likely [X_2 (3) = 9.18, P = .03] than short-term clients to complain of fatigue while equal percentages of the clients complained of <u>severe</u> fatigue. Long-term clients were also significantly less likely [X2 (3) = 9.21, P = .03] than short-term clients to complain of dizziness.

Kutner (1980) reports the average number of hours spent per day in sleep and sedentary leisure versus standing/walking/physical activity did not differ significantly between the clients. Men averaged 12.46 down time hours and 3.94 up time hours, while women averaged 11.95 down time hours and 3.96 up time hours. Among both long-term and short-term employed clients, the percentage of total job hours which was sedentary was greater for women (57%) than for men (46%). Kutner (1980) suggests that both men and women clients need jobs which are at least partially sedentary. No significant correlations between length of dialysis and the objective measures of physical status were found by Kutner (1980).

The Differential Emotion Scale (DES), a graphic type scale ranging from one to five, one being slightly experienced to five being very strongly experienced, was completed by the clients. Kutner (1980) found the subjects had moderate to considerable feelings of physical well-being ($\hat{X}$ = 3.2). In addition little loss of sexual interest over the previous week ($\hat{X}$ = 1.7) was noted. The total group perceived fatigue as slightly experienced

($\hat{X}$ = 2.2) and a positive state of alertness ($\hat{X}$ = 3.5).

Kutner (1980) utilized the Family Environment Scale (FES) to measure the client's perception of the degree to which his/her family fosters personal growth. The mean standard score for the FES is 50. The participants viewed their families as about average on the degree of independence fostered by the family ($\hat{X}$ = 51.9, S.D. = 12.2) and encouragement to achieve or compete ($\hat{X}$ = 53.0, S.D. = 8.8). Low ratings were given to active-recreational orientation ($\hat{X}$ = 39.2, S.D. = 13.8), and conflict ($\hat{X}$ = 36.5, S.D. 10.2). Clients viewed their families as slightly higher than average in their emphasis on order ($\hat{X}$ = 56.6, S.D. =10.2) and average in the degree of hierarchical family organization and rigidity of family rules ($\hat{X}$ = 49.8, S.D. = 9.8). There were no significant difference between the long and short-term dialysis patients.

The Social Dysfunction Rating Scale which is used to assess dysfunctional aspects of adjustment, especially personal satisfaction, self-fulfillment, and social role performance, was used by Kutner (1980). She found the clients to perceive themselves as very mildly dysfunctional. The only areas of mild dysfunction were self-health concern, need for more friends, social contacts, need for more leisure, self-enhancing and satisfying activities, and lack of participation in community affairs. Overall, there were no significant differences between the long and short-term clients.

Kutner (1980) found significant correlations between the physical indicators of rehabilitation and the client's current employment or active student roles. Among both long-term and short-term clients, the likelihood of employment or student status was significantly less among clients who complained of severe fatigue ($p = .0016$ for long-term clients, $p = .007$ for short-term clients, Fischer's exact test). Clients who complained of moderate fatigue were almost as likely to be employed as clients who had mild fatigue or no fatigue complaint. The majority of clients who had mild or no fatigue were not active in either a job or student role. Homemaking tasks, feeding, dressing, and personal hygiene presented no problems to this population.

The final component of Kutner's (1980) study involved clients' rating of their current satisfaction with their life as compared to their satisfaction before developing End Stage Renal Disease. Clients marked a point on a 100 mm line to describe their feelings, with 100 indicating the "same or more satisfying" and 0 indicating "not at all satisfying". Overall, the ratings for long-term and short-term dialysis clients on 13 dimensions were above average. The areas which ranged between 50 and 60 for long-term clients included ability to travel, medical situation, sexual life, and working or homemaking situation. Short-term clients scored below average on sexual life (46.5) and between 50 and 60 on ability to travel, medical situation, working or homemaking, and ability to get around.

Kutner (1980) found fewer than 40% of the men dialysis clients and 20% of the women dialysis clients evaluated in a job or active student status. She attributed the lack of activity, despite the results of the cognitive-motor tests, to the anticipated loss of Social Security benefits if employed. Also, personal satisfaction incentives must equal or exceed the benefits which clients receive as unemployed individuals.

Despite the completeness noted in Kutner's (1980) study several weaknesses in both methodology and the subsequent reporting can be found. Little emphasis was placed on the client's significant other especially in regards to their perceptions of the client's functioning. This aspect would have enhanced the data of the FES, with the ability to make correlations between the client's perception and that of their significant other. Additionally, Kutner (1980) does not report the scale range of the FES nor are inferences made regarding the average scale values and the client's activity level. Certainly, one might surmise that individuals with chronic illness who perceive a higher degree of fostered independence by their family may be more independent. Also, one might question the low degree of conflict perceived by the client within their family. Is this due to suppression of anger or a comfortable degree of mutuality within the family?

Subjective Assessment of Physical Rehabilitation

Numerous studies have been conducted with the ESRD population which address subjective appraisal of health by the client and, to a lesser degree, the spouse or significant other. Friedrich (1980) surveyed 97 clients focusing on each client's perception of various physical and psychosocial stressors. Using various sites within the state of Iowa she found a wide variation in the demographic and treatment variables. The age range was 19-82 years with a mean of 48 years.

The months on dialysis varied from 2-91 months with a mean of 20.3 months, males outnumbered females by 2:1 ratio and the majority were married (N = 75) and unemployed (N = 72). Friedrich designed a questionnaire to identify the physical stressors perceived during dialysis, between treatments and those psychosocial in nature. Subjects were asked to rate the level of distress created by each problem listed on a 5 point Likert Scale. The scale was scored 0 for no distress to 5 indicating extreme distress. Reliability, using test-retest, for the instrument was considered within acceptable limits. Content validity was established by three health care experts in hemodialysis.

Friedrich (1980) found that over 50% perceived fatigue and weakness to cause moderate to extreme distress to the client both during and between dialysis treatments. A total of 44.6% reported moderate to extreme distress in sexual changes, and 42.7% cited distress in sleeping at night. A noted difference in the perceived distress was found on the variables of employment months on dialysis, frequency of dialysis, and gender. Individuals who were unemployed reported significantly more distress with the problems of fatigue ($P< .004$), difficulty in sleeping ($P< .019$) and pain in bones and joints ($P< .058$). As weekly frequency of dialysis decreased the distress associated with nausea ($P< .027$) and bleeding increased ($P< .035$). Increasing months on dialysis was associated with more distress with sleeping ($P< .054$), hypertension ($P< .007$) and bleeding ($P< .029$). Females had more difficulty with excess weight gain ($P< .052$) and dizziness ($P< .009$). The remainder of Friedrich's (1980) study will be presented later in this chapter.

Fatigue is the most frequently cited physiological factor affecting the client's perception of rehabilitation throughout the literature critiqued. Several authors have attempted to provide an explanation for this, and have listed the chronic anemic state as well as the psychosocial stressors as contributing factors (Kutner, 1983; Friedrich, 1980; Baldree, et al, 1982; and Hastings, 1982). Indeed, a feeling of exhaustion will impede participation in activities inside or outside-the-home.

A study conducted by Ferrans and Powers (1985), in which variables influencing the employment potential of dialysis clients, supports this association. In their study of 20 employed and 20 unemployed dialysis clients, all deemed eligible for employment, no significant differences were found in job satisfaction or job importance before starting dialysis. Using a self-anchoring 10-point scale [10 represents the best possible health, and 1 the worst], a subjective health appraisal was then measured. Subjects were also asked to identify physical impediments to current job performance or to returning to work. The mean subjective health ratings for the employed (5.13, S.D. = 2.37) and for the unemployed (5.28, S.D. = 2.56) were not significantly different. Of those subjects who were employed, 60% stated that fatigue interfered with job performance, 25% reported difficulty concentrating, and 5% stated that fistula location was a problem. Of those unemployed, 75% stated fatigue interfered with their ability to return to work, 15% reported difficulty concentrating, and 15% stated that fistula location was a problem. A total of 30% reported no symptoms or other problems.

Employment decision variables for the employed group in Ferrans et al (1985) sample ranged from providing financial assistance to the desire to keep active. Self-esteem and enjoyment of work were cited by 20% of the sample. Those unemployed, 65% stated that poor health was the major reason for not returning to work. This was an interesting finding as the two groups did not rate their subjective health appraisal differently. Unfortunately, Ferrans and Powers (1985) did not include a family appraisal which may have shed light on their findings; nor did they account for other types of gainful activity. The authors attributed the interference of poor health in the unemployed group to: possible perception of symptoms as more severe than the employed group fear of exacerbating the illness with employment, previously held positions may indeed be too strenuous to return to, and job discrimination among employers (Ferrans & Powers, 1985).

Stated earlier, employment although the easiest measurement of gainful activity is not the most appropriate indicator of rehabilitation. Rather, behaviors which encompass a wide spectrum of day-to-day activities must be the basis for such measurement. Bruinsma (1982) incorporated such a broad range of activities and the associated impact of the illness as perceived by the clients in his study.

Bruinsma (1982) utilized the Sickness Impact Profile on 30 clients receiving outpatient hemodialysis. The profile was administered in two phases a year apart to evaluate the rehabilitation within a select population over time and to evaluate the usefulness of the SIP in the dialysis population. The sample demographics of his study included: 8 diabetics and 22 nondiabetics; 19 males and 11 females; with an age range of 10 to 70 years (mean age was 57.6).

In Phase 1 analysis of Bruinsma's (1982) study the diabetics were found to be significantly ($p < .04$) more dysfunctional than the nondiabetics in the categories of Body Care and Movement, Ambulation, Work, Eating, Emotional Behavior, Home Management, and Alertness Behavior. They were more dysfunctional in both the Psychosocial and Physical Dimension as well as the total SIP scores. In Phase 2 the diabetics had significantly more dysfunction than nondiabetics in the categories of Ambulation, Communication, Work, Recreation and Pastimes, the Physical Dimension, and the total SIP scores. Comparing the SIP results from the two phases, the diabetics did improve significantly in functioning in the categories of Sleep and Rest, Emotional Behavior, Body Care and Movement, and the total SIP score. The nondiabetics had an increase in overall dysfunction in the same year.

Bruinsma (1982) found the group to be mildly dysfunctional in all areas of the SIP. Areas above 19% dysfunctional included the Total Psychosocial Dimension, Ambulation, Social Interaction, Communication, Alertness Behavior, and Sleep and Rest. The sample had a mean dysfunction score of 35% in Home Management, 25% in Recreation and Pastimes, and 55% in Work. Bruinsma (1982) concludes that the perceived impact of the illness as it affects day-to-day activities is a necessary assessment component for the health professional.

Evans (1982) also recognized the need to evaluate client perceptions of the illness as it affects them. In his study of 859 ESRD clients, representing all treatment modalities, several objective and subjective measures were obtained. The original intent of Evans (1982) was to rank treatment modalilty in terms of rehabilitation outcomes after controlling for case-mix variables i.e., age, race, sex, education, and number of comorbid conditions. Selected portions of Evans (1982) study will only be presented as they relate to the concepts of the research questions under study.

Evans (1982) randomly selected 347 in-center hemodialysis clients and 287 home hemodialysis clients. The mean age for each group was 47 years for home clients and 51.9 years for in-center clients. Males outnumbered females in the home program, while equal percentages were found in-center. Caucasian (86.5%) was the predominate race in the home program, with near equal ratio's between races in the in-center clients. The comorbid conditions, identified by the clients' physician, included a broad range of additional medical diagnosis and complications of dialysis. The in-center clients had a mean of 1.55 comorbid conditions while home clients had a mean number of .98. The differences between groups was found to be significant (F = 24.6, P = .000).

The Karnofsky index was used as an overall indicator of functional impairment, with the clients' physicians rating each client on the one to ten scale; one representing normal function and ten associated with a morbid condition. The home hemodialysis clients were assessed as a significantly higher level of functioning (x = 2.56) than the in-center clients (x = 3.11, P = .05). This functional status was significantly correlated to the clients age, educational level and modality.

Evans (1982) approached the clients employment status by asking for the respondents answer to "Are you now able to work for pay full-time, part-time, or not at all?" The home clients had a significantly higher (59%, P = .05) perception of their ability to work versus the in-center clients (37%). The length of time on dialysis did not correlate with the functional impairments or ability to work. Evans (1982) did not ask the clients if they were currently working which limits the usefulness of this indicator.

The second phase of Evans' (1982) study was the collection of subjective data on Life satisfaction, well-being, and general affect. This data was then correlated to the objective information and the case-mix variables. The instruments used to obtain the subjective data included: Index of Well-Being, the Index of General Affect, and the Index of life satisfaction. The latter two scales had a response range of one to seven; one indicating very dissatisfied and seven extremely satisfied. Estimates of reliability and validity were not provided for these instruments.

The home clients had a mean of 5.33 on the Index of General Affect and in-center clients had a mean score of

5.15. The mean Life Satisfaction score of the home clients was 5.19, and 5.11 for the in-center clients. The mean Well-Being score for the home clients was 11.12, in-center clients had a mean well-being score of 10.77. The subjective data did not correlate significantly with length of time on dialysis, number of comorbidity factors, or the objective quality of life. However, significant differences (P = .05) were noted between the subjective indexes and age, treatment modality, and education. For the most part clients who were younger had a higher educational level, and were on home dialysis had a higher subjective quality of life.

Although, Evans (1982) incorporated numerous variables in his study, the lack of attention to the client's social network was obvious. In addition, the definition of work was limited to paid employment, eliminating the other types of gainful activity. Both of these variables may have helped to explain the disparity between the physical and psychosocial quality of life indicators.

Summary of Research Studies Relating to Physical Dimension of Rehabilititation

The seven research studies reviewed in this section have certainly added to the body of ESRD literature. For the most part, the portrayal of the dialysis population as severely debilitated was refuted. A number of common concerns were noted between studies which may ultimately affect the clients ability in maximizing their

rehabilitation outcome i.e. fatigue, treatment modality and age. There was no substantial data supporting a linear relationship between the client's physical and psychosocial quality of life. Further, the case-mix variables as described by Evans (1982) were not consistently found to impact the client's physical rehabilitation. In terms of employment status, vocational rehabilitation did not consistently correlate with physical limitations. The underlying assumptions made by Kutner (1980) and Ferrans et al (1985) are the employment impediments of time, need for sedentary positions and disability requirements. Also noted by several authors was the dissatisfaction in the amount of recreation and social activities presently engage in by the clients. Several common methodological weakness were also noted between the studies: the lack of a unifying definition of physical rehabilitation, the variety of approaches in collecting data about or from the client, the failure to include the client's significant other and the lack of conformity between the measuring instruments.

The third component of rehabilitation--psychosocial--may be the key link for rehabilitation. Superimposed is the degree of satisfaction with the present level of functioning. Hafstrom and Schram (1984) state that, through analysis of perceived satisfaction between the couple, interventions can be geared to either increase the present level of functioning or assist the couple in adjusting their expectations, thereby reducing frustration levels.

Psychosocial Rehabilitation

Numerous research endeavors have been undertaken to explore the psychosocial component of rehabilitation. One of the most difficult problems between the various health providers encountered is isolating the physical from the psychosocial component of rehabilitation. For the most part, these two components are indirectly woven and in many ways appear to be dependent upon each other. This fact was noted by Stegman et al (1985) in their recent study on the quality of life as perceived by hemodialysis patients.

Relationship of Physical to Psychosocial Rehabilitation

Stegman et al (1985) conducted a cross-sectional survey involving in-center hemodialysis patients, 18 years and older at four hospitals in the midwest. The purpose of the study was to measure the patient's perceived quality of life. A total of 41 clients were randomly selected after being stratified on the basis of age and sex. The sample included 23 women and 18 men, with a mean age of 57 years. Most (N = 25) were married, 15 were single or widowed and one was divorced. The work status of the 27 patients not retired included 14 homemakers, 7 who worked either full or part time and 6 who were unemployed. The mean length of time on dialysis of the sample was 3.3 years.

Four instruments were used by Stegman et al (1985) to measure quality of life: The Self-Anchoring Striving Scale (SASS), the Additive Activity Profile Test (ADAPT), Educational Status Profile, and Demographics Survey. The estimates of reliability and validity on these instruments were not provided by Stegman et al (1985). Stegman et al (1985) also collected objective data which have been noted in previous research studies to influence the clients perceived quality of life.

Utilizing the SASS, 11-rung self-anchoring ladder, clients were asked to identify the best and worst life situation. After identifying their own end-points the clients were asked to place themselves on the ladder where they predicted they would be in five years. Finally, the clients were instructed to rate their quality of present and anticipated future health in the same way that quality of life was measured. The median score on the SASS was highest for present quality of life (7.0) and lowest for perceived current health status (5.0). The most frequent responses for both best possible life and health status was the absence of kidney disease. The worst possible life situation and the worst possible health state were most often identified as the loss of autonomy resulting in the subject becoming a burden to the family.

Stegman et al (1985) reports a median score of 6 for the clients perception of their future quality of life. Their expectation of health in five years had a median score of 5.5.

The mean scores for the ADAPT, the measure of physical activity, was 57.58 with a range of 18 to 104. Stegman et al (1985) reports that the ADAPT score was the most

important variable in determining the clients perceived satisfaction with their present life, and optimistic future expectations. Interestingly, older clients expressed having a higher quality of life and women were most optimistic about their future quality of life. Neither quality of life nor perceived health status were associated with the client's vocational status.

Stegman et al (1985) summarizes her findings by noting the importance of obtaining subjective measurement for identifying quality of life versus objective indicators. Furthermore, the researchers state that physical activity should be continuously assessed and interventions geared to maintain or improve the dialysis patients current status. This variable was found to be an inherent and consistent component of the quality of life and perception of health among the dialysis clients sampled.

The one weakness found within Stegman et al (1985) study is the failure to include the hemodialysis client's significant other. A common weakness noted in the majority of research conducted.

The correlation of physical to psychosocial rehabilitation has been investigated by several researchers prior to Stegman et al (1985). The findings are not all as clearly correlated which only adds to the complex nature of rehabilitation.

Diamond (1979) recognized the importance of physical functioning to psychosocial rehabilitation and the potential influence of the client's social support system. She conducted a study within a private renal unit to examine the relationship among three sources of social support (family, spouse, and confidant) and adaptation to maintenance hemodialysis. Adaptation was measured in terms of morale and changes in social functioning. The physical status of the subject was held as a major control factor when examining the association between support and adaptation.

Diamond's (1979) non-randomized sample included 36 chronic hemodialysis clients, fourteen of whom were female and 22 were male. The majority of clients (N = 27) were married, 5 were single and 4 were widowed, divorced or separated. The mean age was 46 years with a range of 22 to 77 years. The subjects were evenly distributed between home and in-center hemodialysis, with an average of 32 months on dialysis. The instruments utilized by Diamond included: A 5-point Behavior Morale Scale (BMS), 3 subscales of the Sickness Impact Profile (SIP), (Household Management, Leisure and Recreation, and Social Interaction) the Family Environment Scale (FES), and a single question on the presence or absence of a confidant. Each of the instruments except for the confidant scale had acceptable reliability coefficients of above .80. The number of medical complications secondary to chronic renal failure was used as the measure of medical status. Examples of such problems are: low hematocrit, infections, fluid overload, diarrhea/constipation, hypertension and osteoarthritis. Each medical problem was counted only once making this a measure of different medical complications.

Diamond (1979) collected data over a 6-month period via patient interviews, mailed questionnaires, assessment of spouse support by the renal registered nurse and a review of the medical records.

The mean score for the FES family cohesion scale was 7.0 and the family expressiveness scale was 5, out of a possible score range of 0-9. The amount of spouse support assessed by the renal nurses resulted in a group mean of 39, with a possible range of 12-50. The subjects had a mean adaption score of 58 on the BMS which has a range of 17-85. For each of these scales the higher values indicate a higher degree of the characteristic being measured. The mean SIP percentage scores on Household Management was 21, Leisure/Recreation was 25 and Social Interaction was 19. On these scales the higher the score the greater the percentage of change in social functioning. In terms of the number of medical complications the mean value was 4 for the entire sample.

Diamond (1979) utilized the Pearson r to correlate the relationship between social support and adaptation measures. Each of the social support variables was significantly and positively associated with morale: (family cohesion $r = .44$, $P < .01$, family expressiveness $r = .55$ $P < 01$, confidant $r = .31$ $P < .05$). Family cohesiveness and presence of a confidant had a significant negative correlation with changes in social functioning. Except for family cohesion and spouse support the other measures of social support and adaptation had a significant correlation to the patient's medical status. Greater expressiveness in the family, the presence of a confidant, and higher morale were associated with fewer medical problems ($P < .01$). On the other hand increased changes in social functioning were associated with more medical problems ($r = .52$, $P < .01$).

Diamond (1979) summarizes her findings by stating that family cohesiveness was a key source of support for the dialysis clients in her study. Furthermore, family cohesiveness was significantly associated with higher morale and fewer changes in social functioning.

Diamond's (1979) study offers nursing further evidence of the need to include the hemodialysis client's support system in the rehabilitation process. She is one of the few investigators who recognized the importance of those individuals whom the client deems important to them outside of their immediate family. Despite the insight that Diamond (1979) provides in her study on adaptation, her methodology in measuring social support is weak. The problems of using staff to identify support is fraught with problems as previously noted. In addition the medical complications might have been captured in a more interpretable fashion if she would have utilized the perceptions of the client versus objective measurement through the medical record.

Unlike the studies thus far presented not all researchers correlated their findings on the physical and psychosocial dimensions of rehabilitation. A study, conducted by Kutner (1980) is by far one of the most comprehensive research endeavors carried out among the renal population. [A full description of her research was provided earlier]. She utilized the Self-rating Anxiety Scale (SAS) and the Self-rating Depression Scale (SDS) to identify both the level of depression and anxiety within her dialysis population (N = 128). The mean SDS index of depression for the total group was 57.4 (S.D. = 11.056), the median was 50.0, which falls within the symptomatic range of the SDS norms (symptomatic range is 50-60). The distribution of scores was: normal N = 61 (47.7%), symptomatic N = 33 (25.7%), and depressed N = 34 (26.6%), indicating that 50% of the clients sampled manifested symptoms of depression. A comparison of long-term (N = 34) and short-term (N = 93) dialysis clients indicated significantly greater depression (t = 2.28, p = .02) in the short-term (x = 47.7, S.D. = 10.130) dialysis clients.

The mean SAS index of anxiety for the total group was 44 (S.D. = 9.538). The distribution of clients across the normal, symptomatic, and anxiety categories was: normal N = 70 (55.1%), symptomatic N = 42 (33.1%), and anxiety N = 15 (11.8%). Thus, approximately 45% of these clients manifest symptoms of anxiety primarily in the symptomatic range. Once again, the short-term dialysis clients indicated significantly greater anxiety than the long-term clients (t = 2.12, p = .036).

Collectively, the results of the SDS and SAS indicate that a sizeable portion of these dialysis clients manifest clinical symptoms of both anxiety and depression. These results were in contrast to those obtained within the same population on the Differential Emotion Scale (DES), the Test of Emotional Styles (TES), and the Social Dysfunction Rating Scale (SDRS). On these scales the clients in Kutner's (1980) study were found to perceive themselves as experiencing positive mood states, having normal experience of emotions, comfortable in expressing their feelings, and have a moderately positive attitude towards both the experience and expression of feelings in themselves and in others. The clients saw themselves as minimally dysfunctional with respect to their self-esteem, interpersonal system, and overall performance system. Kutner (1980) suggests that the SAS and SDS, which are designed for the psychiatric population, may not be appropriate for the dialysis population.

Kutner's (1980) findings on the psychosocial dimension depict a rather acceptable level of rehabilitation if indeed the anxiety and depression index are not appropriate for the dialysis population. The results of her study provided an encouraging picture of overall physical and

psychosocial rehabilitation for this particular dialysis sample. Unfortunately she does not attempt any correlations and attributes the overall poor vocational rehabilitation to the financial incentives associated with disability.

Identification of Stressors Associated with Psychosocial Rehabilitation

Through the various research studies conducted in the ESRD population numerous potential problems have been identified for achieving a satisfying life style. Two researchers who conducted independent studies to identify the source of the stress felt by dialysis clients, found similar and disparate results. Upon review of these two studies, the lack of uniformity in measurement tools becomes an evident weakness in trying to compare the two sample groups.

The first study to be reviewed was conducted by Friedrich (1980) and as discussed earlier her study was designed to measure and identify the perceived physical and psychosocial stressors associated with chronic hemodialysis. Psychosocial problems were reported to have varying degrees of distress. Items relating to uncertainty of the future were identified as the most distressful psychosocial problems reported by 65.9% of the subjects. Problems related to social role changes such as necessity to decrease workload and becoming less active outside the home also precipitated high levels of distress, as indicated by over 50% of the sample. Over 49% of the subjects perceived the illness as distressing to their family with 13% citing extreme distress with this item. Only 19% felt that the family had unrealistic physical expectations of the client.

Friedrich (1980) found that the highest degree of distress was identified as occurring with the psychosocial problems rather that with the physical problems. Those who were unemployed reported more distress with all of the psychosocial problems. The greatest difference between the employed and unemployed was with taking financial aid from outside sources: an interesting finding in lieu of Kutner's (1980) report of the financial disincentives associated with work. Months on dialysis was associated with the problem of family distress. The least amount of distress was reported by individuals on dialysis 12-24 months, with 39% reporting no distress. This was in contrast to 16% of those in the 0-12 month group and 19% of those in the 25-91 month group who reported no distress.

Friedrich (1980) concludes that the results of her study should be read in light of the possible denial of the severity of the distress related to each problem. Several other variables not considered in this study include comorbidity factors of the subjects, and assessment of the family's perception.

A similar study was also conducted by Baldree et al (1982) in which they explored the types and severity of stressors for 35 clients on hemodialysis. The clients had a mean age of 42.3 years with an age range of 21 to 60 years. The sample included 19 females and 16 males who had no other major illnesses including psychiatric problems. The majority of clients had been on dialysis between one and four years and were unemployed. A stress indentification scale, which consisted of 29 stressors categorized as either physiological or psychosocial, was developed by the investigators. Estimates of reliability and validity were empirically supported for the scale through the work of Baldree et al (1982) and later by Murphy, Powers and Jalowiec (1985). Murphy et al (1985) found that the original stressor scale actually factored out to three versus two dimensions. They contend that three dimensions had greater homogeneity and suggest that the three dimensions be labeled, psychobiological (r = .83) psychosocial (r = .79) and dependency/ restriction (r = .70). Murphy et al (1985) conclude that further data analysis is essential in supporting the validity of this tool but recognized its value in identifying issues affecting the quality of life for ESRD clients.

The respondents in Baldree's et al (1982) study completed the Stress Identification Scale during dialysis in the presence of the investigator. They were asked to rank the stressors from greatest to least and then rate the extent to which they were troubled by each of the 29 items listed on a scale of 1 to 5. The end-points of the scale were represented by "not at all" to "a great deal."

Baldree et al (1982) found that limitation of fluid was the most frequently reported problem. The other psychosocial stressors which were ranked within the top 10 included uncertainty concerning the future, interference in job, limitation of physical activities, and changes in bodily appearance. The investigators postulate that the stress associated with uncertainty of the future may indicate that clients recognize their inability to control the treatment situation or the future outcomes of their illness.

Contradictory to Friedrich's (1980) findings, the subject's in Baldree's et al (1982) study did not perceive problems concerning the changes in family roles as stressful.

Baldree et al (1982) did not find a significant difference between the amount of distress associated with physical or psychosocial factors (t = .58), The overall mean rating for the entire scale was 71.71 (SD = 20.02) with the highest possible score being 145, indicating extreme distress.

Following completion of the stressor scale the subjects in Baldree's et al (1982) study were administered a coping scale. The coping scale consisted of 40 different coping behaviors considered to be either affective or problem-oriented. This scale was on a 5-point Likert-type format that ranged from never to always. The instrument's reliability via the test-retest method is reported as (r_S [26] = .79, $p < .001$).

In terms of the coping methods most frequently identified, clients scored significantly higher on the problem-oriented subscale ($t = 7.06$, $p < .001$). The least frequently identified methods used were: blaming or taking out tensions on someone else, the use of drugs or alcoholic beverages, and letting someone else handle the situation. Pearson correlation coefficients computed between the stressors and coping scores resulted in no significant correlations. No significant correlations were found between the stressors scores and the demographic data. A chi-square was used to establish a relationship between the lengths of time on dialysis and the reported stressors with no significant relationships identified.

One final note of interest in Baldree's et al (1982) study was the finding, although not significant, that married clients scored higher on the stressor scale than those unmarried. Quite possible, being married entails more responsibilities with greater stress when obligations cannot be met. This may also correlate to the assertions of Levy (1979) that a disparity may exist between the dialysis couple which increases the level of stress and frustration with the dialysis life. Baldree et al (1982) note that no associations between styles of coping and the types and severity of treatment-associated stressors could be extrapolated from their study. In addition, intervening

variables which influence coping responses, such as amount of social support were not available from the data collected, which leaves a number of questions concerning perceptions of stress unanswered.

Inclusion of the Client's Significant Other in the Study of Psychosocial Rehabilitation

Repeatedly, the conclusions and recommendations offered by the previous researchers have been to continue the investigation of variables which may influence the perceptions of dialysis clients towards rehabilitation. Furthermore, the client's support system is often mentioned as an intervening variable which should be considered not only for data collection but inclusion in the treatment plan. This fact is well recognized from a theoretical point of view by Bruhn (1977) who states "Chronic illness especially disrupts the usual ways in which family members behave toward one another and then hampers their ability to overcome the effects of this disruption" (p. 1057). Unfortunately, systematic studies of the psychological problems surrounding the partners of hemodialysis clients are uncommon. As with the literature reviewed for physical and gainful activity, inferences to the client's support system are often made through the eyes of the clients.

A study was conducted by Speidel, Koch, Black, and Kniess (1981) in which a series of standardized tests and a dialysis questionnaire was administered to both dialysis clients and their partners. The instruments included: a

94-item Dialysis Questionnaire, consisting of seven categories that list questions reflective of the dialysis experience, a 12-scale Freiburg Personality Inventory, the Glessen Test--a 6-scale personality inventory in two versions (auto-descriptive and description by another person), a standardized aggression questionnaire, a 3-scale questionnaire to register dissatisfaction between couples, the "quarrel behavior" scale of a questionnaire on work and family situations, and a social demographic questionnaire. Speidel et al (1981) does not report the reliability or validity parameters for any scales used in their study.

Speidel et al (1981) recruited 180 hemodialysis clients and 150 partners from four hospital-based units and three private renal units in Bremen and Hamburg, Germany. The average age of the clients was 48.2 years, and of the partners was 47.5 years. Those dialyzing at home were younger than in-center patients. Approximately 30% of all the clients were drawing pensions premature to age-related retirement. There was a notable difference between home clients, in which only 12% were collecting pensions while 45% of the in-center clients were on pensions.

The clients and partners who responded to the Dialysis Questionnaire (125 clients and 88 partners) felt that dialysis was efficient in detoxifying the blood. They expressed concern over fear of complications, the blood access, and machine alarms. Partners had a stronger degree of concern regarding these fears ($p = < .01$) than the clients, which the investigators hypothesized was due to client delegation of anxiety or denial of concerns. There was a difference in anxiety between partners of home and in-center clients. Home partners had less anxiety whether due to the ability to manage or displace it better than partners of in-center clients.

Speidel et al (1981) found that the clients felt that their partners showed greater consideration ($P< .05$) and an increased sense of responsibility ($P< .10$) since beginning dialysis. Both clients and partners credit each other with being able to put themselves in each other's place, and in general felt their relationship was no less happy during dialysis than it was prior to beginning dialysis. By comparison the partners felt that they more frequently agreed with the opinion of the clients, avoided disputes, and withdrew from quarrels. Again, a difference was noted between the partners of home and in-center clients. Home partners felt they were better able to assert themselves in respect to the clients. In addition the home partners did not feel that the client was keeping information back from them.

Many of the dialysis clients and partners in Speidel's et al (1981) study believed that other people could not put themselves in their place; that their own ability to assert themselves was curtailed, and that they felt highly dependent on other people. Most reported feelings of having to forego things, of restriction of freedom, and restricted leisure because of dialysis. Female partners tended to feel that their freedom was more curtailed than male partners (no statistics provided). A withdrawal from social activities was reported by both clients and partners, although they reject the assertion that they have been avoiding outside contact.

Speidal et at (1981) utilized the Freidburg Personality Inventory and Standardized Aggression Questionnaire to identify the extent to which the personality profile of dialysis clients and their partners display unusual phenomena as compared to the normal population. The clients portrayed themselves as calmer, duller, more self-possessed, more self-confident, and less burdened with feelings of guilt. Partners appeared more irritable and less tolerant. There was a notable difference between partners of home versus in-center clients. Partners of in-center clients characterized themselves as more disturbed psychosomatically, more aggressive, more depressive, more dominant, and more extroverted. Speidel et al (1981) allots this difference more to the selection process used for home patients rather than the setting itself.

Speidel et al (1981) concludes that "irritation attributable to dialysis is delegated, in unconscious interplay, to the partners or it is assumed by them because they, as the ones only indirectly affected by the illness, appear to be fundamentally stronger" (p. 164). The distribution of problems to the partner provides the client with an advantage of being able to see that the partner has developed more sense of responsibility toward the client.

Speidel et al (1981) reports that the self-portrayal by the dialysis client and his/her partner as well as portrayal of each other--both for the present and for the time before dialysis allowed for evaluation of the changes in the images between the couples. Positive social resonance is used clearly more as a descriptive characteristic in the portrayal of the partner ($p = 0.01$). Both describe themselves retrospectively ($p = 0.10$) as stronger in the sense of positive social resonance i.e. they look upon themselves as less attractive than before dialysis. Interestingly, clients and their partners viewed each other as more attractive and esteemed, whereas they allocate this characteristic to themselves a lesser extent ($p = 0.01$). Partners also portrayed themselves as more controlled than clients ($p = 0.05$), but also more depressed and anxious then before dialysis ($p = 0.01$). Both clients and partners describe themselves as more taciturn, more reserved, and more distrustful ($p = 0.05$). Differences were apparent in the self-portrayal by both the client and their partner relating to their basic mood. They each describe themselves as rather depressive and anxious as compared with the time before dialysis ($p = .01$).

The dissatisfaction questionnaire utilized by Speidel et al (1981) was completed by 80 clients and 67 partners.

Couples saw themselves as more satisfied regarding the partnership in comparison to the health comparative sample. Their was a reduction in aggressiveness, which declined with increasing duration of dialysis. Quarrel behavior also decreased with an attempt to establish a lower conflict climate with the partnership. Speidel et al (1981) does not report the actual statistical analysis computed on the dissatisfaction questionnaire, nor is information provided on the health comparative sample utilized for comparison purposes.

Taken together, the results of Speidel's et al (1981) study support the fact that dialysis places a heavy burden on clients and their partners. The researchers did see a notable difference between home clients and their partners versus the in-center couples. The home dialysis couples did resemble the health comparative sample better than the in-center dialysis couples, a fact which the authors associate with the setting itself.

Summary of the Research Reviewed Relating to Rehabilitation

Six research studies were reviewed in relation to the psychosocial dimension of rehabilitation. In general the ESRD population sampled have several common areas of dysfunction: participation in social activities, changes in family communication, fear of increased dependency, and change in their emotional behavior. Family dynamics were noted by Diamond (1979) and Speidel et al (1981) to change in that the family unit becomes more of a closed system.

Although, the system may become more cohesive with less social interaction the amount of family expressiveness declines. The end result in their inability to communicate may be associated with increased complications with dialysis as noted by Diamond (1979). Further, the number of complications may impede their social functioning perpetuating the cycle of problems.

Several concerns can be extrapolated from the literature thus far reviewed. First and foremost is the evidence that families are significantly effected by End Stage Renal Disease. Despite this recognition, very few studies have included the client's significant other in attempts to quantify or qualify the impact. Nor is there readily available research which has been addressed solely to capturing the perceptions of the significant other regarding these changes and their satisfaction and future expectations. Empirically, Corbin and Strauss (1984) have conceptualized that optimal rehabilitation is in part based on the ability of the client and their significant other to reorganize their lives. Incongruent role expectations associated with work, marriage and family will ultimately impede the reorganization process thereby impeding rehabilitation.

The second major concern found within the literature reviewed is the lack of uniformity of research tools. This has made interpretation of results difficult. Energy that could be expended towards refinement of an instrument or data collection from a variety of samples is often rechanneled into establishing initial reliability and validity on new instruments. Finally, the varied definitions of rehabilitation has only compounded the confusion and inconclusive research findings. Based on these concerns, the research study conducted by this investigator was developed in relation to these problems. The definition of rehabilitation developed by the ESRD network was the basis for the study design. In addition the client's significant other was given equal consideration in each of the study questions. Finally, the research instrument used to measure rehabilitation had been utilized within the ESRD population with estimates of reliability and validity established. The following section is a detailed discussion of the Sickness Impact Profile, the rehabilitation measure used in this study.

Reliability and Validity of the Sickness Impact Profile

The instrument utilized in this study was the Sickness Impact Profile (SIP). This was chosen for it's comprehensive approach to rehabilitation as well as it's recognized validity, reliability, and suitability for use in studying rehabilitation in the ESRD population. First developed in 1972, the SIP is a behavioral based measure of the impact of sickness (Pollard, Bobbitt, Bergner, Martin & Gilson, 1976). The sickness dysfunctions were obtained from individuals who were directly or indirectly in sickness episodes as well as from a review of literature.

The goal was to construct a scale which measured clinical outcomes rather than the process or structure involved in clinical management. The latter two have often served as proxies for outcome measures, yet such a substitution will be legitimate only when a relationship has been established (Gilson, Gilson, Bergner, Bobbitt, Kressel, Pollard, and Vesselago, 1975).

The SIP, a measure of behavioral dysfunction geared to everyday activities, provides a valid and practical indicator of health outcomes. The instrument consists of 136 items that broadly cover activities involved in carrying on one's life. These items are grouped into 12 categories, each representing a specific area of activity. Subjects are asked to respond only to those items which they are sure describe themselves at that time and are related to their health. The scoring procedure is designed to provide a total dysfunction score, as well as individual category scores which are further collated into a physical and psychosocial dimensional score.

Field trials of the SIP were conducted in 1973, 1974, and 1976 (Bergner, Bobbit, Carter, & Gilson, 1981). During these trials the instrument was evaluated for reliability, validity, ease of administration, and applicability to any illness. The 1973 and 1974 pilot studies were preliminary trials in which the tool was modified and refined from 312 items to 136. In 1976, the revised form was evaluated to determine: Final content, format and scoring; broad assessment of the discriminant, congruent, and clinical validity; and comparative analysis of reliability and validity of alternative administrative procedures (Bergner et al 1981).

A large stratified random sample of members of a prepaid group practice was utilized for the 1976 field trial. The sample was such that a diverse number of illnesses and sociodemographic characteristics were included that could affect response patterns or sickness levels. The 696 respondents who completed the SIP represented 80% of all random subjects contacted. An additional 199 subjects from a family medicine clinic who considered themselves sick were also interviewed to assure an adequate frequency of response to SIP items.

Reliability was determined by test-retest of 53 subjects who were administered two SIP's within a 24-hour period. Reliability of the overall scores was 0.92 and 0.50 for category items. Bergner et al (1981) suggests that, though subjects change the specific items they respond to within a 24-hour period, the combination of items checked on the two occasions was sufficiently similar in scale value to provide similar overall and category scores. Internal consistency using Chronbach's alpha was 0.94.

Extensive research was conducted in each of the field trials to test the validity of the SIP. The following measures were undertaken by Bergner et al (1981) in 1976 to demonstrate the relationship between sickness impacts and behavioral dysfunction. To determine construct validity, subjects were administered a given category of the SIP and instructed to respond to those statements that described them and were related to their health. Then, they were asked to rate their relative level of dysfunction in that area on a seven-point scale; and finally to rate their overall level of dysfunction. In addition, a number of similar tests were utilized to differentiate the construct of sickness and sickness dysfunction. For example, subjects were asked to complete a self-assessment of sickness which was then correlated to the SIP and self-assessed dysfunction scale. Furthermore, clinicians were asked to rate a client's level of sickness and dysfunction which were also correlated to the client's SIP scores.

Analysis of the data resulted in correlations between the SIP score and self-assessment of dysfunction at 0.69; between the SIP score and self-assessment of sickness at 0.63; between SIP score and the clinician assessment of dysfunction at 0.50; and between SIP score and the clinician assessment of sickness at 0.40. The relationships were further subjected to the multitrait-multimethod methodology and multiple regression technique to assess for convergent and discriminant validity. The SIP was found to have higher reproducibility of category scores and overall scores than any of the correlations among different category scores; this assured minimal redundancy. The higher correlation of category scores to overall scores reiterates the importance of each category to the total SIP. Among all the alternative measures correlated to the SIP, the SIP had a higher degree of reproducibility and was more highly related to those criterion measures considered to be most reflective of the construct of sickness and the methodology employed in the SIP.

Clinical validity of the SIP was established by Bergner et al (1981) through correlation of objective clinical data. The goal was to demonstrate the usefulness of the SIP to evaluate alternative modes of treatment and assess progress of clients. Three disease categories were chosen for which clinicians could identify reliable clinical measures that parallel the client's functional health status. The disease categories were: Hyperthyroidism, rheumatoid arthritis, and total hip replacement. Fifteen clients within each category were followed and administered the SIP three times during the study period. Their clinical progress was correlated based on standard objective data within the same 24-hour period the SIP was administered.

The relationships between the SIP and the clinical measures correlated moderately ($r = 0.41$) to high ($r = 0.84$). Strong relationships were found between the specific disease category and one of the two dimensional SIP scores. For example, the clinical picture of rheumatoid arthritis was correlated to physical dimension of the SIP. The objective clinical data used for comparison included grip strength, walking time, number of painful joints, and degree of pain. The psychosocial dimension and overall SIP score had a lower correlation to the clinical data. Establishing clinical validity for the SIP was an important step in broadening its use in rehabilitation (Bergner, et al, 1981).

The final type of validity sought by Bergner et al (1981) was descriptive validity. The SIP was assessed for its capacity to describe and delineate samples of subjects that differ in mean score and samples that are similar in scores. This information would provide predictable dysfunction within a particular disease, thereby enhancing intervention.

The profiles of the SIP's obtained on the three previously described disease entities were assessed in terms of mean differences, variability differences, and pattern differences. The profiles of hip replacement clients and hyperthyroid clients exhibit characteristics that can be readily discerned among clients within each disease entity. Differences in mean scores across categories confirmed that the severity of dysfunction differed significantly between the points in time.

The extensive testing and revisions of the SIP throughout its developmental stages have resulted in a tool which is reliable and valid for measuring health status. The tool provides the clinician with additional, yet different, information regarding the client's response to clinical treatment.

Summary

In summary, the information presented in chapter three was directed towards providing a history of the research background for End Stage Renal Disease. Data was presented which substantiated the importance of collecting subjective data from both the client and their significant other. In addition the research instrument utilized in this study was introduced with supportive data in its overall reliability and validity. Kalamazoo, MI 49007

CHAPTER IV

METHODOLOGY AND PROCEDURES

Overview

This research study was designed to describe both the degree of perceptual congruence between the hemodialysis client and his/her supportive other regarding the client's present rehabilitation status and their degree of satisfaction with that status. In this chapter, detailed description of the research design will be presented. Attention will be given to: Operationalization of the research variables, sample characteristics, data collection procedures, and the steps taken to insure protection of human rights. Further, the instruments and scoring procedures are outlined as well as the statistical techniques to be utilized for data analysis and presentation.

Research Design

The research methodology consists of self-report survey instruments and the statistical analysis that includes inferential and descriptive statistics. Hemodialysis clients and their identified significant other were asked to complete the Sickness Impact Profile (SIP), a Satisfaction Survey (SS) and a sociodemographic questionnaire. The significant others were instructed to complete the SIP and the SS from their perspective of the client's present rehabilitation status. The satisfaction survey, was geared to reflect the degree of current satisfaction perceived by both the SO and the client in relation to the client's present rehabilitation status.

Table 1

Summary of Research Instruments Administered

Hemodialysis Client	Client's Supportive Other
Sociodemographic Survey	Sociodemographic Survey
Sickness Impact Profile	Modified Sickness Impact Profile for Perception of the Significant Other's Portrayal of the client
Client Satisfaction Survey	Satisfaction of the Significant Other.

The Sample

The study sample was voluntary, with subjects drawn from a hospital-based outpatient dialysis clinic and a home dialysis clinic.

The dialysis clinics were associated with the Michigan Nephrology Center in Kalamazoo, Michigan. This center provides nephrology services for clients who live within a 100-mile radius of Kalamazoo, and offers all four modalities for treatment: in-center hemodialysis, home hemodialysis, continuous ambulatory peritonital dialysis, and renal transplantation. The center is managed by three nephrologists who provide medical coverage for dialysis facilities in Kalamazoo, Battle Creek, and Coldwater, Michigan. The Center's home base is located at Borgess Medical Center, where chronic outpatient dialysis, home training, CAPD training, and transplantation are provided. Total client population as of April 1986 on dialysis in the Michigan Nephrology Center was approximately 149 with 12 clients on home dialysis, 51 clients dialyzing in the Borgess outpatient unit, 19 clients dialyzing in Coldwater, 31 clients dialyzing at Community Hospital in Battle Creek, and 36 clients on CAPD.

Table 2

Clinic Locations and Distribution of Michigan Nephrology Dialysis Clients

Modality	Borgess Medical Center	Community Hospital Battle Creek	Coldwater Hospital
Home Hemodialysis Program	12		
Outpatient Hemodialysis Clinic	51	31	19
Continuous Ambulatory Personal Dialysis Program	36		

Subjects from the home hemodialysis program and Borgess outpatient hemodialysis unit were targeted for inclusion in this study. These clients were chosen due to ease of client access as well as institutional access, making this a convenience sample.

The clients were required to meet the following criteria to be eligible as a potential subject:

1. Have been on hemodialysis for at least six months. This is based on the findings of De-Nour et. al. (1975), who found that psychosocial and physical adjustments to rehabilitation stabilize at six months with relatively no change after that period.

2. Client did not live alone and was able to identify a member of the household he/she considered to be a primary support.

3. Client and his/her significant other were over 18 years of age.

4. Client had been dialyzing in their present setting for at least three months.

5. Both the client and significant other were willing and able to complete the questionnaires independently.

6. The client and his/her significant other had an established relationship prior to the onset of End Stage Renal Disease.

Human Rights Protection

The Michigan State University Committee on Research Including Human Subjects and the Borgess Medical Center Nursing Research Committee have established specific criteria to be followed by researchers when studying human subjects. These procedures and criteria were followed in this research study to ensure protection of the subjects' rights. (See Appendix A).

Since one of the key principles of ethical conduct in research is that participation in studies must be voluntary, all prospective participants must be informed about the study and their voluntary consent secured (Polit & Hungler, 1983). To accomplish this, all potential subjects received a letter of introduction and explanation of the study. (See Appendix B). This letter delineated the purpose of the research, how results would be utilized, and requirements for participation. The letter also included information on confidentiality, and that participation or unwillingness to participate would in no way affect their health care. Subjects were also informed via the cover letter and the consent form of their rights to withdraw from the study at any time. The investigator's name and phone number was given to each participant in case of questions that arose during the study time period.

Initial contact was made by the investigator in person to <u>each</u> hemodialysis client. At that time the client was screened for eligibility and if so was given an overview of the study. If the client agreed to participate, a written letter of introduction for their significant other was given to the client to take home. A telephone or personal contact was then made to answer any questions from either the client or his/her significant other, and to ascertain their <u>joint</u> willingness to participate in the study.

The participants who willingly agreed to participate signed the consent form prior to completing the questionnaires. Participants were assured of confidentiality by the use of precoded case numbers which eliminates the need for personal identification on the study instruments. Also, they were assured that the data would be recorded and analyzed in aggregate form only. This prohibits possible subject identification by demographic data alone. The raw data was destroyed after transferring the responses onto precoded data sheets. Consent forms were kept separate from the completed questionnaires by the investigator. All the participants were offered a summary of the final report in which data was reported in group form.

Operational Definition of Variables

The variables under consideration in this study are: Present perceptions of both the hemodialysis client and his/her significant other regarding the client's rehabilitation status and their present degree of satisfaction with the client's rehabilitation. The operational definitions of the variables follow.

Present Perceptions of the Hemodialysis Client's Rehabilitation Status

The concept of rehabilitation was operationalized on the Sickness Impact Profile. Physical rehabilitation incorporated the client's ability in the areas of body care and movement, ambulation, and mobility. The psychosocial dimension of rehabilitation included: Emotional behavior, social interaction, alertness behavior, and communication.

The final areas, included questions surrounding work, sleep and rest, home management, recreation and pastimes, and eating. These area were operationalized to reflect the dimension of gainful activity proposed by this investigator.

Both the client and his/her self-identified significant other responded to the statements on the Sickness Impact Profile, which they felt reflected the client's current abilities. (See Appendix C). All responses were in the form of a checklist in which the participants checked statements which were applicable to their attitudes and activities. Although the basic stem of the statement remained the same, the SIP was modified for the significant other to reflect his/her perceptions of the client. Examples of the types of questions found within each of the dimensions on the SIP follow:

Physical Dimension

Body Care and Movement: A total of 23 statements were included in this category (BCM-2003). The purpose was to identify the client's ability to care for his/her personal hygiene needs and general body movement. For example:

1. I make difficult moves with help (i.e., getting into or our of cars, bathtubs).

2. I move my hands or fingers with some limitation or difficulty.

3. I do not bathe myself at all, but am bathed by

someone else.

Mobility: This area (M-0719) has 10 statements which were geared to reflect the client's active movement in the home and community. For example:

1. I stay away from home only brief periods of time.

Ambulation: A total of 12 statements were included in A-0842 to identify the client's ability to ambulate. Sample questions include:

1. I walk shorter distances or stop to rest often.
2. I do not walk at all.

Psychosocial Dimension

Emotional Behavior: Nine statements are listed in EB-0705 to identify the client's present emotional stability. Sample statements include:

1. I laugh or cry suddenly.
2. I have attempted suicide.

Social Interaction: This category (SI-1450) was geared to identify the amount of time the client spends with other individuals. Twenty different statements are listed for the client and significant other to respond to. For example:

1. I am going out less to visit people.
2. I isolate myself as much as I can.

Alertness Behavior: Ten statements are listed in AB-0777 which revolve on the client's ability to concentrate. For example:

1. I react slowly to things that are said or done.

2. I have difficulty doing activities involving concentration and thinking.

Communication: Ten statements are listed in C-0725 regarding the client's ability to communicate. Sample statements are:

1. I do not speak clearly when I am under stress.
2. I am having trouble writing or typing.

Gainful Activity

Work: This section (W-0515) had to do with work-related activities outside of home management. If the client no longer works outside the home, he/she is instructed to skip this section. A sample of the nine statements includes:

1. I am not accomplishing as much as usual at work.
2. I am working shorter hours.

Recreation and Pastime: This group of eight statements (RP-0422) has to do with activities engaged in during the client's free time. For example:

1. I do my hobbies and recreation for shorter periods of time.
2. I am going out for entertainment less often.

Sleep and Rest: Seven statements are listed in SR-0499 which were geared to identify the amount of time spent sleeping or resting. For example:

1. I sit during much of the day.
2. I sleep or nap more during the day.

Home Management: These ten statements are founded on the activities required in caring for the client's home or yard. Example statements from HM-0668 are:

1. I do work around the house only for short periods of time or rest often.

2. I am doing less of the regular daily work around the house that I would usually do.

Eating: Nine statements were listed in E-0705 to identify the client's current eating habits. For example:

1. I am eating much less than usual.

2. I just pick or nibble at my food.

Perceptions of Satisfaction with the client's current Rehabilitation Status

The second major concept operationalized in this study was that of satisfaction with the client's present level of rehabilitation. The three dimensions of rehabilitation physicals, psychosocial, and gainful activity and their respective SIP scales were utilized in the construction of the Satisfaction Survey. Twelve statements were formulated to represent each of the various SIP categories: Body Care and Movement, Mobility, Ambulation, Emotional Behavior, Social Interaction, Alertness Behavior, Communication, Work, Recreation and Pastimes, Sleep and Rest, Home Management and Eating. Following each statement was a five-point Likert scale with a range of responses from: (a) very dissatisfied, (b) dissatisfied, (c)mixed, (d) satisfied, and (e) very satisfied. The client and significant other were asked to respond independently to

each statement. The client rated their own satisfaction in each of the twelve areas and the significant other rated their own satisfaction with the client's present abilities. Example of the statements constructed to represent the specific category under each of dimensions of rehabilitation follow. Instructions preceded the statements which included the following core question to guide the respondents: How satisfied are you with <u>your/the client's</u> present ability in each of the following areas. A separate questionnaire was constructed for the SO and the client to avoid confusion. (See Appendix D).

Physical Dimension

Three statements were formulated to represent the overall activities involved in Body Care and Movement, Mobility and Ambulation. For example Body Care and Movement was represented by the statement--ability to care for your his/her physical needs.

Psychosocial Dimension

Four statements were developed in association to the following categories, Emotional Behavior, Social Interaction, Alertness Behavior and Communication. One example within this dimension is:

Alertness Behavior

1. Ability to concentrate

Gainful Activity Dimension

Five statements on the survey represent the rehabilitation categories of Work, Recreation and Pastimes, Sleep and Rest, Home Management and Eating. For example:

Home Management

1. Participation in household tasks.

Extraneous Variables

Data were collected on extraneous variables which may influence the responses of the clients and their significant others on the SIP and SS. General information related to the client and significant other was identified via a sociodemographic questionnaire (See Appendix E). The client questionnaire was divided into three main sections: (a) personal characteristics, (b) treatment plan, and (c) co-morbidity factors. Operational definitions of these sets of variables follow:

Personal Characteristics

There were 8 items which requested information concerning age, ethnic background, marital status, educational level, income, occupation, number of children, and number of persons in the household.

Treatment Plan

There were 6 items which requested information concerning length of time on dialysis, dialysis setting, hours spent dialyzing, type of blood access, time spent in travel, and time spent in the recovery from dialysis.

Co-morbidity Factors

Fifteen items were directed to elicit data concerning length of time between diagnosis of kidney disease and initiation of dialysis, etiology of kidney disease, other chronic health problems, last hospitalization, length of last hospitalization, cause of hospitalization, and current medications.

Sociodemographic data were also collected from the significant other including their health status, and relationship to client. The operational definition for these variables are similar to those listed for the client.

Study Instruments

Reliability and Validity of the Sickness Impact Profile

The instruments which were utilized to measure the present perceptions of client rehabilitation by the hemodialysis client and those held by the client's significant other were the Sickness Impact Profile (SIP). A full description of this profile was outlined in Chapter Three, as well as a review of its use in other studies with the End Stage Renal Disease population. The SIP, a behaviorally based measure of sickness-related dysfunction, is designed to provide a measure of health status. The instrument is comprised of 136 items that broadly cover activities involved in carrying out one's life as reflected by the subject's own perceptions of his/her performance in those activities. The items are aggregated into 12 categories, each representing a specific area of activity (see Table 3).

Table 3

Categories of the Sickness Impact Profile (SIP)

Dimensions	Category	Describes Behaviors Related To
Physical Dimension	A	Ambulation
	M	Mobility
	BCM	Body Care Movement
Psychosocial Dimension	SI	Social Interaction
	C	Communication
	AB	Alertness Behavior
	EB	Emotional Behavior
[a]Gainful Activity	SR	Sleep and Rest
	E	Eating
	W	Work
	HM	Home Management
	RP	Recreation/Pastimes

Note. From The sickness impact profile: development and final revision of a health status measure by Bergner et al., 1981, *Medical Care* *19*(8).

[a]The 5 category scales have been grouped together by this investigator to reflect gainful activity.

Both reliability and validity of the instrument have been established through several field trials (Bergner et al., 1981). The reliability of the SIP was assessed in terms of internal consistency of response patterns, test-retest score comparability, and test-retest agreement in item checking. These tests were carried out under a variety of conditions, including style of administration and a range of sickness or dysfunction. Relevant study populations have been similar to the sample proposed by the current researcher. In general, the coefficients have been well within acceptable limits for the interviewer-administered and interviewer-delivered SIP's (see Table 4).

Table 4

Reliability Summary of the SIP Across Three (3) Field Trails

Reliability	1973 Field Trial	1974 Field Trial	1976 Field Trial
Reproducibility			
Overall Score	0.88	0.88	0.92
Category Items	0.56	0.50	0.50
Internal Consistency			
Cronbach's Alpha	[a]N/A	0.97	0.94

Note. From The sickness impact profile: development and final revision of a health status measure by Bergner et al., 1981, Medical Care 19(8).

[a]N/A = Not applicable

Validity of the SIP has been evaluated by several different measures. Evidence of construct validity was demonstrated by the ability of the SIP to differentiate and discriminate among subgroups in which prior assumptions regarding level of health status could be hypothesized. The instrument was found to be sensitive to both time and level of dysfunction within the groups studied (Bergner et al., 1981). In addition, criterion validity was supported in terms of its relationship to several other measures: Subject's self-assessment of health status, clinician's self-assessment of the subject's health status, and scores obtained on other function assessment instruments. Finally, the areas of clinical and descriptive validity were measured to substantiate the relationship of the SIP to objective clinical data. All of the above dimensions of validity have contributed to the ongoing task of ensuring that the SIP measures illness-related behaviors.

Based on the field trials outlined by Bergner et al. (1981), the SIP must be administered in the following manner to retain its reliability and validity:

1. Selective categories may be administered versus the entire SIP;

2. All items within each category must be administered;

3. Self-administered and interview-style administration is recommended over mail administration;

4. The SIP should be completed in one sitting, as it reflects the present perceptions.

The SIP modified by the investigator for use in identifying the perceptions of the client's significant other regarding the client's illness-related behaviors, involved wording changes to reflect a their viewpoint. There is no reason to expect this change in the cues to significantly affect the reliability and validity of the instrument as reported in previous studies.

Scoring of the SIP

The scoring procedures for the SIP were developed by Gilson et al. (1975). These investigators employed two separate approaches to scoring the SIP items from which a basis for scoring was founded. The first method involved item scaling, whereby the SIP items were rated by a group of 25 judges. The judges assigned each item a value on a 11-point scale ranging from minimal dysfunction to severe dysfunction. After determining that the mean scale values were consistent between the judges, the next step involved a ranking of the items on a 15-point scale to determine which were most dysfunctional to least dysfunctional within the category. This process provided a set of commonly scaled endpoints from which the remaining items could be assigned a mathematic value.

The second procedure involved a practical scaling. The judge's were asked to rate 50 protocols of subjects attained on a field-study. The correlations of each judge's ratings on the 11-point scale again demonstrated consistently high agreement between the judges.

The outcome of these procedures was a standard method of determining a score for each category as well as an overall SIP score. The score for each category is calculated by adding the scale values for each item checked within the category and dividing by the maximum possible dysfunction score for that category. This figure is then multiplied by 100 to obtain the category score which is then reported as a percent of dysfunction.

Two-dimension scores may be calculated in addition to an overall SIP score. The physical dimension score is obtained by adding the scale values for each item checked within the categories body care movement, mobility, and ambulation, dividing the maximum possible dysfunction score for these categories and then multiplying by 100. The psychosocial dimension score is obtained by adding the scale values for each item checked within the categories emotional behavior, social interaction, alertness behavior, and communication, dividing by the maximum possible dysfunction score for these categories and then multiplying by 100. The remaining categories are calculated individually. A total SIP score is obtained by adding the scale values for each item checked across all categories and dividing by the maximum possible dysfunction score for the entire SIP (1003.0). This figure is then multiplied by 100 to obtain the SIP overall score.

The scale values are listed on the SIP adjacent to the individual items. Maximum category scores as well as the total SIP value is also provided on the instrument. Although the scale values are recorded as a whole number the actual value can be obtained by adding one decimal point to that number. For example, in the sleep/rest category if the first item is checked--I spend much of the day lying down in order to rest--the scale value listed is 083, the actual value can be determined by adding a decimal point resulting in an actual item value of 8.3.

Interpretation of the SIP scores must be reserved until analysis has been completed. At that point the group response pattern can be evaluated and compared. The amount of dysfunction will be relative to the group norm and the intervening sociodemographics for each individual.

Reliability and validity of the satisfaction survey

The second set of instruments utilized in this study was the Client Satisfaction Survey and Significant Other Satisfaction Survey. These surveys were developed by the investigator based on the 12 categories of the SIP. For each broad category, a statement was constructed. The subjects were asked to identify on a five-point scale their present degree of satisfaction with the client's current abilities in that particular area.

Reliability and validity for the Satisfaction Surveys had not been established prior to this study. Since establishment of these qualities are essential for interpretation of the data, the instrument was examined to provide preliminary evidence of both reliability and validity after completion of data collection. The following will provide an overview of these two qualities. Emphasis will be placed on the techniques utilized within this study to establish reliability and validity of the Satisfaction Surveys.

Reliability refers to the concept of internal consistency or repeatability. In essence an instrument in which repeated application produce the same or "true" score of the variable being measured is considered reliable (Williamson, Y. 1981). The three aspects of reliability which are commonly referred to are measures of stability, equivalence and homogeneity.

Stability of an instrument is determined by the consistency of the measure on repeated applications. Test-retest using the Pearson product-moment correlation is the most common method for estimating stability. (Williamson, Y. 1981). This approach involves repeated application of the measure to the same subjects after a pre-determined period of time. The test scores are then correlated using the Pearson r. Several problems are noted with the above procedures. First and foremost is the effect of retesting the same group. Certainly subjects may respond differently due to present personal factors, direct influence by the first test administration and genuine changes that may have occurred between testing. The correlation statistic will identify the ordering of responses but will not reflect the magnitude of the score differences. Although, other statistical measures could be utilized the problems inherent to test-retest limit it's usefulness for determining stability. Both the Client and Significant Other Satisfaction Survey were not estimated for stability due to the problems previously outlined as well as the time involved in such a procedure.

The second type of reliability, equivalence, refers to the extent to which different instruments applied to the same individuals at the same time, or different investigators using one instrument to measure the same individuals at the same time, yield consistent results (Williamson, Y. 1981). The methods utilized in estimating equivalence include use of parallel forms and interrater testing. The parallel form technique is applied when repeated measures of the same content is desired. The resulting correlation statistic between the two forms provides an estimate of the errors of measurement associated with errors in item sampling.

Interrater reliability is used when the investigator is concerned that the nature of the measurement error may be attributed to observer influence. "These errors may be the result of transient personal factors associated with the observer, variations in the way the instrument is administered, lack of clarity of the instrument itself or differences in observer knowledge" (Williamson, Y. 1981, p. 159). The satisfaction Surveys were not assessed for their degree of equivalence. Rather, attention was focused on the third type of reliability, homogeneity.

Homogeneity refers to the extent to which individuals' responses to the various items or components of a measuring instrument are consistent. This is frequently referred to as internal consistency and best describes the condition in which there is a high degree of interrelatedness among items. Estimating the degree of internal consistency is the best means of assessing one of the most important sources of measurement error, which is the sampling of content (Polit and Hungler, 1983). A Cronbach's Alpha was computed for the entire Satisfaction Survey. This technique provides the average interitem correlation of all items constituting a scale and probably represents the best estimate of internal consistency. The coefficient alpha ranges from 0.00 to 1.00. The higher the coefficient the more stable the measure. Reliability coefficients in the vicinity of .70 are considered sufficient for making group level comparisons (Polit and Hungler 1983). The reliability coefficient for the Satisfaction Survey are reported in Chapter V with the data analysis

Validity is equally important to reliability and refers to the degree to which the instrument measures what it is intended to measure (WIlliamson, Y. 1981). Establishing validity for instruments measuring abstract concepts is a very difficult and on going process. Three types of validity are often referred to content, predictive, and construct validity The Satisfaction Surveys were evaluated for content validity only. Estimates of both construct and predictive validity were beyond the scope of this study.

Content validity is the degree to which the instrument represents an adequate sampling of the content which is being measured. The two subcategories of content validity is item validity and sampling validity. Item validity refers to the degree in which the test items represent measurement in the intended content area. Sampling validity deals with how well the test samples the total content area. Content validity has no empirical base but logical and statistical procedures can be applied to help ensure that items have content validity (Williamson, Y. 1981). Subjective judgement of the instrument items is often referred to as face validity and provides a point of departure for content validity. The Satisfaction Survey were evaluated for content validity through the subjective appraisal of the items by the researcher's thesis committee and after a review of the current literature.

Scoring

The total raw scores for the Satisfaction Survey have a range from 12 to 60. The raw score is derived from a five choice Likert-type scale associated with each item. The scale ranges from one to five with one associated with very dissatisfied and five very satisfied. A mean score was calculated for each subject and subsequently reported as such in Chapter V. Subjects who had a total mean score of less than 3.0 were considered to reflect a degree of dissatisfaction, while those whose mean score were above 3.0 were considered satisfied, subjects who were neither completely satisfied or dissatisfied score had a mean of 3.0 on the instrument.

Further breakdown of the Satisfaction scores was possible and included a combined score for the physical dimension, the psychosocial dimension and the remaining areas noted to be gainful activity. The score ranges from each of these dimensions are:

Physical Dimension 3 - 15
- Item #3 Body Care Management
- #5 Mobility
- #7 Ambulation

Psychosocial Dimension 4 - 20
- Item #2 Emotional Behavior
- #6 Social Interaction
- #8 Alertness Behavior
- #9 Communication

Gainful Activity 5 - 25
- Item #1 Sleep Rest
- #4 Home Management
- #10 Work
- #11 Recreation and pastimes
- #12 Easting

The third set of instruments utilized in this study included two Sociodemographic Questionnaires, each specifically designed for the client and their significant other. These questionnaires were developed after extensive review of the literature, and were evaluated for readability along with the Satisfaction Survey during a pretest of the study. Three client and significant other dyads from the identified sample were included in a pilot study. During this time, the developed instruments were pretested for readability and data collection procedures evaluated. These cases were not included in subsequent analyses.

Data Collection Procedures

After obtaining permission from the two research committees outlined earlier, a copy of the Research

Proposal and an introductory letter was sent to each nephrologist associated with Michigan Nephrology Center. Meetings were held with the staff from the outpatient hemodialysis unit and the home dialysis program. Upon completion of this communication process, each potential subject was personally contacted by the researcher. The purpose of the initial contact was to identify those clients who met the criteria for inclusion in the study as well as to obtain initial consent for participation.

Clients were asked to identify a member of their household who they considered a primary support to them. Written information was then given to the client to reinforce the discussion on the study. They were instructed to share the information with their identified significant other within a 48-hour period. A follow-up phone call or personal contact was then made by the researcher to the client for further clarification of any issues and to set an appointment for the administration of the study instruments.

The data collection was obtained simultaneously from the client and the significant other. The subjects opted for either a home visit or an appointment before or after their clinic visit. No data collection was attempted during an actual hemodialysis treatment. At the time of data collection, the consent form was signed and collected by the researcher.

The questionnaires and accompanying instructions were individually packaged for the client and his/her significant other. Upon completion, the subjects placed the questionnaires in a self-sealed envelope provided by the investigator. The consent form was not attached to the packet for confidentiality. Questions which arose during administration from the participants were answered by the investigator. The investigator kept the responses consistent and referred to the SIP standard instructions given to the subjects for guidance.

The researcher obtained data from 28 client/ significant other dyads. There was no effort to seek an equal number of men and women clients, nor an equal percentage of home versus in-center dialysis clients.

Data Analysis Procedures

The major study questions and their sub-parts for this research proposal and the statistical procedures utilized to answer them are:

1. What is the degree of congruence between a hemodialysis client and his/her significant other regarding the clients' present overall rehabilitation?
    a. What is the degree of congruence between the client and his/her significant other on the physical dimension of rehabilitation?
    b. What is the degree of perceived congruence between the client and his/her significant other on the psychosocial dimension of rehabilitation?

c. What is the degree of perceived congruence between the client and his/her significant other on the rehabilitation dimensions of home management, work, eating, sleep/rest, and recreation and pastimes?

These questions were answered in the following manner:

1. A dependent t-test was computed between the dyad's scores on the overall dimensional and individual scales of the SIP. The purpose was to identify any significant differences between their individual scores. Since the data were obtained from paired sets of subjects the independent t-test was not applicable. The dependent t-test was considered significant at or below the .05 level.

2. The Pearson product-moment correlation was computed between the days's scores on the overall, dimensional and individual scales of the SIP. These correlations were utilized to evaluate the degree of congruence between the dyad. The r was the most appropriate statistic for the interval data that was collected. The r is a numerical index that expresses the direction and magnitude of a relationship. The value ranges from - 1.00 to 1.00. All correlations that fall between -1.00 and 0.00 are negative relationships, and correlations between 0.00 and 1.00 are positive relationships. For this study the criteria for the strength of correlations between the variables were taken

from Borg and Gall (1979, p. 513-514). 0.00 to 0.20 is indicative of no relationship, 0.20 to 0.35 is a low relationship, 0.35 to 0.85 is a moderate relationship, and 0.85 to 1.00 is a high to perfect relationship.

Research Question II and associated Sub-questions

II. What is the degree of perceived satisfaction regarding the client's rehabilitative status by both the client and his/her significant other?

1. This question was answered by computation of mean SS scores, dependent t-tests and Pearson r's between the clients and their significant others. The rationale for these statistical measures are similar to that provided for Question I. What is he correlation between the degree perceived congruence on the dimensions of rehabilitation and their degree of perceived satisfaction with the client's rehabilitation status?

This question was answered by the use of a correlational matrix and the correlation of absolute disagreement scores. The client and significant other scores from the overall SIP (total and dimensional scores) and the Satisfaction Surveys (total and dimensional scores) were applied to a correctional matrix using the Pearson r. These techniques are the most applicable based on the interval data collected and provides all possible correlations both positive and negative for examination. Disagreement scores between the scores of the client and significant other on the SIP and SS, was computed. These scores were then correlated using the Pearson r to identify the degree of congruency between the dyad on these scales.

Sociodemographic data will be presented using descriptive statistics in order to characterize the sample. Frequencies, percentages, or means were calculated as appropriate. Demographics were evaluated for potential moderating effects on the SIP and satisfaction scores through dependent t-tests and correlation scores. Subjects that failed to respond to each item on the Satisfaction Survey and/or the Sociodemographic Survey will not be included in the data analysis of those areas.

Summary

In Chapter Four the study variables were operationally defined, data collection procedures detailed, and measures to ensure protection of human rights outlined. The instruments to be utilized were discussed in relation to their reliability and validity. The statistical analysis measures were presented in such a manner to assure that all significant data will be presented to answer the research questions under study.

CHAPTER V

DATA PRESENTATION AND ANALYSIS

Overview

The focus of this chapter will be to present data that describes and analyzes the study sample. A discussion of the reliability measures established for each of the measurement scales will be included. Further, data analyses are presented to answer the major research questions of this study and their related subquestions. Prior to presenting the data the results of the pilot study will be discussed.

Results of Pilot Study

A pilot study was conducted with three dyads formed of a hemodialysis dialysis client and their self selected significant other, two clients were on home dialysis and one dialyzed in the outpatient unit. The pilot sample was selected from the total pool of the available hemodialysis clients at Borgess Medical Center. The purpose was to test the instruments for readability and identify potential problems with the data collection procedures. The data obtained from these dyads were not included in the data analysis of the research querstions.

The following changes were made based on the pilot study:

1. Subject criteria to include that the dyadic relationship was established prior to the onset of End

Stage Renal Disease.

2. Interpretation of the SIP instruction "State of Health" to include the weekly time requirement imposed by dialysis.

3. The Likert-type scale on the Satisfaction Surveys was changed from:

> Very Dissatisfied, Somewhat Dissatisfied, Mixed, Somewhat Satisfied, and Very Satisfied. To:
>
> Very Dissatisfied, Dissatisfied, Mixed, Satisfied, and Very Satisfied.

Confusion originated from being unable to differentiate the term "Somewhat" from "Mixed". The pilot subjects suggested the deletion of "Somewhat" from the scale for clarity purposes.

4. The choice "None of the Above" was added to Question 14 of the Significant Other Sociodemographic Survey. This provided for easier identification of those who did not carry out any of the listed activities from those who simply chose not to answer the question at all.

Descriptive Findings of the Study Sample

Following the procedures outlined for sample procurement, 60 chronic outpatient hemodialysis clients at Borgess Medical Center were approached by the investigator during their clinic appointment. A total of fifty clients dialyzed in the Outpatient Unit and ten were on home hemodialysis. Although the home dialysis program has thirteen clients, not all of the home dialysis clients were available during the study period. Only those who had a clinic appointment during the two month collection period were included. Additionally, one outpatient dialysis client was on vacation and not available during the study period.

Only 26 of the 50 outpatient dialysis clients met the criteria for inclusion with 23 of them voluntarily agreeing to participate in the study. Two refused due to poor health and one did not have a willing significant other. Of the 10 home clients approached, eight voluntarily agreed to participate, one refused citing ill health and one did not meet all the study criteria. Three subjects, one from the outpatient unit and two from the home program were then selected for the pilot study leaving 28 client/significant other dyads for the final sample: Twenty-one in the outpatient hemodialysis unit and seven on home dialysis.

Sociodemographics of the Client

The sociodemographics of the clients included personal characteristics, co-morbidity factors and treatment related variables. The decriptive statistics are presented below for the major sociodemographic variables.

Personal Age

The age range of the clients is presented in Table 5. The mean age was 52.6 years with a S.D. of 13.8.

Table 5

Age Breakdown of the Hemodialysis Clients

Category	Respondents No.	%
Age	N=28	100.0
20-29	2	7.1
30-39	4	14.3
40-49	6	21.5
50-59	5	17.8
60-69	8	28.6
70-79	3	10.7
Total	N=28	100.0

Sex

The sample consisted of 17 males (61%) and 11 females (39%).

Race

Over half of the clients (N = 20, 71.4%) were Caucasian with the remaining eight (28.6%) black.

Marital Status

The majority of clients (N = 20, 71.4%) were married, four (14%) were single, one (4%) was divorced and three (11%) were widowed. The range of years married was 2 to 51 years, with a mean of 24.2 years and a S.D. of 15.5 years.

Education

The amount of education varied within the sample. Only one (4%) reported less than seven years of education while two (7%) had completed junior high school, twelve (43%) completed high school, nine (32%) had partial college education, one (4%) had completed a college program and three (11%) had post-baccalaureate education.

Occupation and Income

The sample included six (22%) clients who worked outside the home. The occupations of those six were distributed as follows: one (17%) in a clerical position, three (50%) professionals, and two (33%) skilled workers. The remaining 21 (79%) clients reported to be either retired or unemployed. The income per household was reported by only 21 of the clients, and ranged from less than $10,000/year (N = 4, 19%) to under $50,000/year (N=17, 81%). The average income was between 10,000 and 20,000 dollars a year (N = 11, 52.4%).

Co-Morbidity Variables, Diagnosis and Duration of Kidney Disease

The diagnoses reported include: Polycystic Kidney Disease (N = 8, 28.6%), Systemic Lupus Erythematosus (N = 1, 3.6%), Diabetic Nephropathy (N = 8, 28.6%), Glomerulonephritis (N = 2, 7.1%), and post open-heart surgery (N = 1, 3.6%). The diagnosis was not known by eight (28.6%) of the clients. In terms of the time since

diagnosis, one (4%) reported knowing less than one year ago, four (14%) had been diagnosed one/two years ago, seven diagnosed (25%) three/five years ago, and 16 (57%) diagnosed over five years ago. The majority (82%) had been diagnosed for over three years.

Number and Diagnosis of Additional Chronic Illness

Additional chronic health problems were reported by 20 (71.4%) of the clients sampled. The illnesses included arthritis (N = 7, 25%), hypertension (N = 7, 25%), heart disease (N = 8, 28.6%), diabetes (N = 8, 28.6%), lung disease (N =2, 7.1%), Systemic Lupus Erythematosus (N = 1, 3.6%) and other (N = 3, 10.7%).

Previous Hospitalization in Last Year

Only 39% (N = 11) reported being hospitalized for 1 to 49 days within the last year. The majority (89%) of those hospitalized reported the admissions were a result of their kidney disease.

Treatment Related Variables: Setting and Length of Time on Dialysis

The majority of clients (N = 21, 75%) dialyzed in the outpatient unit. The seven (25%) dialyzing at home reported their dialysis partners as either their spouse (N = 6) or parent (N = 1).

The length of time reported on dialysis by the entire sample (N = 28) was distributed as follows: Six to twelve months (N = 5, 17.9%), two to five years (N = 10, 35.7%)

and greater than five years (N = 13, 46.4%). All had been in their present setting since starting dialysis.

Dialysis Schedule

In Table 6 an overview of the number of days and hours the clients dialyzed a week is presented. As can be seen the average number of days was three per week with four hours per treatment.

Table 6

Number of hours and days spent on dialysis by the clients

Category	Respondents No.	Percentage
No. of Days on Dialysis a Week	N=28	100.0
2	2	7.1
3	22	78.6
4	4	14.3
Total	28	100.0
No. of Hours per Treatment	N=27	96.4
3	1	3.7
4	15	55.6
5	10	37.0
6	1	3.7
Total	27	100.0

Time Spent on Travel and "Recovering" From the Treatment

Those clients (N = 21) who dialyzed in the outpatient unit spent the following amount of time traveling to and from the unit: less than one hour (N = 12, 42.9%), one/two hours (N = 9, 32.1%) and three/four hours (N = 1, 3.6%).

Table 7 presents the data on the actual number of hours needed for "recovery" after each dialysis. The mean number of hours was 8.5 with a S.D. of 7.7 hours.

Table 7

Number of actual "Recovery" hours reported by the clients

No. of Hours Needed for Recovery	N=27	96.4
0 - 1	3	11.0
2 - 3	8	30.0
6 - 8	6	22.0
12	6	22.2
24	4	15.0
Total	27	100.0

Client Profile

From the sociodemographic data obtained on the clients (See Appendix 5), a typical client profile can be developed. The majority (N = 17, 61%) of the clients were males with a mean age of 52.6 years. The clients were predominantly caucasian (N = 20, 71.4%), with 71.4% (N = 20) reporting to be married for approximately 24 years. Over

89 percent (N = 25) had a minimum of 12 years of education, with 46% (N = 13) reporting some college preparation. The average income per client household ranged between $10,00 and $19,999. There was no significant correlation between income and the client variables of employment status or education. A correlational score of -.42 (p = .029) was found between income and age, with age also correlating to both retired (.56, p = .001) and retired due to health (.40, p = .016) in a positive direction. This maybe interpreted that younger clients tended to have a higher income and were more likely to be either employed or disabled, although this is not totally supported by this study. In addtion there were no significant findings between the employment status of the significant others to the clients reported income or current employment. Possibly younger clients had a reported higher income due to opportunities to make money from part-time jobs or projects.

The majority of clients (N = 16, 57.1%) in this sample reported knowing that they have had kidney disease for over five years with 46.4 (N = 13) percent reporting to be on dialysis over five years; a positive correlation (.77, p = .001) was noted between these two variables. This indicates that clients started dialysis near the time of diagnosis.

The most frequently reported diagnoses of kidney disease included Polycystic Kidney Disease (N = 8, 28.6%)

and Diabetes (N = 8, 28.6%) while an additional 28.6% (N = 8) did not know the etiology of their kidney failure. In addition to their ESRD, 74.1% (N = 20) of the clients reported additional chronic health problems; eleven (39%) identifying two or more additional illness. The most frequently identified problems were; Arthritis, Hypertension, Heart Disease and Diabetes. Those who reported additional chronic health problems had no significant correlation between the client variables of age, length of recovery period after dialysis, number of days or hours on dialysis, employment, previous hospitalizations, or duration of kidney disease.

Overall, thirty nine percent (N = 11) of the clients had been hospitalized within the last year for an average of five days. The majority (N = 10, 89%) identified that the hospitalization was directly related to their kidney disease.

Typically the clients dialysis schedule was four hours of dialysis, three days a week. Positive correlations were noted between the number of days on dialysis and the length of time on dialysis (.34, p = .03). In addition the number of days on dialysis also correlated with those who reported being retired due to health (.32, p = .04). These correlations imply that the longer the client has been on dialysis, more hours of dialysis were needed. Further the amount of time spent dialyzing was related to the client's employment status, indicating that increased dialysis time impeded available work time. The number of days on dialysis was negatively correlated with income ($r = -.44$, $p = .02$) which corroborates the time impediment of dialysis on employment. Most of the clients (54.5%) traveled less than one hour to and from dialysis.

The mean number of hours needed for recovery after each dialysis was 8.5 hours. The amount of recovery time reported had a significant negative correlation ($r = -.47$, $p = .006$) to the length of time since diagnosis of kidney disease. This may imply that less time was needed for recovery by those clients who had been on dialysis the longest. Quite possibly this is due to the body's overall adjustment to dialysis in time. There were no significant correlations between the variables of post-dialysis recovery time to the client's age, employment status, number of days or hours on dialysis per week or number of chronic health problems.

In terms of occupation and current work status, over 75 percent ($N = 21$) were presently not working: 13 (61%) clients reported being retired due to poor health and five (23%) identified themselves as disabled, as opposed to retired. The clients who selected retired due to health had an age range of 40 to 71 years. The correlation between age and those retired due to health was found to be positive (.37, $p = .03$). This may indicate that older clients who are near retirement age are more likely to opt for early retirement due to health, versus calling themselves disabled. There was no significant correlation between those retired due to health and the number of reported chronic health problems or distance traveled to and from dialysis. Further, educational level was negatively correlated (r = -.32, p = .05) with the variable retired due to health. This may indicate that those with more education were either retired for reasons not due to their health, currently working, or considered themselves disabled. Those who reported being disabled tended to be younger (r = -.46, p = .006) with no significant correlations among any of the other sociodemographics.

Sociodemographics of the Significant Others

Sociodemographics of the significant others including their personal characteristics, present health status and dialysis related activities were obtained. The following is a presentation of their descriptive statistics.

Personal Demographics

Age and Sex

The age range of the significant others was 25-75 years, with a mean of 52.2 years. There were 20 females (71.4%) and eight males (28.6%).

Race

The majority were Caucasian (N = 21, 75%), the remaining seven (25%) were black. There was one bi-racial marriage.

Marital Status

A total of 23 (82.1%) were married, three (10.7%) were single, one divorced and one widowed. The average number of years married was 28.3 years, SD 15.9.

Education

The amount of reported education ranged from: three (10.7%) completing junior high school, two (7.1%) with partial high school, eleven (39.3%) completing high school, five (17.9%) with partial college education, four (14.3%) completing college and three (10.7%) with graduate education.

Occupation

A small percentage (N = 12, 42.8%) reported working outside the home. The occupations of those currently employed ranged from two (16%) in clerical positions, three (25%) professionals, four (33%) in unskilled jobs and two (16%) reporting other.

Relationship to Client

The majority (N = 20) were spouses while, one, was a child of the client, five were parents and one a nephew to the client.

Health Related Variables

Health Status and Number of Chronic Illnesses

The significant others rated their current health status as follows: 17 (60.7%) reported good health, 6

(21.4%) cited fair health, and three (13.7%) considered themselves in poor health. Only 11 of the significant others (39.3%) reported having a chronic illness. The types of chronic illnesses listed included Arthritis (N = 4, 14.3%), Hypertension (N = 4, 14.3), Heart Disease (N = 1, 3.6%), Diabetes (N = 2, 7.1%), Lung Disease (N = 2, 7.1%), and other (N = 3, 10.7%). Only 19% of the significant other's responded to the question related to the impact of the client's illness on their own health. There was no effect reported in (43% (N=12) of those who responded. Approximately 23% of those reporting indicated that their health actually improved due to the client's illness and one cited a decline in health.

Treatment Related Variables

Activities performed for the client

The significant others reported carrying out the following activities for the client: prepare special meals (N = 19, 67.9%), remind client to take their medications (N = 15, 53.6%), drive the client to and from dialysis (N = 14, 50%), and monitor the client's blood pressure at home (N = 13, 46.4%). Only 14.3% (N = 4) reported not carrying out any of the above activities.

Information Received about the Client

The majority of the significant others (N = 18, 64.3%), reported receiving enough information about the client; four (14.3%) felt they had received some information but would like more, and four (14.3%) did not feel they had received enough information.

Profile of the Significant Others

Data obtained from the significant others Sociodemographic Survey (See Appendix E) can be used to develop a typical profile of the significant other. The majority (71%) of the significant others were white females with a mean age of 52.2 years. Since the majority of the dyads were married, the data obtained on those variables are similar to those presented for the client. There were no significant correlations found between the type of relationship within the dyads and the major research variables.

A total of thirty-nine percent (N = 11) of the significant others had a minimum of a high school education with 43% (N = 12) indicating some amount of college education. Only twelve (42%) of the significant others reported working, ten full-time, and two part-time.

Nearly all of the significant others reported performing activities which were required in the client's care such as: preparing special meals, reminding client's to take medication, driving to and from dialysis and home monitoring of blood pressure. Several correlations were found between number of activities and the client's sociodemographics. The client's number of additional chronic illnesses was significantly correlated to activities performed ($r = .31$, $p = .049$) and the length of time on dialysis had a highly significant and negative correlation to activities performed (r = -.47, p = .005). The average number of activities performed by the significant other was 2.2.

Chronic health problems were reported by thirty-nine percent (N = 11) of the significant others. The most frequently cited illnesses included Arthritis and Hypertension. The number of chronic health problems was positively correlated to age (.35, p = .038). A positive correlation was also found between the number of reported chronic illnesses by the significant other and a decline in their perceived health (.45, p = .010). The overall effect of the clients' illness did not appear to affect the health status of the significant other. In fact, 23.9% (N = 4) reported an increase in their own health as a result of the client's illness.

Two other correlations between the significant others health are worth noting. The number of days the client dialyzed had a positive correlation with the decline of the significant others perceived health status (r = .50, p = .004). Also, the client's retirement due to poor health was significantly correlated to a decline in the significant others health status (.43, p = .013).

For the most part, the significant others felt they had received enough information about the client's condition. Only 28 percent (N = 8) felt the need for additional information. There were no significant correlations between this variable and the other sociodemographic data.

Reliability of the Study Instruments

The reliability of the instruments used in this study was assessed by computing coefficient alpha as outlined in Chapter IV. No scale items were deleted. Refer to Table 8 for the alphas obtained on the Satisfaction Survey.

Table 8

Alpha Coefficient on the Satisfaction Survey

	Overall Satisfaction Survey	Physical Dimension of Sat. Survey	Psychosocial Dimension of Sat. Survey
Clients	.87	.74	.60
Significant Other	.94	.83	.84

The figures in Table 8 represent a high degree of internal consistency among the 12 items of these scales.

In addition to the coefficient alphas computed on the Satisfaction Surveys, alphas were obtained on the Physical and Psychosocial dimensions of the SIP. Although test-retest is the most appropriate measure of reliability for the SIP, the alphas were obtained for the purpose of completeness. Test-Retest of the SIP is the most appropriate reliability measure since the tool was designed to capture the types of dysfunction currently perceived by a patient. Therefore, similar scores and repeated item checking between two close administrations is of critical importance. Table 9 includes the alphas of both the clients and the significant others SIP.

Table 9

Alpha Coefficients of the SIP

	Physical Dimension	Psychosocial Dimension
Clients	.85	.70
Significant Others	.90	.89

Note: Physical Dimension includes Body Care and Movement, Mobility and Ambulation scales, Psychosocial Dimension includes Emotional Behavior, Social Interaction, Alertness Behavior and Communication.

The alphas were indicative of a moderate to high internal consistency within the respective dimensions, and thus reflect an acceptable level of homogeneity between the items.

Analyses Pertinent to Study Questions

In the following section data that answers the study questions will be presented. Each question will be addressed by the statistical procedures outlined in Chapter IV. For all correlations and T-tests, the .05 level of significance was used.

In Table 10 an overview of the clients' and significant others' SIP scores is presented. This table will be referred to while answering questions I, Ia, and Ib.

Question I.

> What is the degree of perceived congruence between the hemodialysis client and his/her significant other regarding the client's rehabilitation status?

As can be noted in Table 10, the overall SIP scores between the clients and significant others correlated moderately (r = .47, p = .006) in a positive direction. There were no significant T-tests between their overall mean scores.

Sub-Research Question Ia.

> What is the degree of perceived congruence between the client and his/her significant other on the physical dimension of rehabilitation?

The physical dimension did have a positive correlation (r = .75, p = .001) between the scores of the clients and their significant others. All other dependent T-tests between the mean scores were non-significant at the 0.5 level.

Sub-Research Question Ib.

> What is the degree of perceived congruence between the client and his/her significant other on the psychosocial dimension of rehabilitation?

The computed correlation on the psychosocial dimension did not indicate the presence of a significant correlation (r = .14, p = .22). Dependent T-tests between their mean scores were not found significant at the .05 level.

Sub-Research Question Ic.

> What is the degree of perceived congruence between the client and his/her significant other on the rehabilitation dimensions of sleep/rest, work, eating, recreation and pastimes, and home management?

These dimensions work, sleep and rest, home management, recreation and pastimes, and eating are individual scales listed on Table 10. The correlation coefficients for sleep and rest, (r = .55, p = .001) home management, (r = .69, p = .001) and work (r = .71, p = .001) reflect a positive degree of congruence between the dyads. The two other sub-scales, recreation and pastimes (r = -.11) and eating, (r = .08) did not have correlations significant at the .05 level..

The areas which posed the greatest degree of perceived dysfunction by the clients and those identified by the significant others are presented in Table 11. The areas are based on the mean dysfunction scores and are listed from greatest to least dysfunction.

Table 10

Overview of SIP Scores and Correlations Between the Clients and Their Significant Others

	Mean Scores		
Category	Client	Significant Other	Pearson Product Moment Correlation
Sleep and Rest	30%	28%	.55 P=.001
Emotional Behavior	16%	23%	.31 P=.049
Body Care and Movement	8%	9%	.75 P=.001
Home Management	34%	27%	.69 P=.001
Mobility	11%	12%	.35 P=.03
Social Interaction	17%	14%	.26 P=.08
Ambulation	18%	17%	.68 P=.001
Alertness Behavior	12%	14%	- .09 P=.32
Communication	5%	4%	.30 P=.05
Work	12%	12%	.71 P=.001
Recreation and Pastimes	29%	23%	- .11 P=.27
Eating	9%	8%	.08 P=.32
Physical Dimension	11%	11%	.75 P=.001
Psychosocial Dimension	13%	14%	.14 P=.22
Overall SIP Score	17%	16%	.47 P=.006

Note. Mean dysfunction scores have been rounded-off to the next highest number.

Table 11

Rank Order of Perceived Dysfunction by the Client and Significant Other

Client	Significant Other
Home management	Sleep and rest
Sleep and rest	Home management
Recreation and Pastimes	Recreation and Pastimes
Ambulation	Emotional behavior
Social interaction	Ambulation
Emotional behavior	Social interaction
Alertness behavior	Alertness behavior
Work	Mobility
Mobility	Work
Eating	Body care and movement
Body care and movement	Eating
Communication	Communication

The one striking difference in their perceived order is the placement of emotional behavior. Referring to Table 10, one can note that the correlation between the dyads on emotional behavior was .31 (p = .049) which indicates a low but positive correlation. The T-test between the mean scores on this scale was 1.51 (p = .14) which had the greatest significant difference among all the mean scores.

Data are available to present the correlation scores among the various SIP scales of the clients and the significant others separately. In Table 12 a summary of the correlation coefficients amond the clients dimensional and scale scores is presented. The data reflect a positive but moderate correlation between the clients score on the physical and psychosocial dimensions of the SIP. Strong correlations are found between the physical dimension and home management, recreation/pastimes, and sleep/rest. Similarily, strong correlations are noted between the psychosocial dimension and home management, and recreation/pastimes. Interestingly, there is no significant association between work and either the physical or psychosocial dimensions. The only significant correlations that can be found between all the SIP scales and work was Alertness Behavior (.40 p = .01) and Eating (.49 p = .003).

Table 12

Correlations of Significant Others SIP Scores

Category	Physical Dimension	Psychosocial Dimension
Physical	- -	- -
Psychosocial	.41 P= .01	- -
Home Management	.73 P= .001	.55 P= .001
Recreation and Pastimes	.44 P= .009	.36 P= .02
Work	- .14 P= .22	.16 P= .19
Eating	.22 P= .12	.25 P= .09
Sleep/Rest	.55 p= .001	.16 P= .197

The data obtained for the significant others are presented in Table 13. Again, the psychosocial and physical dimensions have a positive correlation. Unlike the correlations among the client's SIP scores, the significant others had a positive correlation between the two major dimensions and the scales intrinsic within the gainful activity dimension. The physical dimension had strong correlations with Home Management (r = .83, p = .001), Recreation/Pastimes (r = .72, p = .001), Sleep/Rest (r = .73, p = .001). A low but significant correlation (r = .39, p = .02) was also found between the physical dimension scores and the Eating scale. The psychosocial dimension also had strong correlations with recreation and pastimes (r = .70, p = .001), and sleep/rest (r = .66, p = .001). Moderate correlations to the psychosocial dimension were found with the Home Management Scale (r = .49, p = .004) and the Eating Scale (r = .41, p = .015). This indicated that the significant others associated dysfunction in one area with similar dysfunction in the other areas, thereby perceiving an interrelationship between the dimensions of rehabilitation.

Table 13

Correlations of Significant Others SIP Scores

Category	Physical Dimension	Psychosocial Dimension
Physical	- -	- -
Psychosocial	.58 P= .001	- -
Home Management	.83 P= .001	.49 P= .004
Recreation and Pastimes	.72 P= .001	.70 P= .001
Work	.19 P= .15	- .10 P= .30
Eating	.38 P= .02	.41 P= .015
Sleep/Rest	.73 P= .001	.66 P= .001

Question II:

> What is the degree of perceptual congruence between the client and his/her significant other regrading their satisfaction with the client's present rehabilitation?

The data presented in Table 14 will be used to answer question II. This question will be addressed in terms of the client's satisfaction scores and those of their significant others followed by correlations between the two sets of scores.

Table 14

Results of the Satisfaction Surveys From the Clients and Significant Others

		Mean Scores				
		Client		Significant Other		
		Mean	SD	Mean	SD	Pearson r
Total Satisfaction Score		N=23		N=22		.61
		3.64	.66	3.73	.97	P=.005
Satisfaction Questions						
Sleep and Rest	1.	N=28		N=28		.58
		3.50	.96	3.60	1.22	P=.001
Emotional Behavior	2.	N=28		N=28		.18
		3.57	.83	3.85	1.00	P=.16
Body Care & Movement	3.	N=28		N=28		.60
		3.90	.83	4.25	1.10	P=.001
Home Management	4.	N=28		N=28		.29
		3.14	1.17	3.10	1.44	P=.06
Mobility	5.	N=28		N=28		.37
		3.64	1.19	3.57	1.28	P=.02
Social Interaction	6.	N=27		N=28		.29
		3.14	1.13	3.21	1.37	P=.06
Ambulation	7.	N=28		N=28		.47
		3.96	.92	4.21	1.03	P=.005
Alertness Behavior	8.	N=27		N=27		.37
		3.96	.89	3.92	.99	P=.03
Communication	9.	N=27		N=28		.18
		4.22	.80	4.28	1.11	P=.18
Work	10.	N=24		N=23		.35
		2.6	1.46	3.08	1.67	P=.06
Recreation & Pastime	11.	N=27		N=25		.69
		2.88	1.18	3.24	1.42	P=.001
Eating	12.	N=28		N=27		.40
		3.64	.95	3.85	1.02	P=.01
Physical Dimension of Satisfaction Survey		N=28		N=28		.53
		3.85	.80	4.01	.98	P=.002
Psychosocial Dimension of Satisfaction Survey		N=27		N=27		.47
		3.73	.62	3.78	,92	P=.007

The mean overall satisfaction score for the clients was 3.64, indicating a positive degree of perceived satisfaction. The two dimensions, physical and psychosocial, also had means which tended to reflect more satisfaction than dissatisfaction 3.85 and 3.73 respectively.

The mean overall satisfaction score ($\hat{X}$ = 3.73) of the significant other and their two dimensional scores (physical: $\hat{X}$ = 4.01, psychosocial: $\hat{X}$ = 3.78) were also on the positive end of the Likert scale. All dependent T-tests between their mean scores were not significant. For the most part the significant others were more satisfied in all areas except home management, mobility and alertness behavior, than the clients. The overall satisfaction score and dimensional satisfaction scores between the members of the dyads did have a significant yet moderate correlation ($r = .61$, $p = .005$). This would reflect a moderate degree of congruence between the dyads.

In Table 15 a rank ordering of the satisfaction questions by the clients and significant others is presented. The areas are listed in order of high to low satisfaction based on the mean satisfaction scores.

Table 15

Rank order of Satisfaction Scores between the Clients and Significant Others

Clients	Significant Others
Communication	Communication
Ambulation	Body Care & Movement
Alertness Behavior	Ambulation
Body Care & Movement	Alertness Behavior
Eating	Eating
Mobility	Emotional Behavior
Emotional Behavior	Sleep/Rest
Sleep/Rest	Mobility
Home Management	Recreation/Pastimes
Social Interaction	Social Interaction
Recreation/Pastimes	Home Management
Work	Work

Sub-Research Question IIa

> What is the correlation between perceived congruence on the dimensions of rehabilitation, and their degree of perceived satisfaction with the client's rehabilitation status?

The first set of data to be discussed is that of the individual correlation between the clients SIP and SS scores, and the scores of the significant other. In both Tables 16 & 17, one can immediately note the presence of negative correlations in every area; denoting that the higher the subjects scored on the SIP, indicating the presence of perceived dysfunction, the lower their satisfaction in that area. Despite this obvious trend not all the correlations were significant at the .05 level.

Table 16

Correlations Using Pearson r Between Clients Satisfaction Scores and SIP Scale Scores

	SIP Scales											
Satisfaction Question	Sleep/Rest	Emotional Behavior	Body Care & Movement	Home Management	Mobility	Social Interaction	Ambulation	Alertness Behavior	Communication	Work	Recreation & Pastimes	Eating
1 Sleep/Rest	- .18 P=.168											
2 Emotional Behavior		- .32 P=.047										
3 Body Care & Movement			- .29 P=.064									
4 Home Management				- .44 P=.008								
5 Mobility					- .58 P=.001							
6 Social Interaction						- .28 P=.076						
7 Ambulation							- .47 P=.005					
8 Alertness Behavior								- .74 P=.001				
9 Communication									- .02 P=.446			
10 Work										- .33 P=.056		
11 Recreation & Pastimes											- .39 P=.020	
12 Eating												- .17 P=.19

Table 17

Correlation Scores Using the Pearson r Between Significant Other's Satisfaction Scores and SIP Scores

	SIP Scales											
Satisfaction Question	Sleep & Rest	Emotional Behavior	Body Care & Movement	Home Management	Mobility	Social Interaction	Ambulation	Alertness Behavior	Communication	Work	Recreation & Pastimes	Eating
1 Sleep/Rest	- .29 P=.06											
2 Emotional Behavior		- .66 P=.001										
3 Body Care & Movement			- .37 P=.025									
4 Home Management				- .51 P=.002								
5 Mobility					- .62 P=.001							
6 Social Interaction						- .45 P=.008						
7 Ambulation							- .26 P=.084					
8 Alertness Behavior								- .43 P=.012				
9 Communication									- .23 P=.11			
10 Work										- .09 P=.33		
11 Recreation & Pastimes											- .55 P=.002	
12 Eating												- .42 P=.014

The correlation between the SIP and SS for the Clients and Significant Others are presented in Tables 18 and 19.

Table 18

Correlation of Significant Other scores on SIP and SS using the Pearson r

	Overall Satisfaction	Physical Dimension Satisfaction	Psychosocial Dimension Satisfaction
Overall SIP	$-.60$ ($p < .05$)	-	-
Physical Dimension	-	$-.46$ $p < .05$	-
Psychosocial Dimension	-	-	$-.71$ $p < .05$

Table 19

Correlation of Clients scores on SIP and SS using the Pearson r

	Overall Satisfaction	Physical Dimension of Satisfaction	Psychosocial Dimension of Satisfaction
Overall SIP	$-.60$ ($p < .001$)	-	-
Physical Dimension	-	$-.54$ ($p < .001$)	-
Psychosocial Dimension	-	-	$-.51$ ($p < .003$)

The overall and dimensional scores between the SIP and SS of the clients and significant others were all negatively correlated to each other at or below the .05 level of significance.

Agreement scores were computed between the dyad on both the SIP and SS. The absolute disagreement scores were then correlated to identify perceived congruence on both SIP and SS dimensions. In Table 20 a summary of the correlations is provided.

Interestingly, the areas included in the dimension of gainful activity, Work, Sleep and Rest, Home Management, Recreation and Pastimes and Eating, were all found to have no significant correlation between the disagreement scores. In addition the disagreement scores of the physical dimension were not significantly correlated. This indicates that there was no relationship between the dyad members in their amount of disagreement between dysfunction and satisfaction.

Correlations Among the Sociodemographic Data and the SIP and SS

The final section of this chapter will be the presentation of the interrelationships found among the sociodemographics and the SIP and SS. Data will be presented separately for the clients and the significant others.

Table 20

Correlations Using the Pearson r, of Absolute Disagreement Scores Between the Client and Significant Other

Pearson r Correlation Between	Correlation Score of Absolute Disagreement	P Value	N
A SIP - A SAT	.54	.012	17
A Phys - A Phys SIP - SAT	.20	.149	28
A Psycho - A Psycho SIP - SAT	.49	.005	26
Sleep/Rest - Sleep/Rest SIP - SAT	.22	.127	28
Home Man - Home Man SIP - SAT	.06	.37	28
Work - Work SIP - SAT	.21	.18	19
Eating - Eating SIP - SAT	- .11	.28	27
Rec Past - Rec Past SIP - SAT	.22	.15	24
A Phys - A Psycho SIP - SIP	.46	.006	28
A SAT - A SAT Phys - Psycho	.34	.042	26

Several of the clients sociodemographic characteristics were found to correlate significantly with their responses on the SIP and SS. These variables include the number of additional chronic health problems, "recovery" time post dialysis, length of kidney disease and age. In Table 21 an overview of these variables and the client's SIP scores is provided. The one dimension which was impacted by all four variables was home management which was also the highest dysfunctional score among the clients sampled.

Table 21

Correlations using the Pearson r among the clients variables: Number of chronic illnesses, recovery time post dialysis, age, length of kidney disease and the SIP.

Scale Category	No. of Chronic Illnesses	Recovery Time	Age	Length of Kidney Disease
Overall SIP Score	.45	N.S.	N.S.	- .32
Physical Dim.	N.S.	N.S.	.49	N.S.
Psychosocial Dim.	.53	N.S.	N.S.	N.S.
Work Scale	N.S.	N.S.	-.49	N.S.
Eating Scale	.38	N.S.	N.S.	- .41
Home Man. Scale	.40	.35	.45	- .34
Sleep/Rest Scale	N.S.	N.S.	.51	N.S.

[All correlations significant at p = .05]

The negative correlations found between length of kidney disease and the overall SIP score, eating scale and home management denote less dysfunction as time passes.

The data presented in Table 22 are the correlations between the client variables, number of chronic illness, recovery time post dialysis, age, and length of kidney disease and their satisfaction scores. The negative correlations found between these variables imply that their satisfaction is increased when the client has less of the particular condition or attribute.

Table 22

Correlations using the Pearson r between the client variables: Number of chronic illnesses, recovery time post- dialysis, age, length of kidney disease and the Satisfaction Scales.

Scale Category	No. of Chronic Illnesses	Recovery Time	Age	Length of Kidney Disease
Overall Satisfaction	- .40	- .45	N.S.	N.S.
Physical Dim. of Satisfaction	- .53	N.S.	N.S.	N.S.
Work	N.S.	- .45	N.S.	N.S.
Eating	- .34	- .36	N.S.	.42
Sleep/Rest	N.S.	- .36	N.S.	.35
Recreation/Pastime	- .34	- .40	- .38	N.S.
Home Management	- .44	- .44	N.S.	.34

(All correlations significant at p = .05)

An interesting finding was the positive correlations between length of kidney disease and the satisfaction with eating, sleep/rest and home management. These correlations may imply that the client has the ability to readjust his/her satisfaction as the years of illness increase.

The data obtained on the SIP and SS from the significant others were correlated with their own sociodemographics and selected variables from the clients' sociodemographic data. Several patterns were noted between the variables. First, there were no significant correlations between the significant others SIP or SS scores and the perceived number of chronic illnesses by the client, length of clients kidney disease, "recovery" time required after dialysis, the clients retirement due to health, or disability status.

The clients who did work were perceived by the significant other as less dysfunctional in the following areas: Overall SIP, physical SIP Dimension, psychosocial SIP Dimension, Home Management and the Sleep/Rest scale. Positive correlations were found between those clients who were retired and the same categories listed above except the sleep/rest scale. Table 23 provides the actual correlations between these variables and SIP dimensions.

Table 23

Correlations between the Significant Others responses on the SIP to the Client Variables: Retirement and Employment Status

	Retired	Currently Working
Overall SIP	.53	- .47
Physical Dimension of SIP	.49	- .32
Psychosocial Dimension of SIP	.35	- .37
Home Management Scale	.42	- .35
Sleep/Rest Scale	- .48	- .40

[All correlations are significant at p = .05]

The number of hours on dialysis per treatment was also found to correlate with several of the significant others responses on the SIP. Table 24 provides an overview of these correlations.

Table 24

Correlations between the Significant Others responses on the SIP to the Client variable: Number of hours on dialysis

	Number of Hours on Dialysis
Overall SIP Score	- .32
Physical Dimension of SIP	- .39
Home Management Scale	- .51
Recreation and Pastimes	- .33

[All correlations are significant at p = .05]

The negative correlations indicate that those clients who are on dialysis for longer hours are perceived with less dysfunction in the listedareas by their significant other.

The other sociodemographic variable which correlated with the responses of the significant others on the SIP and SS was the amount of information given to the significant other about the client's illness. Recall from the discussion of the significant other's sociodemographics, that 30% (8 subjects) did not feel that they had received an adequate amount of information about the client's illness. Positive correlations were noted between the significant others responses on the sleep/rest SIP scale (.40, p = .02) the recreation and pastime SIP scale (.40, p = .02) and the amount of information received. The positive correlations indicate that those who perceived a lack of information also perceived greater dysfunction. The amount of satisfaction perceived by the Significant Other was also impacted by the amount of information. Table 25 provides the correlations between the SS and the amount of information received by the significant other.

The negative correlations indicate in Table 25 denote that the satisfaction of the significant other decreased as the amount of perceived information decreased. There were no other significant correlations with this particular variable within the Significant Others sociodemographic data.

able 25

orrelations using Pearson r between the amount of nformation received by SO, and their degree of atisfaction with clients current rehabilitation status

	Amount of Information
verall Satisfaction Score	- .55
hysical Dimension f Satisfaction	- .39
sychosocial Dimension f Satisfaction	- .44
ome Management	- .50
ecreation and Pastimes	- .38

[All correlations are significant at $p < .05$]

Summary

The content within Chapter five provides the tatistical analysis pertinent to the study questions. In ddition, the reliability coefficients of the study nstruments were provided. Data to support or clarify the articular findings were also presented.

Chapter VI

SUMMARY AND CONCLUSIONS

Overview

In Chapter VI the research findings will be discussed. he descriptive statistics of the sample will be presented ith comparisons to other research samples. The nferential statistics will be used to draw conclusions rom the research questions. Based upon these conclusion mplications for nursing practice, education and research ill be addressed.

Sample

The sociodemographic information for the 28 ESRD dyads ncluded age, sex, race, marital status, education, income, nd employment. Additional extraneous variables utilized o describe the ESRD clients included current health roblems, and the prescribed treatment regime. The current ealth status and treatment related variables were also ollected to describe the significant others.

Sociodemographic Data of the ESRD Clients

ge and sex

The sample included 17 males (61%) and 11 females 39%). The mean age for the entire sample was 52.6 years ith a total age range of 29 to 73 years. These figures re congruent with those found by several researchers Gutman,et al 1981, Matthews 1980, Kutner 1980, Friedrich

980, Bruinsma, 1982, and Evans 1982). For the most artmen on dialysis outnumber females by a 2:1, margin Matthews, 1980). This may be due to the greater incidence f illnesses among men which contribute to kidney disease .e., cardiovascular disease (Brundage 1980). In terms of he mean age this would be expected in lieu of the types of nderlying disease processes in this sample i.e. polycystic idney disease, diabetic nephropathy. Such diseases are ommonly found to affect renal function in the mid-life ears. In addition, the mean age of most samples is eflective of the fact that children and adults do not ialyze in the same unit. This is due to the special needs f these age groups. The program at the Michigan ephrology Center is centered strictly on adults.

ace

The distribution of clients between the races in this tudy is in contrast to other research samples. In Evans t al (1982) sample of 347 in-center hemodialysis clients he ratio of whites to blacks were fairly similar (41.9% lack, 54% white), while clients from the home program were onsiderably different (8.6% black, 86.5% white). The iscrepancy noted in the sample obtained for the present tudy, (71.4% caucasian and 28.6% black) could be due to ne subject criteria which eliminated over half of the vailable clients, thereby potentially skewing the emographic data.

arital Status

Congruent with most of the rehabilitation research, he majority of clients in this sample were married 71.4%). Friedrich's (1980) study of 97 hemodialysis lients had almost identical percentages (75% married). gain, due to the subject criteria and mean age of the resent sample, the disproportional number married was xpected. There was very little variation in the type of elationship between the significant other and the client, herefore potential differences in the study variables were ot evaluated.

ducation

The majority of clients in this study had a minimum, 2 years of education (89%) with college education obtained y forty-six percent of the clients. The educational tatus of this sample was higher than that found by Gutman t al (1981), Friedrich (1980), and Evans et al (1982). he clients in their studies were mainly high school raduates with a small percentage citing college reparation. Once again the subject criteria could have nfluenced the proportions found in this study.

Educational level has been correlated to employment tatus by several researchers. Ferrans and Powers (1985), n their study of 20 employed and 20 unemployed dialysis atients (all eligible for employment), found that 75% of hose employed had education beyond high school. Similarly utman et al (1981), also found that employment was orrelated to advanced education. These findings orrespond to those within this sample. Education had a egative correlation to those who were retired due to ealth (r = -.32, p = .05). Although this correlation is ow there does appear to be an association between ducation and those who may have opted for early etirement. The underlying assumption as noted by Gutman t al (1981), and Ferrans et al (1985), is that the types f occupations associated with higher education are ongruent with the physical limitations and time onstraints of dialysis.

ccupation and Income

Only 22% (N = 6) of the clients sampled were currently nployed outside the home. Of the 78% (N = 21) not orking, 61% (N = 13) identified themselves as retired due health reasons, while 23% (N = 5) considered themselves .sabled and 16% (N = 3) reported being retired. iterestingly, 38% of those retired due to health were ients *not* near the typical retirement age (range 41-58 ars). The positive but *low correlation* between age and is variable (r = .37, p = .03) brings forth several estions as to why a middle age adult would identify m/herself as retired from the work force. To remove eself from the work-world may denote the relinquishment past roles often experienced with ESRD. Such a linquishment of the work role may be associated with eir attempt to adapt to the confusing nature of the sick

ole. This inference may be supported by the low atisfaction perceived by the clients ($\hat{x}$ = 2.6) in relation o their ability to work and the negative correlation r = -.36, p = .039) between the sociodemographic data, etired due to health and their work satisfaction score.

Contrasting the age of those retired with clients who dentified themselves as disabled, a negative correlation as found between age and disability (r = -.46, p = .006). his may imply that the younger clients view their present roblems as temporary with the future holding options utside of hemodialysis.

The small percentage of clients in this study found to e currently employed is congruent with other research amples. In Kutner's (1980) sample of 132 chronic emodialysis clients less than 40% of the male dialysis lients and 20% of the female dialysis clients were ctively working outside the home. Ferrans and Powers 1985) found only 23% of the clients from a potential pool f 195 were considered eligible for work, with only half of hose eligible currently employed. Both of these authors ite numerous reasons for the poor employment rates within he ESRD population. One of the most prominent is the isincentives imposed by the current Social Security isability Benefits (Kutner, 1980). Other causes include ime constraints, poor work history, fear of potentiating he illness and psychological apathy (Rounds et al, 1985).

iagnosis of Kidney Disease

Equal percentages of this sample reported the etiology f kidney disease as Diabetic Nephropathy (28%) and olycystic Kidney Disease (28%). An additional 28% did not now the cause of their kidney dysfunction. Evans et al 1982) found in his sample of 364 hemodialysis clients, hat 23% were diagnosed with Polycystic Kidney Disease, and 8.% had Diabetic Nephropathy. Although, the percentages re higher in the clients sampled for this study, the esults are not that unusual. The limitations imposed by he sample criteria most probably effected the large roportion of these two illnesses. The 28% who could not dentify the etiology of their kidney disease is also not nusual. Evans et al (1982) cites the difficulty in omenclature used in kidney disease due to the interrelated ature of the different disease processes.

The majority of clients (82%) in this sample reported nowing they had kidney disease for over three years. nterestingly, no comparisons can be found within the esearch studies critiqued. Most of the demographics nclude length of time on dialysis rather than length of idney disease. Apparently, the focus of most ehabilitation studies and efforts occur after the client s started on dialysis. Such a realization may partially xplain the problems facing the clients and their ignificant others. These findings suggest they may have een trying to cope with the issues of rehabilitation long efore the actual start of dialysis, setting into place neir patterns of adaptation. The ability of the dyads in eeting the challenges presented by ESRD is essential for a rowth-producing relationship. The work associated with SRD begins at the time of diagnosis not at the start of ialysis. This concept is supported by Molumphy and oorakowski (1984) and Rounds and Israel (1985) who infer nat family disorganization begins with the initial iagnosis and assumes a cyclical pattern as the disease rogresses.

Unfortunately, due to the wording of this particular uestion on the Sociodemographic Survey, as well as the vailable time choice offered between length of time on ialysis, and time since diagnosis the ability to ccurately identify the pretreatment period is hampered. though the majority of clients (82%) sampled, reported e time since starting dialysis and the length of their dney disease within similar time frames thereby inferring short pre-dialysis period.

A positive and strong correlation (r .77, p = .001) tween length of kidney disease and time on dialysis was so found. The possibility that most of the clients began alysis at or near the time of diagnosis does exist. This uld not be unusual since kidney disease is often not tected until considerable renal tissue is destroyed. undage (1980) noted that the client may remain ymptomatic until 50% of the nephrons are dysfunctional,

with diagnosis being made through a routine physical.

If clients do start dialysis shortly after their initial diagnosis is made, a number of issues related to the dyads adaptation need to be considered. The ability for adaptation may be seriously compromised by the multiple stressors imposed upon the dyad any point along the continuum. This view of the dialysis experience cannot be examined in this study but will be among the suggestions for further research.

Number of Chronic Health Problems

Unlike the findings of Matthews (1980) the clients age in this study did not significantly correlate with the number of additional chronic health problems. The discrepancy between these variables may be explained by the difference in the type of respondents. Matthews (1980) utilized professional judgement versus actual subjective response to note additional health problems. Quite likely, health providers may associate additional health problems s complications of kidney disease rather than unrelated problems. Unlike clients who may view the problems distinct from each other.

The list of chronic illnesses used in this study did ave association with ESRD, such as arthritis, hyperten- ion, heart disease, and diabetes. Quite possibly the arge number (N = 20, 71.4%) reporting additional illnesses s explained by the fact that the clients viewed them as istinct illnesses not associated with their kidney disease.

The number of reported chronic illnesses in this tudy was congruent with those reported by Evans et al 1982). In his study of 347 in-center hemodialysis clients he average number of co-morbidity factors was 1.55 per lient, correlating to the mean of 1.6 number of illnesses er client in this study. The list of illnesses used by vans et al (1982) could also be interpreted by some as omplications of dialysis versus separate disease entities.

There was no correlation in the subjects of this study etween number of additional chronic illnesses and nployment status, length of kidney disease, or number of ays or hours spent on dialysis. Due to the potential isinterpretation by the client when responding to the umber of additional health problems, further assumptions e limited.

alysis Prescription

The typical dialysis schedule for the clients in this udy was four hours of dialysis, three times a week. This escription is characteristic of the clients sampled by immings, Becker, Kirscht and Levin (1982), Cheek (1982), d Murphy et al (1985).

A number of interesting correlations were noted tween the other sociodemographic data and these riables. A positive but low correlation (r = .34, p=.05) s computed between the number of days on dialysis and ient's who reported being retired due to health. Again, is would corroborate the decision to opt for early etirement from work due to the time impediments of ialysis. Noting the negative correlation (r = -.44, = .02) between number of days on dialysis and income, the ime required for dialysis may indeed be the problem for aintaining paid employment. Ferrans and Powers (1985) ote several reasons for the number of unemployed ESRD lients, one of which is the time needed for treatment. ilver (1980) states that one immediate result of being on ialysis three times a week is that the patient cannot work normal job schedule. This means that one of three things ust occur: reduce working hours, quit working or find a ob that offers a flexible work schedule. The barriers to inding a flexible job or reducing one's work hours are uch that, quitting work all together becomes the best lternative.

Recovery" Time Post Dialysis

The mean number of hours reported by the clients for recovery" after each dialysis treatment was 8.5 hours. nterestingly, 22% (N = 6) reported needing 12 hours to eel better and 15% (N = 4) actually required 24 hours. ere were no available comparisons to other research mples found in the literature. Kutner (1980) did report e mean number of "down" time per male and female clients 12.46 hours, and 11.95 hours respectively. She does not rrelate the "down" time with their dialysis schedule.

Attempts were made to explain the amount of time eded in this sample. There were no significant correlations between the post dialysis recovery time and the client's age, employment status, number of days or hours on dialysis or number of additional chronic health problems. The only significant finding was the negative correlation between recovery time and length of kidney disease (r = -.47, p = .05).

Matthews (1980), found in her study which included 129 chronic hemodialysis patients that their overall adjustment increased over time. She states that clients can adjust to dialysis and incorporate the physical and psychosocial demands into their lives. The amount of ecovery time in this study declined in relation to the ength of the clients kidney failure. Certainly, one might peculate that over time the clients were able to adjust to he physiological changes that occur during dialysis. ther factors which may contribute to the amount of recovery" time required after dialysis include: ompliance of dietary and fluid restrictions, ardiovascular complications during dialysis, anxiety experienced with dialysis, time of day the client dialyzed, r the spacing of dialysis treatments. Unfortunately, none f these potential variables were measured in this study. he most striking significance of this finding though, was he realization that for four individuals by the time they elt better, a dialysis treatment was most likely cheduled.

The following section will be devoted to the interpretation of the sociodemographics of the significant others. The lack of available data from other research samples on the ESRD client's significant other limits the ability to make comparisons to other samples. The demographic data obtained on this sample included: age, sex, race, marital status, education, and occupation. Extraneous variables pertaining to their overall health status and dialysis related activities were also measured.

Sociodemographic Data of the Significant Others

Age and Sex

The significant other's were primarily females (71.4%) with a mean age of 52.2 years. These figures would be expected since the majority of the dyads were married (71.4%). Due to the low proportion of male to female significant others, no attempts were made to identify potential differences in their responses to the study variables. The fact that the majority were females will be considered when discussing the major study variables.

Race

The significant others, like their partners, were primarily caucasian (75%), with the remaining 25% within the black race. These figures were expected due to the relationship between the dyads.

Education

Over 39% of the significant others completed high school, with 43% citing college preparation. Comparing this sample to Hafstroms and Schram's (1984), non-renal sample of wives with chronically ill spouses the educational level is higher. Hafstrom et al (1984), found an average of 13.8 years (N = 37) of education. Molumphy et al (1984) noted an average of 8.9 years in their sample of 20% hemodialysis spouses. The differences noted between samples may be due to sampling bias.

Occupation

Only 43% of the significant others worked outside the home in either full (N = 10) or part-time (N = 2) positions. Occupations ranged from unskilled laborer, to professional positions.

There were no significant correlations between the employment status of the significant other and any other sociodemographics. Further discussion of this variable will be incorporated with the major study questions.

Health Status

The majority of the significant others in this study rated their overall health status as good (60.7%, N = 17). Fair health was cited by 21.4% and 13.7% considered their health as poor. Overall, the significant others who responded did not perceive an affect on their health due to the client's illness. In fact 23% reported that their actual health improved.

The reported increase in health by four of the significant others, might be explained by an acute awareness of personal health risks. They may recognize the importance of maintaining their own health in order to carry out the additional responsibilities assumed due to the client's illness.

The number of significant others reporting chronic health problems (N = 11, 39.%) did correlate (r = .45, p = .010) with a decline in their perceived health. Further, the age of the significant other also correlated to the number of reported chronic illness (r = .35, p = .038). These findings may be typical not only due to their particular age group ($\tilde{x}$ = 52 years), but also in comparison to other research samples. A third of a group of wives (N = 30) sampled by Sexton and Munro (1985), who did not have a chronically ill husband were noted to have a chronic illness. While the wives of the COPD clients not only reported more health problems but rated their overall health lower than the wives of the non COPD sample. No comparisons to a renal sample was available.

Several correlations between the health status of the significant other and the client's sociodemographics were interesting. The number of days the client dialyzed had a positive correlation to the decline in the significant other's health (r =.50, p = .004). A positive but low correlation was also found between clients who retired due to their health and significant others who reported a lower health status. (r = .43, p = .013). These correlations may be partially explained by the fact that the same clients' who dialyzed more per week also had retired early and were older. Therefore, the significant other's were probably older and more prone to developing chronic health problems.

The positive correlations between these sociodemographic data may also be attributed to the difficulties experienced by older adults with chronic illness. Matthews (1982), found that older clients have difficulty with role adjustments and experience more stress in their overall adjustment. Recognizing that ESRD affects the significant others equally, one might hypothesize that the older significant other will also have increased stress. Ultimately, the health of the client's significant other may decline in response to this stress.

Activities Performed For the Clients

The majority of the significant others reported assisting the client in various health-related activities. These activities included preparation of special meals, reminding the client to take their medications, transportation to and from dialysis and monitoring their blood pressure at home. There were no significant correlations between the activities performed and the sociodemographics of the significant others. Finding the high percentage of significant others who assist the client would not be that unusual, especially since the majority of significant others were females.

Diamond (1979), notes that the client's family is often the first provider of care. Responsibilities may be delegated to the significant others by both the client and the health team. De Nour et al (1980) and Rounds and Israel (1985), have found that the client often assumes that his/her significant other is a partner in their health care. The client may wish to foster a dependent role on the family to help buffer the overwhelming losses associated with chronic illness.

The significant other may respond generously to the client's needs. Given the opportunity to perform specific tasks the individual may initially feel less stress and in a sense relief. Problems arise though, when the significant other is not relinquished of the care taking role. The situation may be such that the significant other now feels controlled by the illness. Personal time infringements may ultimately impede upon the significant others social network limiting the support he/she needs.

A significant negative correlation was found between the number of activities performed and the length of time the client had been on dialysis (r = -47, p = .005). This would indicate that the client either becomes more independent in time or the significant other begins to relinquish, care responsibilities the longer the client is on dialysis. Such a situation may occur when the significant other does not see a benefit of the activity to the client's health or tires of the chronicity of care requirements.

Finally, a positive correlation was noted between the number of performed activities and the clients who had a number of chronic illnesses (r = .31, p = .05). For the most part, this low correlation would be indicative of the increased dependence on others in relation to the number of client illnesses.

Information Received

The majority of the significant others (70%, N = 20) felt they had received adequate information about the client's illness. Those who did not feel they had received adequate information (N = 8, 30%) had no significant correlations to the other sociodemographics. This particular variable will be discussed in greater detail later in this chapter. Inferences will be limited due to the wording and response menu of this question on the sociodemographic survey.

Implications of the Sociodemographic Data to Nursing Practice and Education

Several areas within the client and significant others' demographics must be considered in advanced nursing practice. The nursing process is dependent upon the assessment of the individuals prior to the planning and rendering of nursing care. The Clinical Nurse Specialist (CNS) must consider the variables which influence the perceptions of the individual. In view of the complex nature of man the number of variables which influence the individuals perceptions is also complex. The sociodemographic data of the clients and their significant others were found to have several interrelationships. Each correlation provided a clearer profile of the ESRD dyad. Ultimately, these profiles will serve as a guide to identifying those individuals who are at risk in adjusting to ESRD. Such information, can be used to direct the energies of the CNS towards those clients and their significant others.

In addition to the assessor role, the CNS must model both the methods and necessity of obtaining an adequate profile of the client and their significant other. Through role modeling, the CNS will have the opportunity to demonstrate to other health care workers how to individualize their own assessments based on key high risk factors. Often times, the health providers in chronic care begin to approach their care in a set pattern regardless of the client profile. In time generalizations are made based on limited data resulting in, interventions that are limited and frustrating. This scenario was apply described by Diamond (1980), who noted the essence of chronic care beginning with assessment of the dyad.

Finally, the CNS must educate fellow health workers on the complex nature of man and his/her response to chronic illness. The educational process may occur through both discussion and the written assessment. Furthermore, the emphasis on family versus client assessment must begin in the academic setting. All levels of nursing education need to focus the basis of interventions on a theoretical framework derived from the family assessment.

King's (1980), nursing theory was utilized to develop the theoretical framework of this study. The pictorial representation (See Figure 3) included a list of intervening variables under the client and the significant other. These lists may be misleading due to their limited nature. Each variable is only one potential modifying factor influencing the individual's perception. Recalling from King's (1981), theory, perceptions are derived from an individual's awareness of persons, objects and events in relation to their own self, body image, time and space. The variables as cited in the current framework are incomplete. The following change to the nursing model will avoid any mispresentation of the types of variables which must be considered with ESRD.

Under the client, the influencing variables should include seven broad categories: Personal Characteristics, History of Chronic Illness, History of the Dialysis Prescription, Concurrent Health Problems, Current Social and Family Roles, and a financial profile. Certainly, one researcher could not incorporate each variable into one research study, but, readers can recognize the possible number of intervening variables. Through this addition, interpretation of research findings will be made easier.

The influencing variables listed under the significant other also need to be replaced with five broad categories. These would include: Personal Characteristics, Health History, History of Family and Social roles, Relationship with the Health Care System and current knowledge and expectations of the client's illness. Again, the purpose of the broad categories is to depict the numerous variables involved in the significant others perceptions. Nursing education must provide the theoretical framework of the complex nature of man and his/her response to illness.

Implications of the Sociodemographic Data to Nursing Research

The revision of the nursing model as suggested, will serve as a cornerstone for future research. Each of the intervening categories must be critically examined in relationship to each other, to assist in identification of high risk factors. Further, evaluation of nursing interventions aimed at modifying one of the variables will be made easier.

Several modifications are necessary on the sociodemographic survey used in the study. The changes are due in most part to the difficulty found in interpretation of the responses. On the client's survey (See Appendix E), the following questions require clarity in either the stem or the response menu:

Question #14

The response menu should be altered so that the time intervals are mutually exclusive and more specific, i.e., less than 6 months, six to 11 months, 12 months to 24 months.

Question #13

The stem should read, how long did you know of your kidney disease before starting on dialysis. The response menu should also be more specific as noted in question #14.

Question #16

Modify the stem to read, chronic illnesses not associated with kidney disease.

Question #7

Homemaker should be added to the response menu.

In addition, the following information should be included in the sociodemographic survey:

Number and types of complications during and after dialysis.

and

Retirement age

Although these changes will not encompass all of the influencing variables they will improve the interpretation of the current survey.

On the significant other's sociodemographic survey the following changes are recommended:

Question #7

Homemaker should be added to the response menu.

and

Question #15

> The stem should include a time frame such as, currently have you received enough information about the client's illness. The response menu should then be made more specific.

Again, these changes would only clarify the variables which have been selected from the broad categories.

Finally, through the identification of a broad client profile and potential risk factors, nurses can design their research methodology more appropriately. As with this sample, a number of potential subjects did not meet the study criteria due to physical limitations such as poor eye sight. In retrospect, an interviewer administered design would have been more conducive to these subjects. One of the main problems noted by Osberg, Meares, McKee and Burne's (1980) in the ESRD research, is the small sample sizes. Quite possibly researchers have failed to recognize the limitations imposed by their study criteria.

Interpretation of The Major Research Questions and their Sub-Parts

The next section will be interpretation of the major research questions and their sub-parts. Since the sample was limited in size and convenience in nature, no generalizations to the population can be made.

Perceptions of Rehabilitation: Question I, Ia, Ib, and Ic

Question I

> What is the degree of perceived congruence between the hemodialysis client and his/her significant other regarding the client's rehabilitation status?

A positive correlation (.47, p = .006) was found between the overall SIP scores of the client and their significant others. This highly significant correlation would indicate that the perceptions between the dyads are moderately congruent. Each perceived the client's current dysfunction in a similar direction. Since the overall score is a composite of the dimensional SIP scores, the moderately low correlation was not unexpected. This will become clearer as the dimensional scores are discussed.

Question Ia

> What is the degree of perceived congruence between the client and his/her significant other on the physical dimension of rehabilitation?

Again, a positive correlation (.75, p = .001) was found between the dyad in relation to the perceived physical dysfunction. This correlation with it's strong significance level reflects a high degree of congruence between the dyad. The ability to see physical dysfunction is supported by the work of Landsman (1979), and Falvo, et al (1982). Disabilities that are readily observable offer the client environmental feedback.

An interesting comparison of the perceptions of a non-renal group of chronically ill clients and their spouses can be found in Foxall, Ekberg, and Griffith (1985) study. Using a variety of chronic illnesses Foxall et al (1985) found that spouses perceived less physical dysfunction then their chronically ill partner. Foxall et al (1985) noted that the spouses could either not objectively evaluate their partners or did not want to "see" them as disabled.

<u>Question Ib</u>

> What is the degree of perceived congruence between the client and his/her significant other on the psychosocial dimension of rehabilitation?

The correlation computed between the scores of the clients and their significant others on the psychosocial dimension (.14, p = .22), did not reflect a significant degree of congruence, between members of dyad. Clients perceived more dysfunction on the social interaction scale while the significant others perceived more dysfunction in the client's emotional and alertness behavior.

The components of this dimension have been well documented in the literature as problematic for ESRD clients and their significant others. Falvo et al (1982), cites the difficulties in recognizing limitations outside of those that are directly observable. The discrepancy between the dyads in this study may have resulted from the difficulty in evaluating one's own behavior. The types of questions included in the psychosocial dimension, called for some amount of introspection on part of the client. Since, the client was given limited time to complete the survey, this may have affected their response. Furthermore, difficulty may ensue in trying to evaluate one's behavior in their own social system. This would help explain the fact that the clients perceived less dysfunction in their emotional and alertness behavior. The significant other being on the receiving end of the behavior, may be in a better position to evaluate the client.

The lack of a significant relationship between the perceptions of the dyads in these areas may affect their patterns of interaction. Speidel et al (1981), found that dialysis partners tended to avoid disputes, withdraw from quarrels and frequently agreed with the client's opinion. If the partner does not have a social outlet for anger, he/she may experience more anxiety and depression.

In terms of the client's social interaction, the significant others perceived less dysfunction than the clients. The questions in this scale surround the amount of time the client engaged with other people. Quite possible, the significant others included the client's time spent dialyzing, in a social sense.

The changes in social activities is not an uncommon finding in dialysis samples. Numerous authors have found that the amount of time spent with others is significantly lower than pre-dialysis (Kutner, 1980; Evans, 1982;

Bruinsma, 1982). Rounds et al (1985), states that the change in social interaction may be self-imposed as well as due to the time commitment for dialysis. Loss of social contact often occurs because individuals may not have enough energy to spend with others. Those who have lost jobs no longer have contact with co-workers. The end result for many ESRD clients can be a change in or shrinking of their social network at a time when support is most needed.

Examination of the subjects sociodemographics provides nursing the opportunity to identify clients who may be at risk for dysfunction in the psychosocial dimension. In this sample the client's who reported having additional chronic illnesses had more psychosocial dysfunction ($r = .53$, $p = .05$). The problems imposed by other chronic illnesses may only compound the emotional adjustment. A "wearing" down effect is quite possible, leaving the client with a feeling of depression and hopelesness.

In addition the significant others perceived clients who were <u>retired</u> with a greater pyschosocial dysfunction area than those who were currently working. The association between the client's retirement and the perceptions of the significant other can be interpreted in several ways. One of the most common findings is the difficulty in adjustment of the older adult (Matthews, 1980). Since there was a moderately high correlation between retirement and age (.63, $p = .001$) this explanation may be valid. Secondly, the difficulties of retirement often experienced by individuals may only be compounded with the losses associated with a chronic illness. In either situation these variables will provide nurses with strategies for intervention.

Question Ic

> What is the degree of perceived congruence between the client and his/her significant other on the rehabilitation dimensions of work, sleep/rest, eating, recreation and pastimes and home management?

These scales were utilized to measure the clients' gainful activity. Congruent with the literature, these areas had the greatest degree of dysfunction.

The perceived dysfunction on the SIP Scales of sleep/rest, home management, and work had a moderate degree of congruency between the members of the dyads. Two of the areas, recreation and pastimes and eating, did not have significant correlations between dysfunction scores.

The high dysfunction scores noted in the sleep rest scale has been well documented by other researchers (Kutner, 1980; Friedrich, 1980; Ferrans et al, 1985; and Bruinsma, 1982). The underlying etiology has been attributed to the client's low hematocrits as well as a symptom of the depressed nature of these clients. In either situation, the problem appears to be fairly universal and cited as distressing in other research samples (Kutner, 1980).

Interestingly, both the sleep/rest scores of the clients and their significant others were significantly correlated to their individual physical dysfunction scores. In fact the significant others scores had a high correlation ($r = .73$) that was significant at the $p = .001$ level. The implication of these correlations is that increased physical dysfunction is associated with sleep/rest disturbances. The sleep/rest scores from the significant others also had a high correlation to their scores on the psychosocial dimension. The significant others may associate the client's sleep/rest disturbance with impediments to social interaction and a cause of their altered alertness and emotional behavior. Finally, the significant others perceived less dysfunction in the sleep/rest category in those clients who were either retired or currently working. The potential explanation for this may be that in either case, the client is less fatigued due to relinquishment of the breadwinner role or is less fatigued thus able to work.

Home management was the highest ranked area of dysfunction by the clients, where as the significant others ranked sleep/rest disturbance above home management. Again, dysfunction in this area is not unusual as noted by Kutner (1980), Bruinsma (1982) and Diamond (1979). The problems have been attributed to both fatigue, lack of time, and relinquishment of usual roles. In this sample, since the majority of clients were male, dysfunction in home management may reflect their inability to do the heavier chores often associated with the male role.

Interestingly, from the client's perspective the number of chronic illnesses, amount of time needed for recovery after dialysis, and age, all had positive correlations with home management, while length of kidney disease was negatively correlated. Again, the data provides further evidence that the longer the client is on dialysis the less amount of dysfunction is noted. Yet, the one area of the client's life most apt to be affected by the treatment process is their home responsibilites. In addition, correlation of the clients scores between home management and the psychosocial dimension of the SIP were correlated in a positive direction. This would suggest that the clients who do not or cannot perform their usual home roles may be experiencing greater emotional turmoil. In relation to their perceived difficulty is the stress which may be experienced by their significant others.

The significant other also perceived dysfunction in the area of home management. Although, the scores were slightly lower than the clients, they also had positive correlations with both the physical and psychosocial SIP dimensions.

The underlying question becomes, how have the significant others responded to such a situation? Most likely, they have assumed the responsibility for the home

management roles usually performed by the client and equally have had to contend with the client's behavioral changes, or found others to do it making client feel even less helpful. Since the correlation between the significant others Home Management scores and the physical dimension was high ($r = .83$, $p = .001$) could the significant others be perpetuating the sick role. Levy (1979) cautions ESRD health care providers in being alert for situations in which family roles are readjusted to the detriment of the client's self-image.

One last finding which may provide more insight into the home management area is the correlation between number of hours on dialysis and the amount of dysfunction perceived by the significant other. For the most part, the significant others perceived less dysfunction with increased hours on dialysis. Brundage (1980), has cited that a range of efficiencies is possible with dialysis therapy. Clients who dialyze longer may have better clearances, thereby experience less physical dysfunction and able to carry out some response. Most clients do not opt for longer hours despite this fact. Increased dialysis time may be associated with greater dependency and restriction of freedom.

The recreation and pastimes dysfunction scores between the clients and their significant others were not significantly correlated to each other. Despite the lack of a relationship, each perceived a high amount of dysfunction in this area. Based on the literature, the reduced recreational orientation experienced by clients has been consistently cited as a stressor (Hastings, 1982; Kutner, 1980; Bruinsma, 1982; and Friedrich, 1980). The possible explanations may include lack of time, reduced social network, fatigue or inability to partake in the more strenuous activities once enjoyed.

The absence of a significant correlation between the dyads in lieu of mutually high dysfunction scores is puzzling. One explanation could be the disparity of perceptions in this area between the dyads even before dialysis. Quiter possible, each member of the dyad had their own activities not shared.

The amount of dysfunction perceived by the clients and their significant others in the clients's functioning at work also correlated. This result was somewhat surprising in lieu of the expressed difficulty by the significant others in evaluating the client's in this area. Indeed the other surprising fact was the low amount of perceived dysfunction. Possibly, the computed dysfunction low due to the number of employed clients thereby, not reflective of the true impact of ESRD on work performance. Equally, the negative correlation between age and the work scale indicates that those who were younger had less dysfunction at work.

The other two scales, eating and communication, had scores of less than 10% by both the client and significant other. These scales were not truly applicable to the dialysis sample. For example the eating scale gave dysfunctional scores for being on a special diet. In this population, a special diet is part of the treatment program and should not be considered dysfunctional. On the communication scale, the subject criteria ruled out those individuals who would have had difficulty with many of the items. Due to these reasons, the findings on those scales will not be discussed.

Implications of Question I, Ia, Ib, and Ic to Nursing Practice and Education

Kings' (1981) theory of interacting systems was found to provide the structural framework needed for study question I, Ia, Ib, and Ic. Although only a small portion of the model was tested, the data can be applied to the entire framework for development of nursing interventions.

Theiss (1982) identifies the critical nature of exploring perceptions as the first step in the nursing care of ESRD dyads. Noting that perceptions are time specific, the rehabilitation data collected in this study were specific to the dyad's time interval on dialysis. Therefore, the congruency or lack of between the dyad members was a result of past reactions, interactions and transactions.

Such information provides the nurse with insight on the types of issues the dyad has previously dealt with and those presently facing the dyad. Further, by noting the

significance of the moderating variables, the nurse may be able to detect those dyads who are at high risk for dysfunction. After identifying the perceptions of the dyad's members, there will be a clearer understanding of the reactions and interactions occurring between the dyad. Through this assessment process, the dyad can be assisted in recognizing their differences. Mutuality can then be developed and energy directed towards optimal rehabilitation.

An additional goal of the nurse should be to teach effective communication techniques to the dyad. Role modeling of open communication will allow the ESRD dyad opportunity to explore new ways of managing their differences. Such an intervention was supported by Hastings (1985) who found improvement.

Despite the fact that length of time on dialysis and length of kidney disease were not found to consistently correlate with the dyad's perceptions of dysfunction or satisfaction these variables are considered as critical components in rehabilitation (Rounds et al 1985). The process of rehabilitation begins at the time of diagnosis and continues in a cyclic fashion over the years. Recognizing this fact, the nurse must develop strategies to foster mutuality before the start of dialysis. One such intervention would be the development of a pre-dialysis education program. In this environment, clients and their significant others can learn about kidney disease and begin

to explore the impact of ESRD on their lives. Favoring such a program is the benefit derived from social interaction with other couples.

Up to this point the nursing interventions developed have been focused on perceptions of the chronic illness. Often, the entire area of health promotion is neglected, due to the overwhelming problems of ESRD and dialysis. From the data collected in this study, additional health problems were found to correlate with increased dysfunction. The compounding problems of complications from dialysis as well as from other diseases is discouraging to both members of the dyad (Evans, 1982; Rounds et al 1985). For this reason the nurse must not neglect health promotion activities when rendering care to both the client and their significant other.

Since the majority of nurses practicing within the ESRD health system are not in advanced practice, continuing education is essential. Considering that generic nursing education is primarily centered around acute care, most nurses have not been well-prepared to work with chronic illness. The shifting of health needs from acute episodic care to outpatient chronic care mandates a knowledge base of adaptation, compliance, and theories on role and loss (Foxall et al 1985, Corbin et al 1984). Such information must be integrated into generic nursing programs.

Current nursing staff should be offered courses and seminars focused on rehabilitation of the chronically ill

adult. Essential information will be needed in interviewing and counseling techniques, and the pathophysiology of ESRD.

Finally, nurses must be encouraged to explore their own perceptions of rehabilitation in lieu of the theoretical frameworks available for chronic care. Only through this process will nurses be able to provide the vital link to transactions in Kings (1981) theoretical framework.

Implications of Question I, Ia, Ib, and Ic to Nursing Research

The optimal research design for studying rehabilitation in ESRD client's and their significant others would be longitudinal. Rehabilitation is a process with distinct phases over a period of years. Several researchers have identified certain problems intrinsic within each period and the relationship to adjustment (Rounds et al 1985, Levy 1979). Therefore, longitudinal research as well as time specific studies are needed to help guide intervention of the health team for optimal rehabilitation. The SIP would be an appropriate measure for a study with multiple administration over time to the same population. Gilson et al (1975) recommends repeated administrations of the SIP as a basis for evaluating health interventions. In essence, the SIP dysfunction score would be expected to change in relation to the treatment plan.

Research should also be conducted in which the perceptions of the client, significant other and the primary health provider are correlated. Such investigation is essential based on the relationship between the perceptions of the nurse and the dyad in King's (1981) theory. Supporting the inter-relationship between these individuals are Rounds and Israel (1985), and Anger and Anger (1974).

In terms of the usefulness of the SIP in the measurement of rehabilitation of the ESRD client, several considerations must be noted. The scale on eating must be altered in relation to being on a special diet. Most chronic illnesses especially ESRD are associated with dietary recommendations which should not be considered dysfunctional. Portions of the scale in the physical dimension and the communication scale were not found to be applicable to ESRD clients. For the most part these areas were not affected by ESRD which was also reflected in Bruinsma's (1982) study. Therefore, selected scales may be more appropriate, discussion of tool revisions time in other correlating issues.

Perceptions of Satisfaction: Question II, and IIa

Question II

What is the degree of perceptual congruence between the client and his/her significant other regarding their satisfaction with the client's present rehabilitation?

The entire discussion on the results from the satisfaction scale must be precluded by the weaknesses of the scale despite the acceptable alphas computed. The individual questions representing each SIP scale are very broad. Interpretation could vary between individuals on the meaning of each area. For example, the client's present emotional behavior could imply the amount of depressive behaviors to amount of expressed overt anger. For this reason only broad inferences will be possible.

The second potential weakness is in the possible responses available. The scale is limited in the ability to finely discriminate the amount of satisfaction. The "mixed" response may be appropriate for the types of broad questions included in this satisfaction survey since a range of activities are incorporated in each statement. The subject may have different degree's of satisfaction associated with the various components, thereby having an overall mixed level. This area will ultimately require further evaluation to determine the components and their associated degree of satisfaction. In addition to the difficulties with interpretation, equal problems are found in comparing the satisfaction scores of this survey to the scores of other more specific scales. Recommendations will be offered later in this chapter for tool revisions.

Not surprising was the finding that the ESRD dyads are fairly satisfied with the client's overall rehabilitation ($\bar{X} = 3.64$ for Clients; $\bar{X} = 3.73$ for S.O.), the moderate yet positive correlation (.61, $p = .005$) between their satisfaction scores. Speidel et al (1981) found similar results between ESRD couples in their study. They also note that the ESRD couples sampled perceived greater satisfaction then the non-renal dyads. The perceived quality despite dysfunction is evident from nearly all the studies reviewed.

Stegman et al (1985) used the SASS, an 11-rung self-anchoring scale, in their study and found the dialysis clients rated their satisfaction above average. Comparing their findings to the recent SASS reports from osteo-arthritic patients ($\hat{X} = 5.2$), and coronary by-pass patients ($\hat{X} = 6.58$) and the U.S. sample in general ($\hat{X} = 6.6$), ESRD clients have substantially higher scores. This does indicate the overall resilience and adjustment to the ESRD (Stegman et al, 1985).

The two dimensional satisfaction scores, physical and psychosocial, between the dyad members also had positive correlations. Again this indicates a moderate degree of congruence between the client and significant other. In addition, all of the questions corresponding to the areas of gainful activity, except communication and emotional behavior had positive correlations between the dyad members.

The moderating variables of the clients which were negatively associated with their overall satisfaction included number of chronic illnesses and recovery time post dialysis. In addition the number of additional chronic illnesses correlated negatively to several satisfaction scales: physical dimension, eating, recreation/pastimes, and home management. The satisfaction in relation to additional chronic illnesses may have been judged by the client how he/she was prior to the additional burden of ESRD. Unfortunately, the information regarding addtional health problems obtained on the sociodemographic survey was not specific enough to substantiate this conclusion. The number of additional illnesses was not found to impact the clients perceived satisfaction in Evan's (1982) study. Once again, the discrepancy between complications and actual chronic illnesses interfere with interpretation. Furthermore, the amount of recovery time had negative correlations significant at .05 with all the areas of gainful activity except communication. This may imply that these areas are the most valued and any amount of dysfunction is perceived with less satisfaction.

The length of kidney disease had a postive correlation between the client's response on the satisfaction questions: eating, sleep/rest and home management. Several reasons for this association are possible. Clients, through time are able to make comparisons of where they were to where they are now. The dietary restrictions become easier to manage and more routine, thereby increasing satisfaction. The amount of time spent sleeping or resting may change as the client adjusts his/her lifestyle to a less strenuous level. Possibly, the significant other may have reduced the demands, and encouraged the client to "take it easy". This would decrease the client's anxiety, facilitating satisfaction. Such a scenario would also explain the satisfaction with home management as the clients length of kidney disease increases. Unfortunately, the lack of specificity in the sociodemographics in this area impedes further assumptions from the study data. The findings in this study are similar to those of Kutner (1980), in which she found that long term clients (< 4 years) were generally more satisfied than short term clients.

The sociodemographics of the significant other also provide valuable insight into their satisfaction. The one area which was found to associate with their overall, dimensional, home management and recreation/pastimes satisfaction scores was the perceived amount of information regarding the client's illness. Adequate amount of information correlated with more satisfaction in these areas. Although, there are no comparisons available to other samples, the importance of education for the significant other was noted by Rounds et al (1985), Matthews (1980) and Hastings (1984).

Due to the lack of specific data obtained on this variable broad inference can only be surmised. The significant others may have expected dialysis to reverse the client's dysfunction. Often, they are told by the health team how effective dialysis is for survival. Not having experience with chronic dysfunction, the significant other may have had higher expectations. The amount of interaction the significant other had with other dialysis dyads may also be the point of reference used for determining satisfaction. Comparisons may be made to other dyads, with dissatisfaction resulting from perceived lack of information on the client's ability. Matthews (1980), found the spouses in her study requested honest answers about the client's illness. The apparent lack of trust or amount of information received will be a key point for nursing interventions.

Further, the areas which were perceived with more dissatisfaction in relation to information, could have a direct impact on the role changes and responsibilities assumed by the significant other. The crucial questions which would help to explain these correlations are: from whom does the SO receive information, was information given but not received, and how satisfied are the significant others with _their_ _own_ quality of life.

Finally, the satisfaction perceived in the clients physical abilities by the significant other was negatively correlated to the number of activities they performed in the client's care. The low but significant correlation ($r = -.36$, $p = .03$) may be interpreted and partially explain the problems associated with the chronicity of care requirements. The significant others may attribute the physical limitations as the most interfering or cumbersome facet of ESRD. This is further supported by the absence of a significant relationship between activities performed and the other satisfaction dimensions.

Question IIa

What is the correlation between perceived congruence on the dimensions of rehabilitation, and their degree of perceived satisfaction with the client's rehabilitation status?

The amount of disagreement between the dyad on their Overall SIP and Psychosocial SIP dimension Scores was correlated with the amount of disagreement between their overall satisfaction and psychosocial satisfaction scores. This denotes that the amount of disagreement between the dyad on each of those SIP scales was similar on the correlating satisfaction scales. Therefore, a relationship between the amount of dysfunction and the amount of satisfaction can be implied.

The disagreement scores from the other two dimensions, physical and gainful activity, were not found to correlate between members of the dyad. Basically, these results would not be that unusual even though similar comparisons to other samples are not available.

Satisfactions are determined differently between individuals (Campbell et al 1976). The amount of perceived disruption imposed by the dysfunction on their individual trajectories may well be different (Corbin et al, 1984). In this sample the significant others and clients perceived significant dysfunction in the client's participation in

recreation/pastimes. Yet, the significant others were more satisfied than clients who perceived the amount of dysfunction with less satisfaction. These differences may stem from the perceived impact on their own lives. The significant others may have more satisfaction, since the clients actually experience with more intensity the loss of usual activities.

Similarly, the amount of perceived dysfunction between the dyad in the client's social interaction was less from the significant others view point. Despite less dysfunction, the significant other's were more dissatisfied than the client in this area. Quite possibly the lack of client social interaction directly impacts on the social outlets for the significant other. Interestingly, the area of home management also presents discrepancy between dysfunction and satisfaction. The significant others were more dissatisfied than the clients despite congruency between their SIP dysfunction scores. This presents another example of the outcome of additional responsibilities which may be placed on the significant other. The client may have adjusted their own satisfaction in the area of home management in relation to the renegotiated role responsibilities.

Several pieces of additional data not collected in this study would have helped to explain these relationships. The satisfaction with the client's ability in each of these areas prior to the onset of kidney disease

and dialysis would offer greater comparability. Also, the individual interpretation of the satisfaction areas may have been so different that the relationships are not real.

Implication of Question II and IIa to Nursing Practice and Education

Identifying the current satisfactions within the ESRD dyad, provides the nurse with numerous avenues for intervention. Kutner (1980) cites that personal satisfaction incentives must equal or exceed the benefits currently experienced by the client. Intimately, linked to satisfaction is the concept of motivation which is the driving force behind change (Anger and Anger, 1974). These two concepts must be incorporated by the nurse when working with the ESRD dyad. The first step, as noted in the theoretical framework of this study, is to identify current perceptions of satisfaction. Together with perceived dysfunction the individuals then make judgments for or against change. The data from this study clearly supports that dysfunction does not have a perfect correlation with satisfaction. Neglecting to assess for satisfaction will impede mutual goal setting for rehabilitation.

Several nursing interventions can be identified from the data and supporting literature obtained from Question II and IIa. Information was found to be a key variable in the satisfaction of the significant other. Supporting this need was the research findings of Matthews (1980). She found the significant others to be sorely neglected both in

support and education. The nurse must first recognize that the ESRD dyad is the recipient of care, not just the client. A trusting relationship between the nurse and each member of the dyad should be carefully established and nurtured. Continual assessment of the dyad both together and separately must be maintained in order to meet their educational needs. Education on the disease process, options for treatment, management techniques and typical coping issues are to be centered on the dyad.

The nurse must continually be aware of the risk factors which may predispose the dyad for incongruent satisfactions. Some of these are: the number of chronic illnesses/complications, "recovery" time required post dialysis, and length of kidney disease. The first two listed factors may lend themselves to simple adjustments in the dialysis schedule or prescribed regimen. For example, clients who require eight or more hours after each dialysis for "recovery" may find an evening schedule less imposing on their "free" time.

The educational process for nurses must include groundwork in family and role theory in relation to chronic illness. Theories on motivation would also be beneficial for developing nursing interventions. Further, the critical nature of the assessment process must not be underestimated in generic or advanced nursing education. Nurses must take personal responsibility to keep abreast of assessment and communication techniques. Especially in

chronic illness where the intensity of client interaction becomes demanding, nurses must not forsake their commitment to individual holistic care for routine technical service.

Implications of Question II and IIa to Nursing Research

The concept of satisfaction as applied to King's (1981) model lends itself to further nursing research. Longitudinal studies are needed to identify how satisfaction in conjunction with dysfunction changes over time. Such studies must be started <u>prior</u> to the initiation of dialysis, thereby affording the opportunity to compare previous levels of satisfactions. Dyads who were dissatisfied with role responsibilities prior to dialysis may find the additional burdens of dialysis unmanageable.

Nursing research should also be focused on evaluating interventions for increasing satisfaction. Hastings (1982) did find that support groups for the ESRD dyad were beneficial for overcoming dysfunction and improving upon the family current functioning. Theory based interventions will only be made possible through such research efforts.

The disparity between quantity and quality in defining rehabilitation in the ESRD population will hinge on the availability of current research. Gutman's et al (1980) initial findings of a debilitated ESRD population has since been refuted. Quality of life does remain within acceptable standards and therefore must be incorporated into the definition of rehabilitation.

The study instruments used to measure satisfaction in this study need to be revised for future research. The scale items need to be expanded, so to include several statements per scale. This would provide a more discriminant tool for comparison to the SIP scales. Secondly, the response set should be expanded to a seven point scale. Campbell et al (1976) utilized the following possible responses in their survey on the quality of American life: very dissatisfied, dissatisfied, somewhat dissatisfied, neutral, somewhat satisfied, satisfied, and very satisfied. This particular response set is the recommended change for the Satisfaction Survey.

Modifications to the Theoretical Nursing Framework

Throughout this chapter references have been made to the nursing theoretical framework used in this study. The original framework developed in Chapter Two, was not found to adequately depict the multidimensional nature of ESRD. In Figure 5, the revised model is shown with the appropriate expansion of the moderating variables. From this revision nurses will be able to note easily the complexity of variables which may alter perceptions. As previously indicated, nursing research must be carefully designed so to include elements from the moderating variables. Interpretation of subsequent research findings can then be made in relation to those variables not included in the design.

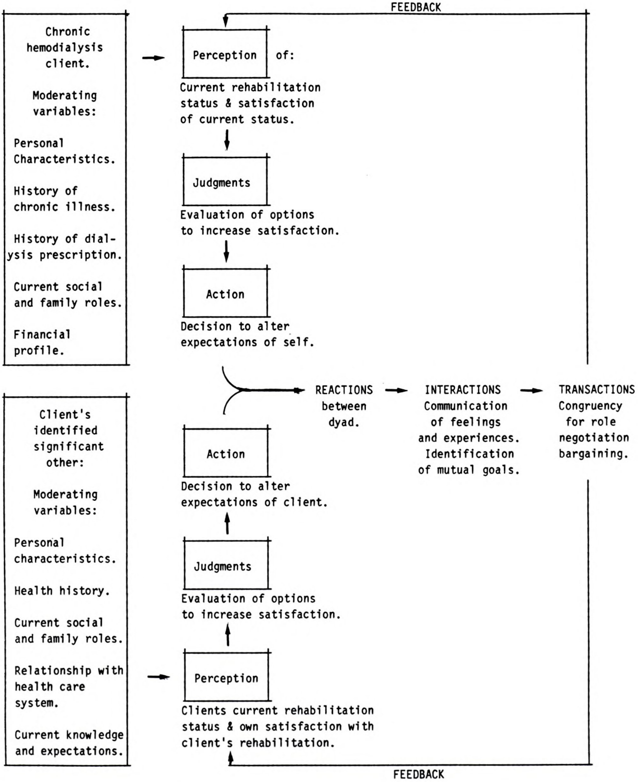

Figure 5. Modification of King's Theoretical Framework

The nursing component also needs to be added to the theoretical framework. Figure 6 is a pictorial representation of King's (1981) model with the nursing component. Although not depicted the nurse also has several moderating variables which will influence his/her perceptions such as: educational background, (both formal and informal), work history, philosophical framework of nursing, and personal characteristics. The solid arrows on the framework from the nurse to each member of the dyads is meant to indicate the direct nursing relationship. Several options are available to the nurse, once the initial assessment of the client and significant other is completed. The nurse may opt to interact with both members of the dyad together or individually if appropriate. Regardless, the resulting feedback from the interaction/transaction will always affect both members of the dyad. This fact must not be negated when individual interventions are chosen by the nurse.

King (1981) identifies several exterior boundaries in her theory of goal attainment: Interactions occur in a two-person group, are limited to a licensed professional nurse and occur in natural environments. The first boundary is a limitation in applying her theory to an ESRD dyad. Such a limitation does not dismiss the appropriateness of the other interrelated concepts in Kings's (1981) theory. Rather, through continued testing of the model via nursing research, the model may be revised to include the client's significant other.

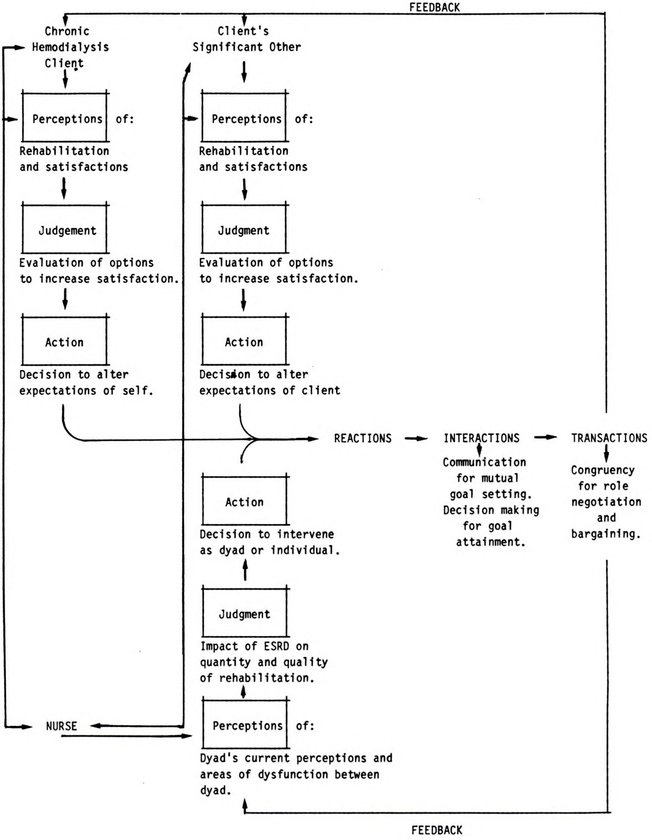

Figure 6. Addition of Nursing to King's Framework

Summary of Nursing Implications to Practice and Education

The nurse in advanced practice will be a valued member of the ESRD health team. Bringing a variety of theory based interventions and expertise in family assessment the CNS will be influential in promoting rehabilitation. Through role-modeling, consultation, collaboration and direct education, the dialysis staff will emulate the CNS creating an atmosphere conducive for transactions.

The key to nursing interventions is a thorough assessment of the ESRD dyad. Awareness of satisfactions in relation to dysfunction should be incorporated into the interactional sequence of King's (1981) model. Through this assessment process the nurse will be able to make inferences to previous interactions between the dyad.

Several suggestions were made throughout this Chapter regarding the need for formal and informal nursing education. In summary, the generic programs can no longer focus attention solely on acute illness. The changing health care needs will require a base knowledge of chronic illness for effective interactions. Nurses must be encouraged to advance their knowledge base through continuing education. Supportive courses in the theories of family, role, and loss would broaden the scope of nursing interventions. Finally, through continuing education, nurses will gain a greater perspective of their own perceptions and potential influence on clients/ significant other interactions.

Recommendations for Future Research

Certain implications for further nursing research may be drawn from this study.

Replication

1. Replication of this research study is recommended only after revisions are made to the sociodemographic and satisfaction survey. The proposed changes in these tools were outlined earlier in this chapter.

2. Replication incorporating several dialysis centers in order to obtain a larger sample size.

3. Replication using the interviewer administered SIP and Satisfaction Survey, thereby broadening the criteria for subject inclusion. This would be most appropriate in light of the number of ESRD clients with limited eyesight.

4. Replication across time with the same group would add to the findings. Such research must begin at time of diagnosis not with the first dialysis.

5. Replications using another chronic disease sample would provide useful information on the differences in perceptions among various chronic illnesses. Further, research using the SIP for both clients and their significant others will lend support to it's usefulness in such a manner and provide comparison for dysfunction scores.

Expanded Research

1. Selected dimensions and scales of the SIP could be utilized in conjunction with a more in depth satisfaction survey. The narrowed focus would permit the researcher to explore in more detail the moderating variables, without infringing on the subject's time. The eating scale of the SIP is not recommended for future ESRD research due to the inappropriateness of the statements. The reliability and validity of the SIP does remain stable when selected scales are solely used.

2. Each of the moderating variables provide direction to future research. Efforts to identify the critical components within each variable will support nursing interventions.

3. The perceptions of the nurse in conjunction with those of the ESRD dyad would provide a clearer picture for rehabilitation. Nurses must increase their own awareness of the impact they have on client outcomes.

4. Research should be conducted which compares and contrasts those ESRD clients who live with someone and those who live alone. It would be interesting to not only compare dysfunction and satisfactions, but examine the types of relationships to their significant other.

Experimental Research

Research is needed to evaluate various nursing interventions based on the significant findings from descriptive surveys. For example, different education programs geared towards the significant other could be evaluated in respect to their pre and post satisfaction levels. Similarly a study designed to evaluate a group versus individual counseling for promoting optimal rehabilitation would offer useful information in designing dialysis programs. For the most part behavioral interventions have not been well studied in the ESRD population.

Health Promotion in ESRD

Studies are needed in which the present health promotion activities of the ESRD client and significant other are examined. Noting the relationship of additional chronic illnesses to satisfaction, lends credence for interventions for health promotion. Prior to intervening, descriptive surveys are needed to define current practices.

Stressors Resulting from Incongruency

Once incongruent perceptions have been identified, the resultant interactions between the dyad need to be explored. Various issues such as non-compliance, depression, and apathy, may be the result of strained interactions, thereby impeding rehabilitation.

Conclusion

The need for continued research in the area of ESRD cannot be overly emphasized. Investigators must not only design studies that focus on evaluation of strategies

offered by previous ESRD researchers but also focus on the methodological issues that arise in conducting dyadical ESRD research. The most common problems are clustered within the area of subject selection (Osberg et al. 1980).

Indeed, the major methodological weakness within this research study is also found within this area. Since the subjects in this study were obtained from only one dialysis center a number of problems were encountered. First and foremost was the inability to utilize a random sampling technique. The absence of random sampling severely limits the ability to generalize the findings outside of the actual study sample. Further, the limitations of a small sample pool were found in analyzing the data in relationship to key sociodemographic variables. The client characteristics were unevenly distributed within the sample, thereby limiting the ability to make comparisons. These problems could be minimized by utilizing multicenters for subject selection.

Although a multi-center approach would be the optimal choice for subject selection it is not always feasible due to time, money or convenience. Therefore, investigators must take full advantage of their available pool of subjects. In order to obtain data from clients with similar key variables of interest i.e. length of time on dialysis, specific disease process, the investigator may opt to conduct an interview-administered versus a self-administered instrument. This would enlarge the potential pool of clients since the ability to read and write due to deteriorating vision was found as a limitation for a sizable portion of the available subjects for this study. The decision to utilize the interview-administered approach must be weighed upon its advantages and disadvantages. The advantages include not only the ability to enlarge the available pool of subjects but also have the following: (a) A higher response rate than self-administered, (b) protection against ambiguous or confusing questions, (c) control over the order of presentation of the questions, and (d) the ability to produce additional data through observation (Polit et al. 1983). In contrast the disadvantages of the interview style include cost, lack of respondent anonymity and, are subject to interviewer biases. In addition the actual inability to read and/or write must be considered as a potential intervening variable.

Utilizing the interview-administered approach in this study may have affected the research findings in several ways. First, a number of questions on the Sociodimographic Survey and the Satisfaction Survey were left unanswered thereby limiting data analysis in those areas. In addition, the Satisfaction Survey, a newly developed instrument, could have been further refined benefiting from the amount of clarification needed by the respondents. Finally, although the interview style would enlarge the sample pool, the problems associated with the inability to read and/or write must be considered. Certainly, the client who is experiencing deteriorating eyesight may have greater dysfunction and a lower satisfaction than the client who had limited education. These potential differences would need to be accounted for when interpreting the research findings.

Despite the method selected for administration of the study instruments several other considerations should be included in the overall research design. The problems intrinsic within ESRD rehabilitation must be examined from a family perspective with emphasis on role relationships. Unlike other chronic illnesses the ESRD dyad is often subject to numerous threats in their established family and social roles. The task of identifying problems in the client's overall rehabilitation will be made easier if the investigator is able to quantify the type and number of role changes facing the dyad.

Also important in the research design is the client's history of chronic illness. Through a review of the client's medical record or by the self-report method the number and type of chronic problems the client has had prior to dialysis can be identified. This information may help to differentiate between chronic complications often associated with ESRD (which may be both preventable and reversible) from those which are not associated with ESRD. Further, the amount of perceived disruption imposed by the chronic illness prior to ESRD may have provided the client with additional coping skills from which to draw upon. Likewise, clients who are faced with additional chronic health problems concurrent to their ESRD may experience greater dysfunction and frustration impeding their ability in restoring an optimal life style.

Finally, future researchers must be encouraged to conduct longitudinal studies in order to capture the cyclical problems know to ESRD. Such studies would ideally be geared to follow the adjustments of clients from time of diagnosis through the first three to five years of dialysis. Further, such a design would lend itself to the other design considerations previously mentioned. Unfortunately, the difficulties associated with longitudinal studies cannot be ignored. Such studies are typically expensive, time consuming and plagued with the problem of attrition. Although attrition may not appear to be a problem with a "captive" sample such as ESRD clients, the fact that many clients switch modalities can impede the ability to follow clients through the hemodialysis experience. In addition, attrition may be accentuated by the waning interest of subjects over time.

In conclusion, the current interest in ESRD rehabilitation can be attributed to both the lack of consistent research data and the financial burden of ESRD on the federal medicare budget. Health care providers are now being challenged to focus their attention in maximizing the available resources and promoting optimal rehabilitation.

One strategy in meeting this challange is to focus the energy of practitioners into early intervention and development of a high risk client profile. Such a profile would alert providers to those ESRD dyads who may have more difficulty adjusting to the demands of ESRD. In this study several of the sociodemographic variables were associated with greater dysfunction and less satisfaction: number of additional chronic illnesses, recovery time after dialysis, age, length of kidney disease, employment status and number of hours on dialysis. These particular characteristics have been noted in several of the research studies critiqued. Continued investigation is needed to thoroughly understand their relationship to rehabilitation.

The nursing management of ESRD brings both challenges and rewards to the nurses in acute and primary care setting. In the midst of a routine and purely technical process, human interactions remain far from routine. The nurse in such an opportune position can assist ESRD dyads in achieving a mutually rewarding lifestyle. This study on perceptions will contribute to the nursing body of knowledge in both application of nursing theory and the concept of rehabilitation.

King's (1981) theory did provide an integrative framework for the study questions. Although actual interactions were not measured, the degree of congruency between the dyads offered speculation on the quality of previous interactions. The end goal of interactions and

transactions will be congruency and satisfaction between the dyad. Perceptions as hypothesized by King (1981) are the key to understanding human interactions and transactions.

In Chapter VI the research findings were presented. The description and analysis of the study sample was compared to other research samples. Implications and recommendations to nursing practice, education and research was discussed.

APPENDICES

APPENDIX A

VERIFICATION OF RESEARCH APPROVAL

VERIFICATION OF RESEARCH APPROVAL

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

April 8, 1986

Ms. Judi Daniels
26838 CR 653
Gobles, Michigan 49005

Dear Ms. Daniels:

Subject: Proposal Entitled, "Perceptions of Rehabilitation by Hemodialysis Clients and Their Significant Others"

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on April 7, 1986.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to April 7, 1987.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck
Chairman, UCRIHS

HEB/jms

cc: Dr. Barbara Given

VERIFICATION OF RESEARCH APPROVAL

BORGESS MEDICAL CENTER

NURSING RESEARCH COMMITTEE

REVIEW OF NURSING RESEARCH PROPOSAL

APPROVAL NOTIFICATION

Directions: Complete this form. Notification of the committee's action will be sent to you following the decision.

Investigator(s) J Davies

Title of Project Perceptions of Facilitators to Hemodialysis Clients and their Significant Others

Send this form to: ____________________
(Name)

____
(Address)

____

The Nursing Research Committee has reviewed your request on 4/3/86
(Date)

and has reached the following decision:

Approved

Approved with modifications ✓

Not approved ____________

Comments: See attached

Signature [illegible] PhD. RN
Nursing Research Committee
Chairperson for Review of
Research

Borgess Medical Center
1521 Gull Road
Kalamazoo, Michigan 49001
Telephone 616-383-7000

Member of
Sisters of St. Joseph
Health System, Inc.
Nazareth, Michigan

VERIFICATION OF RESEARCH APPROVAL

BORGESS
Medical Center

The Borgess Medical Center Nursing Research Committee requests that you make the following modifications in your proposal:

① Add to 5. b. "Once data is coded, the list will be destroyed."

② Indicate that an abstract of the study will be provided to the committee once the study is completed.

③ Add a box to the consent form which subjects can check if they would like to receive a summary of the study.

④ On the client Information Sheet:
  a) Change "client" to "patient"
  b.) Under 2. change repercussions in to "effect on"
  c.) Check the use of "effect" vs "affect"

⑤ Consider changing significant other to supportive other or defining significant other as part of your information sheet.

⑥ Substitute "a questionnaire on how you carry out your daily activities" for Sickness Impact Profile on the Patient Information Sheet and consent form.

You might also consider the following suggestions:

① Revise the language of the information sheet to make it easier to understand.

② Add the category "other" to the Significant Other questionnaire number 10.

③ Reproduce the scale at the top of the second page of the S.O. Satisfaction Questionnaire

APPENDIX B

LETTER OF INTRODUCTION AND CONSENT FORMS

LETTER OF INTRODUCATION AND CONSENT FORMS

PATIENT INFORMATION SHEET

Overview

Some studies have been conducted that are related to the effect of hemodialysis on the ability of patients to carry out their usual daily activities. Few studies have included the opinions of both the patient and his/her supportive other regarding the impact of renal failure on the patient's rehabilitation. Nurses feel that it is important to consider the needs of the patient's supportive other as well as the patient in planning dialysis programs to assist in rehabilitation.

I am conducting a study to find out how both hemodialysis patients and their supportive others view the effects of kidney disease on the patient's ability to carry out daily activities and how satisfied they are with current activity levels.

I would appreciate 20-30 minutes of your time to complete a general information questionnaire, a questionnaire on how you carry out your daily activities, and a satisfaction questionnaire. This study has been approved by Borgess Medical Center Research Committee and Michigan State University Human Rights Committee.

If you participate in this study:

1. All information will be treated confidentially.

2. You will have the right to withdraw from this study at any time with no effect on your health care.

3. Participation or nonparticipation in this study will in no way effect the health care you or your supportive other are receiving.

4. You may request a summary of the completed study, if you so desire.

If you agree to participate in this study, you will be asked to identify a person with whom you live that you consider the most supportive person in your life. The individual must be over the age of 18, be able to complete the questionnaire by him-/herself, and agree to participate by signing a consent form.

I will contact you at your home within the next two days to answer any questions regarding the study and to schedule an appointment to meet with you and your supportive other together. If you have any questions at any time, please feel free to contact Judi Daniels at either (616) 383-8320 or (616) 628-2490.

LETTER OF INTRODUCTION AND CONSENT FORMS

SUPPORTIVE OTHER INFORMATION SHEET

Overview

Some studies have been conducted that are related to the effect of hemodialysis on the ability of patients to carry out their usual daily activities. Few studies have included the opinions of both the patient and his/her supportive other regarding the impact of renal failure on the patient's rehabilitation. Nurses feel that it is important to consider the needs of the patient's supportive other as well as the patient in planning dialysis programs to assist in rehabilitation.

I am conducting a study to find out how both hemodialysis patients and their supportive others view the effects of kidney disease on the patient's ability to carry out daily activities and how satisfied they are with current activity levels. of the study

I would appreciate 20-30 minutes of your time to complete a general information questionnaire and a satisfaction questionnaire. This study has been approved by Borgess Medical Center Research Committee and Michigan State University Human Rights Committee.

If you participate in this study:

1. All information will be treated confidentially.

2. You will have the right to withdraw from this study at any time with no effect on your health care.

3. Participation or nonparticipation in this study will in no way effect the health care you or the patient are receiving.

4. You may request a summary of the completed study, if you so desire.

I will contact you at your home within the next two days to answer any questions regarding the study and to schedule an appointment to meet with you and the patient together. If you have any questions at any time, please feel free to contact Judi Daniels at either (616) 383-8320 or (616) 628-2490.

LETTER OF INTRODUCTION AND CONSENT FORMS

INFORMED CONSENT

Judi Daniels, R.N., is conducting a study to measure the effect of chronic renal failure on the patient's abilities to perform usual daily activities as viewed by the patent and his/her identified supportive other. While studies are present which describe the effect of chronic renal failure perceived by the patient, few studies are available which include the patient's supportive other.

If we voluntarily consent to participate in this study, I understand that:

1. There will be a general information questionnaire, a questionnaire on daily activities, and a satisfaction questionnaire to complete by the patient and the supportive other independently.

2. This study will in no way affect the health care being delivered to the patient or supportive other.

3. All information regarding our participation will be kept confidential by the use of code numbers. No names will appear on any of the questionnaires. The questionnaires will be destroyed after the study is completed.

4. A summary of the study will be available upon request.

We acknowledge that:

1. We have been given an opportunity to ask questions about this study and they have been answered.

2. If we have further questions, we may contact Judi Daniels, R.N., at (616) 383-8320 or (616) 628-2490.

3. Participation in this study will in no way effect the health care delivered to the patient or the supportive other.

4. The investigator has my permission to release the information gained from this study to nursing literature. We understand that no names will be used which could identify the participants.

5. We have received a copy of this consent form.

Date	Hemodialysis Client
Date	Significant Other
Date	Researcher

☐ Check this box if you would like a summary of the study.

APPENDIX C

SICKNESS IMPACT PROFILES

SICKNESS IMPACT PROFILES

THE FOLLOWING INSTRUCTIONS ARE FOR THE SELF-ADMINISTERED QUESTIONNAIRE.

PLEASE READ THE ENTIRE INTRODUCTION BEFORE YOU READ THE QUESTIONNAIRE. IT IS VERY IMPORTANT THAT EVERYONE TAKING THE QUESTIONNAIRE FOLLOWS THE SAME INSTRUCTIONS.

INTRODUCTION TO RESPONDENT

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about any changes that describe you today and are related to your state of health.

The questionnaire booklet lists statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they describe you today and are related to your state of health. As you read the questionnaire, think of yourself today. When you read a statement that you are sure describes you and is related to your health, place a check on the line to the right of the statement. For example:

I am not driving my car ___✓___ (026-031)

If you have not been driving for some time because of your health, and are still not driving today, you should respond to this statement.

On the other hand, if you never drive or are not driving today because your car is being repaired, the statement, "I am not driving my car" is not related to your health and you should not check it. If you simply are driving less, or are driving shorter distances, and feel that the statement only partially describes you, do not check it. In all of these cases you would leave the line to the right of the statement blank. For example:

I am not driving my car ______ (026-031)

Remember that we want you to check this statement only if you are sure it describes you today and is related to your state of health.

Read the introduction to each group of statements and then consider the statements in the order listed. While some of the statements may not apply to you, we ask that you please read all of them. Check those that describe you as you go along. Some of the statements will differ only in a few words, so please read each one carefully. While you may go back change a response, your first answer is usually the best. Please do not read ahead in the booklet.

Once you have started the questionnaire, it is very important that you complete it within one day (24 hours).

If you find it hard to keep your mind on the statements, take a short break and then continue. When you have read all of the statements on a page, put a check in the BOX in the lower right-hand corner. If you have any questions, please refer back to these instructions.

Please do not discuss the statements with anyone, including family members, while doing the questionnaire.

Now turn to the questionnaire booklet and read the statements. Remember we are interested in the recent or longstanding changes in your activities that are related to your health.

(SR-0499)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

(52) 1. I spend much of the day lying down in order to rest ______ (070-083)

(53) 2. I sit during much of the day ______ (062-049)

(54) 3. I am sleeping or dozing most of the time - day and night ______ (063-104)

(55) 4. I lie down more often during the day in order to rest ______ (066-058)

(56) 5. I sit around half-asleep ______ (065-084)

(57) 6. I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently ______ (069-061)

(58) 7. I sleep or nap more during the day ______ (071-060)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(EB-0705)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

(59) 1. I say how bad or useless I am, for example, that I am a burden on others _____ (274-087)

(60) 2. I laugh or cry suddenly _____ (272-068)

(61) 3. I often moan and groan in pain or discomfort _____ (269-069)

(62) 4. I have attempted suicide _____ (281-132)

(63) 5. I act nervous or restless _____ (284-046)

(64) 6. I keep rubbing or holding areas of my body that hurt or are uncomfortable _____ (262-062)

(65) 7. I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen _____ (273-078)

(66) 8. I talk about the future in a hopeless way _____ (283-089)

(67) 9. I get sudden frights _____ (278-074)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(BCM-2003)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

(68) 1. I make difficult moves with help, for example, getting into or out of cars, bathtubs ______ (168-084)

(69) 2. I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid ______ (170-121)

(70) 3. I stand only for short periods of time ______ (155-072)

(71) 4. I do not maintain balance ______ (146-098)

(72) 5. I move my hands or fingers with some limitation or difficulty ______ (152-064)

(73) 6. I stand up only with someone's help ______ (165-100)

(74) 7. I kneel, stoop, or bend down only by holding on to something ______ (171-064)

(75) 8. I am in a restricted position all the time ______ (158-125)

(76) 9. I am very clumsy in body movements ______ (148-058)

(77) 10. I get in and out of bed or chairs by grasping something for support or using a cane or walker ______ (169-082)

(78) 11. I stay lying down most of the time ______ (162-113)

(79) 12. I change position frequently ______ (147-030)

(80) 13. I hold on to something to move myself around in bed ______ (143-086)

(81) 14. I do not bathe myself completely, for example, require assistance with bathing ______ (310-089)

(82) 15. I do not bathe myself at all, but am bathed by someone else ______ (312-115)

83) 16. I use bedpan with assistance ______ (292-114)

84) 17. I have trouble getting shoes, socks, or stockings on ______ (305-057)

85) 18. I do not have control of my bladder ______ (290-124)

(CONTINUED FROM PAGE 7)

(86) 19. I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces _____ (298-074)

(87) 20. I spend most of the time partly undressed or in pajamas _____ (302-074)

(88) 21. I do not have control of my bowels _____ (295-128)

(89) 22. I dress myself, but do so very slowly _____ (300-043)

(90) 23. I get dressed only with someone's help _____ (297-088)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(HM-0668)

THIS GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO IN CARING FOR YOUR HOME OR YARD. CONSIDERING JUST THOSE THINGS THAT YOU DO, PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH

---

(91) 1. I do work around the house only for short periods of time or rest often ______ (117-054)

(92) 2. I am doing less of the regular daily work around the house than I would usually do ______ (119-044)

(93) 3. I am not doing any of the regular daily work around the house that I would usually do ______ (120-086)

(94) 4. I am not doing any of the maintenance or repair work that I would usually do in my home or yard ______ (001-062)

95) 5. I am not doing any of the shopping that I would usually do ______ (106-071)

(96) 6. I am not doing any of the house cleaning that I would usually do ______ (116-077)

(97) 7. I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry ______ (107-069)

(98) 8. I am not doing any of the clothes washing that I would usually do ______ (111-077)

99) 9. I am not doing heavy work around the house ______ (115-044)

00)10. I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget ______ (105-084)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(M-0719)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

(101) 1. I am getting around only within one building _____ (134-086)

(102) 2. I stay within one room _____ (128-106)

(103) 3. I am staying in bed more _____ (130-081)

(104) 4. I am staying in bed most of the time _____ (131-109)

(105) 5. I am not now using public transportation _____ (140-041)

06) 6. I stay home most of the time _____ (133-066)

107) 7. I am only going to places with restrooms nearby _____ (125-056)

108) 8. I am not going into town _____ (124-048)

109) 9. I stay away from home only for brief periods of time _____ (139-054)

110) 10. I do not get around in the dark or in unlit places without someone's help _____ (121-072)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(SI-1450)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

(111) 1. I am going out less to visit people _____ (028-044)

(112) 2. I am not going out to visit people at all _____ (029-101)

(113) 3. I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help _____ (003-067)

114) 4. I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily _____ (015-084)

115) 5. I show less affection _____ (007-052)

116) 6. I am doing fewer social activities with groups of people _____ (012-036)

117) 7. I am cutting down the length of visits with friends _____ (027-043)

118) 8. I am avoiding social visits from others _____ (034-080)

119) 9. My sexual activity is decreased _____ (039-051)

120) 10. I often express concern over what might be happening to my health _____ (018-052)

121) 11. I talk less with those around me _____ (002-056)

122) 12. I make many demands, for example, insist that people do things for me, tell them how to do things _____ (038-088)

123) 13. I stay alone much of the time _____ (023-086)

124) 14. I act disagreeable to family members, for example, I act spiteful, I am stubborn _____ (249-088)

125) 15. I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them _____ (240-119)

126) 16. I isolate myself as much as I can from the rest of the family _____ (237-102)

(CONTINUED FROM PAGE 11)

(127) 17. I am paying less attention to the children ______ (238-064)

(128) 18. I refuse contact with family members, for example, turn away from them ______ (256-115)

(129) 19. I am not doing the things I usually do to take care of my children or family ______ (242-079)

(130) 20. I am not joking with family members as I usually do ______ (255-043)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(A-0842)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

131) 1. I walk shorter distances or stop to rest often ______ (050-048)

132) 2. I do not walk up or down hills ______ (046-056)

133) 3. I use stairs only with mechanical support, for example, handrail, cane, crutches ______ (042-067)

34) 4. I walk up or down stairs only with assistance from someone else ______ (044-076)

35) 5. I get around in a wheelchair ______ (057-096)

6) 6. I do not walk at all ______ (052-105)

37) 7. I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg ______ (049-055)

38) 8. I walk only with help from someone ______ (053-088)

9) 9. I go up and down stairs more slowly, for example, one step at a time, stop often ______ (040-054)

0) 10. I do not use stairs at all ______ (041-083)

) 11. I get around only by using a walker, crutches, cane, walls, or furniture ______ (047-079)

) 12. I walk more slowly ______ (051-035)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(AB-0777)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

143) 1. I am confused and start several actions at a time _____ (223-090)

144) 2. I have more minor accidents, for example, drop things, trip and fall, bump into things _____ (234-075)

145) 3. I react slowly to things that are said or done _____ (228-059)

146) 4. I do not finish things I start _____ (227-067)

147) 5. I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things _____ (224-084)

148) 6. I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is _____ (231-113)

49) 7. I forget a lot, for example, things that happened recently, where I put things, appointments _____ (222-078)

50) 8. I do not keep my attention on any activity for long _____ (220-067)

51) 9. I make more mistakes than usual _____ (225-064)

52) 10. I have difficulty doing activities involving concentration and thinking _____ (217-080)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(C-0725)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

153) 1. I am having trouble writing or typing _____ (191-070)

154) 2. I communicate mostly by gestures, for example, moving head, pointing, sign language _____ (177-102)

155) 3. My speech is understood only by a few people who know me well _____ (179-093)

156) 4. I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly _____ (197-083)

157) 5. I don't write except to sign my name _____ (188-083)

158) 6. I carry on a conversation only when very close to the other person or looking at him _____ (178-067)

159) 7. I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words _____ (176-076)

60) 8. I am understood with difficulty _____ (200-087)

61) 9. I do not speak clearly when I am under stress _____ (201-064)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

THE NEXT GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO OTHER THAN MANAGING YOUR HOME. BY THIS WE MEAN ANYTHING THAT YOU REGARD AS WORK THAT YOU DO ON A REGULAR BASIS.

62) DO YOU USUALLY DO WORK OTHER THAN MANAGING YOUR HOME? ____ YES ____ NO

➡ IF YOU ANSWERED YES, GO ON TO THE NEXT PAGE.

➡ IF YOU ANSWERED NO:

(163) ARE YOU RETIRED? ____ YES ____ NO

(164) IF YOU ARE RETIRED, WAS YOUR RETIREMENT RELATED TO YOUR HEALTH? ____ YES ____ NO

(165) IF YOU ARE NOT RETIRED, BUT ARE <u>NOT</u> WORKING, IS THIS RELATED TO YOUR HEALTH? ____ YES ____ NO

➡ NOW SKIP THE NEXT PAGE.

(W-0515)

IF YOU ARE NOT WORKING AND IT IS <u>NOT</u> BECAUSE OF YOUR HEALTH, PLEASE SKIP THIS PAGE.

NOW CONSIDER THE WORK YOU DO AND RESPOND TO (CHECK) <u>ONLY</u> THOSE STATEMENTS THAT YOU ARE <u>SURE</u> DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH. (IF TODAY IS A SATURDAY OR SUNDAY OR SOME OTHER DAY THAT YOU WOULD USUALLY HAVE OFF, PLEASE RESPOND AS IF TODAY WERE A WORKING DAY.)

---

66) 1. I am not working at all ______ (100-361)

(IF YOU CHECKED THIS STATEMENT, SKIP TO THE NEXT PAGE.)

67) 2. I am doing part of my job at home ______ (094-037)

68) 3. I am not accomplishing as much as usual at work ______ (096-055)

69) 4. I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily ______ (088-080)

70) 5. I am working shorter hours ______ (095-043)

71) 6. I am doing only light work ______ (086-050)

72) 7. I work only for short periods of time or take frequent rests ______ (090-061)

73) 8. I am working at my usual job but with some changes, for example, using different tools or special aids, trading some tasks with other workers ______ (092-034)

74) 9. I do not do my job as carefully and accurately as usual ______ (097-062)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(RP-0422)

THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

175) 1. I do my hobbies and recreation for shorter periods of time _____ (215-039)

176) 2. I am going out for entertainment less often _____ (214-036)

177) 3. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading _____ (207-059)

178) 4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading _____ (208-084)

79) 5. I am doing more inactive pastimes in place of my other usual activities _____ (211-051)

80) 6. I am doing fewer community activities _____ (216-033)

81) 7. I am cutting down on some of my usual physical recreation or activities _____ (210-043)

82) 8. I am not doing any of my usual physical recreation or activities _____ (209-077)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

(E-0705)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

---

183) 1. I am eating much less than usual ______ (085-037)

184) 2. I feed myself but only by using specially prepared food or utensils ______ (073-077)

185) 3. I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low-sugar ______ (081-043)

186) 4. I eat no food at all but am taking fluids ______ (077-104)

87) 5. I just pick or nibble at my food ______ (083-059)

188) 6. I am drinking less fluids ______ (080-036)

189) 7. I feed myself with help from someone else ______ (074-099)

190) 8. I do not feed myself at all, but must be fed ______ (075-117)

191) 9. I am eating no food at all, nutrition is taken through tubes or intravenous fluids ______ (076-133)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE ☐

NOW, PLEASE REVIEW THE QUESTIONNAIRE TO BE CERTAIN YOU HAVE FILLED OUT ALL THE INFORMATION. LOOK OVER THE BOXES ON EACH PAGE TO MAKE SURE EACH ONE IS CHECKED SHOWING THAT YOU HAVE READ ALL OF THE STATEMENTS. IF YOU FIND A BOX WITHOUT A CHECK, THEN READ THE STATEMENTS ON THAT PAGE.

APPENDIX D

EXAMPLES FROM MODIFIED SICKNESS IMPACT PROFILE FOR THE SIGNIFICANT OTHER

EXAMPLES FROM MODIFIED SICKNESS IMPACT PROFILE FOR THE SIGNIFICANT OTHER

Each participant on hemodialysis identified someone in his/her home whom the participant considered to be a primary support person. The following questionnaire is to reflect your opinion of the dialysis patient's current activity level.

Please read the entire introduction before you read the questionnaire. It is very important that everyone completing the questionnaire follows the same instructions.

INTRODUCTION TO RESPONDENT

Patients have certain activities that they do in carrying on their lives. Sometimes they do all of these activities. At other times, because of their state of health, they don't do these activities in the usual way: They may cut some out; they may do some for shorter lengths of time; they may do some in different ways. These changes in their activities might be recent or long-standing. We are interested in learning about any changes that describe the dialysis patient today and are related to his/her state of health.

The questionnaire booklet lists statements that people have told us describe them when they are not completely well. Whether or not you consider the patient sick, there may be some statements that will stand out because they describe the patient today and are related to his/her state of health. As you read the questionnaire, think of the patient today. When you read a statement that you are sure describes the patient and is related to his/her health, place a check on the line to the right of the statement. For example:

He/she is not driving his/her car. ✓ **(026-031)**

If the patient has not been driving for some time because of his/her health, and the patient is still not driving today, you should respond to this statement.

On the other hand, if the patient has never driven or is not driving today because his/her car is being repaired, the statement "**He/she is not driving his/her car**" is not related to the patient's health and you should not check it. If the patient is simply driving less or is driving shorter distances, and you feel that the statement only partially describes him/her, do not check it. In all of these cases you would leave the line to the right of the statement blank. For example:

He/she is not driving his/her car. ______ **(026-031)**

Remember that we want you to check this statement only if you are sure it describes the patient today and is related to his/her state of health.

Read the introduction to each group of statements and then consider the statements in the order listed. While some of the statements may not apply to the patient, we ask that you please read <u>all</u> of them. Check those that describe the patient as you go along. Some of the statements will differ only in a few words, so please read each one carefully. While you may go back and change a response, your first answer is usually the best. Please do not read ahead in the booklet.

<u>Once you have started the questionnaire, it is very important that you complete it within one day (24 hours)</u>.

If you find it hard to keep your mind on the statements, take a short break and then continue. When you have read all of the statements on a page, put a check in the BOX in the lower right-hand corner. If you have any questions, please refer back to these instructions.

<u>Please do not discuss the statements with anyone, including family members, while doing the questionnaire</u>.

Now, turn to the questionnaire booklet and read the statements. Remember, we are interested in the recent or long-standing changes in the patient's activities that are related to his/her health.

(SR-0499)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE THE PATIENT TODAY AND ARE RELATED TO HIS/HER STATE OF HEALTH.

---

1. He/she spends much of the day lying down in order to rest. ______ (070-083)
2. He/she sits during much of the day. ______ (062-049)
3. He/she sleeps or dozes most of the time--day and night. ______ (063-104)
4. He/she lies down more often during the day in order to rest. ______ (066-058)
5. He/she sits around half-asleep. ______ (065-084)
6. He/she sleeps less at night; for example, wakes up too early, doesn't fall asleep for a long time, awakens frequently. ______ (069-061)
7. He/she sleeps or naps more during the day. ______ (071-060)

CHECK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE ☐

(EB-0705)

PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE THE PATIENT TODAY AND ARE RELATED TO HIS/HER STATE OF HEALTH.

---

1. He/she says how bad or useless he/she is; for example, that he/she is a burden on others. ________ (274-087)
2. He/she laughs or cries suddenly. ________ (272-068)
3. He/she often moans and groans in pain or discomfort. ________ (269-069)
4. He/she has often attempted suicide. ________ (281-132)
5. He/she acts nervous or restless. ________ (284-046)
6. He/she keeps rubbing or holding areas of his/her body that hurt or are uncomfortable. ________ (262-062)
7. He/she acts irritable and impatient with him-/herself; for example, talks badly about self, swears at self, blames self for things that happen. ________ (273-078)
8. He/she talks about the future in a hopeless way. ________ (283-089)
9. He/she gets sudden frights. ________ (278-074)

CHECK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE ☐

APPENDIX E

SATISFACTION SURVEYS

PATIENT SATISFACTION SCALE

INSTRUCTIONS: Equally important to knowing what activities you can and cannot presently carry out is how satisfied you are with your present abilities. To each of the following statements, please circle the degree of satisfaction that best describes your feelings.

SCALE

1 = Very Dissatisfied

2 = Dissatisfied

3 = Mixed

4 = Satisfied

5 = Very Satisfied

(192)	1.	Total amount of time spent sleeping.	1	2	3	4	5
(193)	2.	Present emotional behavior.	1	2	3	4	5
(194)	3.	Ability to provide daily care of personal needs.	1	2	3	4	5
(195)	4.	Participation in household chores.	1	2	3	4	5
(196)	5.	Ability to leave home for shopping, work, health care, or social activities.	1	2	3	4	5

SCALE

1 = Very Dissatisfied

2 = Dissatisfied

3 = Mixed

4 = Satisfied

5 = Very Satisfied

---

(197)	6.	Amount of time spent in social activities.	1	2	3	4	5
(198)	7.	Ability to move around without help.	1	2	3	4	5
(199)	8.	Ability to concentrate.	1	2	3	4	5
(200)	9.	Ability to talk clearly with others.	1	2	3	4	5
(201)	10.	Stamina to continue working in a job outside the home.	1	2	3	4	5
(202)	11.	Participation in usual pastime activities.	1	2	3	4	5
(203)	12.	Present dietary intake	1	2	3	4	5

SUPPORTIVE OTHER SATISFACTION SCALE

INSTRUCTIONS: Equally important to knowing what activities the patient can and cannot presently carry out is how satisfied you are with his/her present abilities. To each of the following statements, please circle the degree of satisfaction that best describes your feelings about the patient's behavior.

SCALE

1 = Very Dissatisfied
2 = Dissatisfied
3 = Mixed
4 = Satisfied
5 = Very Satisfied

---

(180) 1. Amount of time spent sleeping, both at night and during the day. 1 2 3 4 5
(181) 2. Present emotional behavior 1 2 3 4 5
(182) 3. Ability to provide daily care of personal needs 1 2 3 4 5
(183) 4. Participation in household chores. 1 2 3 4 5

SCALE

1 = Very Dissatisfied

2 = Dissatisfied

3 = Mixed

4 = Satisfied

5 = Very Satisfied

---

(184)	5.	Ability to leave home for shopping, work, health care, or social activities.	1	2	3	4	5
(185)	6.	Amount of time spent in social activities.	1	2	3	4	5
(186)	7.	Ability to move around without help.	1	2	3	4	5
(187)	8.	Ability to concentrate	1	2	3	4	5
(188)	9.	Ability to talk clearly with others.	1	2	3	4	5
(189)	10.	Stamina to continue working in a job outside the home.	1	2	3	4	5
(190)	11.	Participation in usual pastime activities.	1	2	3	4	5
(191)	12.	Present dietary intake.	1	2	3	4	5

APPENDIX F

SOCIODEMOGRAPHIC SURVEYS

I.D.______________
(1-2)
CARD NO.______________

SUPPORTIVE OTHER SOCIODEMOGRAPHIC SURVEY

The following questions describe general things about yourself. Please answer all the questions to the best of your ability. All information will be kept confidential.

---

1. Age:______ (3-4) 2. Sex: M______ F______ (5)

(6) 3. Ethnic Background:
______White ______Afro-American
______Oriental ______Mexican-American
______Indian ______Other (Please specify)
____

(7) 4. Marital Status:
______Married ______Divorced
______Single ______Widowed
______Separated

(8-9) 5. How long have you been married to your current spouse?______________

(10) 6. Your educational level (please check [✓] highest grade completed):
______Fewer than seven years of school (grades 1-6)
______Junior high school (grades 7-9)
______Partial high school (grades 10-11)
______High school (completed 12th grade)
______Partial college education (3 years or less)
______College education (4 years)
______Beyond 4 years of college

(11) 7. What is your current occupation (Please check [✓] one)?
______Clerical
______Professional
______Executive in large-to-medium-sized business
______Skilled worker
______Semiskilled or unskilled worker
______Owner of business establishment
______Retired
______Currently unemployed but looking for work
______Other (Please specify)______________________

(12) 8. If employed outside the home, do you work
(Please check [✓] one):
______Full-time?
______Part-time?
______On call?

(13) 9. Do you have any chronic health problem?
______yes ______no

(14-21) 10. If yes, please check [✓] all those that pertain
to you:
______Arthritis
______High Blood Pressure
______Heart disease
______Diabetes
______Cancer
______Lung Disease
______Lupus
______Other
(Please specify)
____

(22) 11. Are you currently taking any medications?
______yes ______no

(23-30) 12. If yes, please check [√] all that apply to you:
______Blood pressure pills
______Pills to control blood sugar
______Heart pills
______Pills to control anxiety
______Pills to promote sleep
______Pain pills
______Vitamins
______Other

(31) 13. Relationship to the patient: (Check [✓] one)
______Spouse
______Child
______Brother/Sister
______Parent
______Grandparent
______Relative
______Other (Please specify)________________________

(32-36) 14. Please check [✓] all of the following activities
which you do to provide care for the patient:
______Prepare special meals based on diet
______Remind to take medications
______Drive to and from dialysis
______Check his/her blood pressure at home
______Assist with personal hygiene

(37) 15. Was enough information given to you regarding the
patient's health problems?
______yes ______no
______some, but would like more

(38) 16. How would you rate your own current health status?
______good
______fair
______poor

(39) 17. How has your health been since the patient has had kidney disease?
own health?
______a lot better
______somewhat better
______stayed the same
______somewhat worse
______a lot worse

I.D.__________________
(1-2)
CARD NO.______________

PATIENT SOCIODEMOGRAPHIC SURVEY

The following questions describe general things about yourself. Please answer all the questions to the best of your ability. All information will be kept confidential.

---

1. Age:______ (3-4) Sex: M______ F______ (5)

(6) 3. Ethnic Background: (Check [✓] one)
______White
______Oriental
______Indian
______Afro-American
______Mexican-American
______Other (please specify)

(7) 4. Marital Status: (Check [✓] one)
______Married
______Single
______Separated
______Divorced
______Widowed

(8-9) 5. If married, for how long?__________________

(10) 6. Your educational level (please check [✓] highest grade completed):
______Fewer than seven years of school (grades 1-6)
______Junior high school (grades 7-9)
______Partial high school (grades 10-11)
______High school (completed 12th grade)
______Partial college education (3 years or less)
______College education (4 years)
______Beyond 4 years of college

(11) 7. What is your current occupation? (Check [✓] one)
______Clerical
______Professional
______Executive in large-to-medium-sized business
______Skilled worker
______Semiskilled or unskilled worker
______Owner of business establishment
______Retired
______Currently unemployed but looking for work
______Other (Please specify)______________________

(12) 8. What is the approximate amount of income in your household?

______0 - 9,999
______10,000 - 19,999
______20,000 - 29,999
______30,000 - 39,999
______40,000 - 49,000
______50,000 - 59,000
______Over 60,000

(13) 9. How long ago were you first told you had a chronic renal disease? Please check [✓] to the nearest year.

______Less than 1 year
______1 to 2 years
______3 to 5 years
______Greater than 5 years

(14) 10. How long have you been on hemodialysis? (Please check [✓] to the nearest number.)

______ 6 to 12 months
______13 to 23 months
______ 2 to 5 years
______ Greater than 5 years

(15) 11. Where do you currently dialyze? (Please check [✓] one.)

______Hospital/outpatient unit
______Home

(16) 12. How long have you dialyzed in your current setting? (Please check [✓] to the nearest number.)

______ 3 to 6 months
______ 7 to 12 months
______13 to 23 months
______ 2 to 5 years
______ Over 5 years

(17) 13. If at home, who usually assists you with your dialysis? (Please check [✓] only one.)

______Spouse
______Child
______Friend
______Parent
______Other (Please specify)______________________

(18) 14. If you currently dialyze in a hospital/outpatient unit, did you ever dialyze at home?
______yes ______no

(19) 15. If you know the cause of your kidney disease, please fill in the blank:________________________

(20) 16. Do you have any other chronic health problems?
______yes ______no

(21-28) 17. If yes, please check [✓] all that apply:
______Arthritis
______High blood pressure
______Heart disease
______Diabetes
______Other (Please specify)______________________
______Cancer
______Lung disease
______Lupus

(29) 18. Have you been hospitalized within the last year?
______yes ______no

(30-31) 19. If yes, for how long? ___________________________

(32) 20. Was your hospitalization due to problems associated with kidney disease?
______yes ______no

(33-42) 21. What type of medications do you currently take? (Check [✓] all that apply)
______Blood pressure pills
______Pills to control blood sugar
______Heart pills
______Pills to reduce anxiety
______Pills to promote sleep
______Pain pills
______Vitamins
______Calcium pills
______Phosphate binders
______Other

(43) 22. Do you have children living with you at home?
______yes ______no

(44) 23. If yes, how many?____________

(45) 24. How many people besides yourself are currently living in your house?____________

(46) 25. What type of blood access do you have? (Please check [✓] one)
______Graft
______Fistula
______Shunt

(47) 26. How many days a week on the average do you dialyze?
______1 day a week
______2 days a week
______3 days a week
______4 days a week
______5 or more days a week

(48) 27. How many hours do you spend on dialysis per treatment? (Please check [✓] one)
______3 hours
______4 hours
______5 hours
______6 hours
______Other

(49-50) 28. Approximately how long does it take you to feel rested after each dialysis? ____________________

(51) 29. If you dialyze in the hospital outpatient unit, approximately how much time do you spend traveling from your home to the unit and back home again? (Please check [✓] one)
______less than 1 hour
______1 to 2 hours
______3 to 4 hours
______5 to 6 hours

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