KNOWLEDGE, ATTITUDES, AND UNCERTAINTY OF ADULT PATIENTS WITH DECREASED KIDNEY FUNCTION

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

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* * * * *

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DEDICATION

TO MY PARENTS

WILMA DOROTHY EVANS CHAMBERS

and

JOE CHAMBERS, DECEASED
ACKNOWLEDGMENTS

I wish to express appreciation to my major advisor Professor David L. Boggs for his support and encouragement during my doctoral studies. I also gratefully acknowledge the assistance of Professors Emmalou Van Tilburg Norland and Sandra J. Cornett for their guidance and suggestions during the development and implementation of this investigation.

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CHAPTER I
INTRODUCTION

End-stage kidney failure is considered to be present when the patient has significant symptoms of kidney failure and/or the presence of life-threatening problems which can only be treated by renal replacement therapy. (Luke & Strom, 1990) Renal replacement therapy options include hemodialysis, peritoneal dialysis, and/or renal transplantation.

The progressive deterioration of kidney failure results in biochemical, physiological and psychological changes. For individuals with kidney disease, the rate at which kidney function decreases will vary. In some patients, the rate of deterioration may be over a period of several months. For others, the deterioration may progress over a period of many years. (Walker & Mitch, 1988; Luke & Strom, 1990)

The biochemical assessment of kidney function alteration is primarily through blood tests that measure creatinine and urea nitrogen levels. Changes in serum levels of bicarbonate, calcium, and phosphate also occur with decreasing kidney function. (Hakim & Lazarus, 1988) The serum creatinine level is most commonly used to
establish a trend, i.e. stable, worsening, improving.

The physical symptoms of kidney failure may include nausea, vomiting, loss of appetite, fatigue and lethargy, muscle cramps, and itching. (Brenner & Lazarus, 1991) In addition, severe fluid retention, shortness of breath, hypertension (high blood pressure), electrolyte and acid-base imbalances may become life-threatening. When the person with kidney failure develops persistent symptoms, or physiologic alterations that become life-threatening, kidney dialysis or transplantation must be initiated. (Brenner & Lazarus, 1991)

When there are no medical contraindications to modality selection, the patient may choose either hemodialysis or peritoneal dialysis. (Rosansky, 1983; McCauley, Johnson, & Copley, 1989) For many individuals, kidney transplantation is also a treatment option for consideration. (Rosansky, 1983) The selection of the initial type of renal replacement therapy may represent a difficult decision for the patient and family.

In addition to the physical symptoms and life-threatening problems associated with kidney failure, the
patients usually experience changes in intellectual functioning. Cognitive alterations with advancing kidney failure include 1) decreased attention span, 2) inability to concentrate, 3) decreased short term memory, and 4) altered reasoning and information processing. (McDaniel, 1971; Ginn, 1975; Mahoney & Arieff, 1982; Luke & Strom, 1990) These changes may not be apparent to the individual, but family and co-workers are often aware of changes in mental status. (Luke & Strom, 1990)

Some patients who have had regular medical care may have had opportunities to become informed about their disease and the treatment options. Other patients may have had regular medical care but have actively resisted or passively ignored explanations about the changes in their health status. Some patients have not had the opportunity for on-going explanations because of lack of knowledge about the presence of kidney disease and/or lack of medical care. Ideally, patients should be involved in decisions about treatment options. (Pierce, 1985; McCauley, Johnson, & Copley, 1989; Luke & Strom, 1990)
STATEMENT OF THE PROBLEM

The patient with kidney failure confronts the need to make major medical decisions concerning treatment during a time when biochemical alterations are impairing cognitive functioning. The decision concerns treatment to extend one's life, but the patient's cognitive abilities are impaired.

Interest in the information processing and information seeking behavior of individuals with kidney failure in the pre-dialysis stage has developed in the 10 plus years that this researcher has been involved in teaching and counseling patients and family members. The purpose of physician referral for pre-dialysis counseling is to assist patients and family members to understand about the various treatment options and the associated routines and requirements.

In these pre-dialysis counseling sessions, patients are informed of their kidney failure and the eventual need for dialysis by their physician. For some patients, dialysis is necessary within several weeks; for others, the need for dialysis is not expected for 6-12 months. And, for some patients, dialysis treatments are already initiated.
The level of knowledge and understanding of these patients varies widely. Some patients and family members present evidence of advance reading and/or other explanations about the treatment options for kidney failure. Some patients are not able to even identify the reason for the pre-dialysis counseling session and have virtually no recall of previous discussions with the physician about the existence of kidney failure and/or the need for chronic dialysis.

Similarly, reports are received from colleagues that many of the patients with whom treatment options had been discussed seemingly have no recall of the content of these discussions. Other patients report that the sessions are extremely valuable in allaying anxiety and in helping them to make decisions about which modality to select. These observations about the apparent lack of effectiveness of some of these pre-dialysis educational counseling sessions coupled, with the need for this information by the patients for informed decision-making, have lead to the interest in conducting this study.

The findings from this study offer a beginning examination of the educational needs and attitudes of pre-
end stage renal failure patients. It is important that health care providers assist patients to become informed about treatment options and thus potentially facilitate a smooth transition into a renal replacement therapy. This information further serves to identify areas for additional development in areas such as educational programming and related resource materials.

RESEARCH QUESTIONS

This investigation explores the following questions.

1. What is the nature of the relationship between a decrease in kidney function and achievement on a test of knowledge about kidney failure?

2. What is the nature of the relationship between a decrease in kidney function and attitudes toward kidney failure and treatment options?

3. What is the nature of the relationship between a decrease in kidney function and uncertainty in illness?
PURPOSE

The purpose of this study is to explore the knowledge, attitudes, and uncertainty of persons whose renal function is decreased, but has not reached the stage where renal replacement therapy is necessary. This descriptive, exploratory study is an essential preparatory procedure for the design and implementation of future educational efforts with individuals who confront the need to make a decision that will influence the maintenance and extension of life.

SIGNIFICANCE OF THE PROBLEM

During the period of January 1 - December 31, 1988, 172,506 patients were enrolled in the End Stage Renal Disease Program (ESRD), which is a 8.5% increase from the rate for 1987. (USRDS Annual Data Report, 1990) This number represents about 93% of the total, as non-medicare patients, including individuals treated in veterans facilities, are not included in this summation. (USRDS Annual Data Report, 1990) Since 1985, the annual growth rate has been 9.8% per year (USRDS Annual Report, 1990).
As life-extending treatments, dialysis and transplantation are extremely expensive. Annual Medicare and other related payments for the ESRD program were reported to exceed $5.4 billion for 1988, a 23% increase from the $4.4 billion in 1987. (USRDS Annual Data Report, 1990) These figures do not include costs resulting from lost income, other productivity considerations, or other personal losses.

Strategies that assure the early recognition of alterations in cognitive functioning, as well as enhancing individual interest in obtaining information about health status and medical treatment, are necessary to assure appropriate educational and counseling interventions for patients in the pre-dialysis period.

ASSUMPTIONS

The study assumes the following:

1. Cooperating nephrologists made an effort to identify all those appropriate for potential study participation.

2. No respondent had started chronic renal replacement therapy.
3. The measurement instruments were reliable and valid.
4. Respondents participated voluntarily.
5. Respondents responded honestly.
6. The serum creatinine was measured accurately and recorded correctly.

LIMITATIONS

This was an exploratory study designed to describe the knowledge, attitudes, and uncertainty in patients with decreased renal failure. The intent was to describe the characteristics, knowledge, and attitudes of a population of individuals that has not been previously researched.

Subjects made the decision about participation. In addition, no attempt was made to identify whether there was altered cognitive functioning from uremia. During the course of the study, some subjects became symptomatic and renal replacement therapy was initiated. These potential participants were either eliminated from follow-up procedures or their responses were not included in the data analysis. Some subjects were reported by a family member to have expired, suggesting a potential error in the sampling frame.
Data were collected by a questionnaire mailed to the subject's own home. Therefore, the subject could have sought help from family or friends, or looked up information in reference books, if available. By knowing that they were part of a study, some subjects may have felt compelled to give either more positive or more negative responses, or to remain neutral. Similarly, some subjects may have been so recently diagnosed that their attitudes and level of uncertainty were not even clear to themselves.

The elusivity of study participants is a limitation. Randomization procedures were not possible and therefore the reader is advised to use caution when considering potential application of the findings. The study is also potentially limited by the situation that the most recently recorded serum creatinine level could have been collected as much as twelve months prior to actual data collection. Further, as the intent of the study was to explore for possible relationships, no hypotheses were tested.
DEFINITION OF TERMS

Azotemia - The accumulation of waste products in the blood resulting from impaired kidney function.

Creatinine - a protein waste product derived primarily from skeletal muscle metabolism that is excreted primarily by the kidneys

Chronic renal failure - Renal failure that has progressed beyond the level of insufficiency; significant deterioration in renal function; renal replacement therapy will be required when uremic symptoms or life-threatening problems present.

End-stage renal disease (E.S.R.D.) - Irreversible, permanent deterioration of the kidneys sufficient to cause death unless renal replacement therapy is initiated.

Pre-end stage renal failure - The period that precedes the onset of symptomatic renal failure.
Renal insufficiency - Describes the status of kidney function; refers to less than normal kidney function, but function is sufficient to prevent the individual from experiencing symptoms of uremia from kidney failure.

Renal replacement therapy - Methods of sustaining life when kidney failure with symptoms or life-threatening problems exists; options include peritoneal dialysis, hemodialysis, or transplantation.

Uremia - The clinical manifestations of waste product accumulation in the blood resulting from kidney failure; may also be referred to as azotemia with clinical symptoms.

Uremic Symptoms - Subjective manifestations of renal failure including some of the following: anorexia (lack of appetite), nausea and/or vomiting, muscle cramps, itching, fatigue, forgetfulness, inability to concentrate. This is not an inclusive listing of uremic symptoms.
SUMMARY

Kidney failure is fatal unless treated with renal replacement therapy. The patient should be involved in making the decision about whether to have treatment and what type of therapy to have. Cognitive and physical changes, as well as the emotional and social stressors of confronting a life-threatening illness, complicate efforts to educate patients about the effects of kidney failure and the treatment options. No prior research has been directed at describing patients during the pre-end stage period. This study describes and explores the knowledge, attitude, and uncertainty in patients with decreased kidney function who have not started renal replacement therapy.
CHAPTER II

This chapter presents a review of the literature and a discussion of the conceptual framework for the investigation. The literature review includes relevant studies of the neurological effects of uremia, the psychosocial effects of renal failure, and studies addressing treatment selection and compliance in patients with renal failure. The conceptual framework for the study includes a discussion of concepts central to the study derived from models and theories in nursing, education, and psychology.

REVIEW OF THE LITERATURE

The review of the literature for this study addresses the neurological effects of uremia upon cognitive functioning, the psychosocial concerns of patients with renal failure, and education for treatment selection and adherence in pre-dialysis and dialysis patients.
Neurological Effects of Uremia

Uremia is defined as "...a toxic condition caused by the presence in the blood of waste products that are not being eliminated in the urine because of a failure of the kidneys to secrete urine." (Neufeldt, 1988, p. 1468) Luke and Strom state that "...the measurement of blood urea (or blood urea nitrogen, B.U.N.) offers the best single laboratory index of the likelihood of certain symptoms being 'uremic' in origin." (Luke & Strom, 1990, p. 805) The definition offered in Webster' (Neufeldt) is slightly erroneous in that patients with uremia may secrete [sic] (excrete) urine but the urine produced lacks sufficient levels of waste products (e.g. urea nitrogen and creatinine) to prevent the person from becoming sick with the symptoms of uremia. Uremia is defined by Luke and Strom (1990, p. 801) as "...the signs and symptoms associated with the retention of the end products of nitrogen metabolism."

Numerous studies have reported on the various neuropsychological effects of uremia associated with kidney failure. (Mahoney & Arieff, 1982; Souheaver, Ryan, & Dewolfe, 1982; Teschan, et al, 1979; and Ginn, 1975) In addition, the cognitive alterations present in uremia have
also been described. (McDaniel, 1971; Ginn, 1975; Missenson, Levin, Klawans, & Nausieda, 1977; Stewart & Stewart, 1979) These alterations include mental confusion, alterations in mental concentration ability, decreases in short-term memory, and difficulties in mental reasoning. The effects of kidney failure, specifically uremia, upon general and specific neurological functions is well documented.

Most studies have focused on the general effectiveness of dialysis for obtaining a reversal of the systemic effects of uremia. (Teschan, et al, 1979; Mahoney & Arieff, 1982) More recently, studies have addressed how specific modalities (hemodialysis, peritoneal dialysis, and/or transplantation) may vary in the respective improvement of mental functioning. (McKee, Burnett, Raft, Batten, & Bain, 1982; Osberg, Meares, McKee, & Burnett, 1982; Gilli & De Bastiani, 1983; Ratner, Adams, Levin, & Rourke, 1983; Jackson, Warrington, Roe, & Baker, 1987; Wolcott, Wellisch, Marsh, Schaeffer, Landsverk, & Nissenson, 1988)

These studies do not report on specific changes that occur as the azotemia (i.e., the accumulation of waste products in the blood) is worsening prior to the need for
the initiation of dialysis. Teschan et al (1979) reported on quantitative indices of uremia in patients with renal failure prior to starting dialysis, six months after hemodialysis, and following renal transplantation. In this study, patients did demonstrate improvement following the initiation of hemodialysis and further improvement following renal transplantation. The patients in the pre-dialysis group were classified as either "low azotemic" or "high azotemic," depending upon their serum creatinine level. As serum creatinine is directly related to muscle mass, higher levels reflect less kidney function only within the individual, not necessarily when individuals are compared to each other. Therefore, the classification of "low azotemcs" and "high azotemcs" is an arbitrary distinction. Teschan used performance measures of cognitive functioning to assess sustained attention, selective attention, speed of decision-making, short-term memory, and mental manipulation of symbols.

Souheaver, et al (1982) described a study in which patients with advanced renal failure, neurological disorders, and medical and/or non-psychiatric diagnoses were evaluated with regard to neuropsychological functioning.
Each of the three groups were administered the Halstead-Reitan Battery (12 subtests); the results revealed that the patients with uremia and neurological disorders had a similar Average Impairment Rating (AIR). (Souheaver, et al, 1982) With the application of statistical analytical procedures for each group and for each of the subtests, the data revealed that the uremics had unique patterns of deficit. In comparison with the neurological disorder group, uremics performed better on auditory alertness and finger oscillation speed; they were equally impaired on subtests of visual alertness, flexible thinking, and speed of mental manipulations. In comparison with the medical-psychiatric patients, the uremics were more impaired in general and specifically were more impaired on subtests of visual alertness, flexible thinking, and rapid mental manipulation. According to Souheaver (1982, p. 495) the findings "...suggest that uremic patients do not show an attention deficit per se - as long as the task that confronts them requires only passive and automatic reception of auditory stimuli and without effort to organize the material or to establish mnemonic devices." Further, they wrote that "...such findings indicate that uremic patients
experience great difficulty with novel problem-solving tasks and are unable to deal rapidly and effectively with situations that require assimilation of two or more pieces of information simultaneously." (Souheaver, et al, 1982, p. 495) This report of the unique patterns of strengths and weaknesses experienced by uremic patients has potentially significant implications for the assessment and planning of care for persons with end-stage renal failure.

Smith and Winslow (1990) reported on a study of cognitive functioning in two groups of hemodialysis patients (n=12). The Number Connection Test was administered prior to a dialysis treatment and one hour after the start of the treatment. The order of test administration was reversed for each group. The findings suggested a possibility of decreased cognitive functioning during the dialysis treatment. This finding is of potential significance as most hemodialysis patient teaching takes place when the patient is receiving the treatment.
Psychosocial Concerns of Renal Failure Patients

Chambers (1986) reported on staff nurse perceptions of nursing diagnoses most often experienced by hospitalized dialysis patients. Respondents were asked to rate the frequency of use of each of ninety diagnostic labels. Seventy of the nursing diagnoses had been accepted for clinical use and testing by the Third and Fourth Congresses of the North American Nursing Diagnosis Association. Twenty additional labels were included as developed within the primary testing institution. Forty-eight nurses from two hospitals representing three renal units (two dialysis units and one inpatient renal/medicine unit) completed the survey tool. Thirty-eight of the respondents had thirty-six months or more of renal nursing experience. The most frequently selected psychosocial nursing diagnoses were those concerning fear (79%), anticipatory anxiety (73%), frustration (68%), mild anxiety and body image disturbance (65% for each), independence-dependence conflict (63%), powerlessness (60%), moderate anxiety (58%), sexual dysfunction (58%), and ineffective individual coping (52%). Procedures for establishing reliability and validity of the survey instrument were not described.
Frank (1988) described the use of Roy’s Adaptation Model in the psychosocial assessment of renal dialysis patients. The author suggests potential questions for assessing the patient’s emotional and social status in adjusting to dialysis in the four adaption areas of Roy’s Model: self-concept, roles, interdependence, and physical/physiologic. Suggestions about potential nursing diagnoses applicable to these patients are suggested. Only limited references are cited and there was no reference to the previously described study (Chambers, 1986) of staff nurse perceptions of most frequently used nursing diagnoses. Publication delays may have contributed to this omission.

Bihl, Ferrans, and Powers (1988) reported on a study comparing perceptions of hemodialysis patients (n=18) and continuous ambulatory peritoneal dialysis (CAPD) (n=18) patients about stressors and quality of life. The age range of respondents was 27-75, with the hemodialysis respondents having a mean of 50 years of age (S.D.= 13.97) and the CAPD respondents having a mean of 50 years of age (S.D.=14.38) The Hemodialysis Stressor Scale (rewritten with appropriate wording for CAPD patients) identifies psychosocial and physiological stressors. Uncertainty about the future and
limits on time for vacation were the most highly ranked psychosocial stressor in CAPD patients. Uncertainty about the future ranked sixth for hemodialysis patients. On the basis of biophysical factors, the CAPD group had a more positive response to treatment, but the two groups were similar with regard to stressors, quality of life ratings, and perception of health. This study was limited by relatively small sample size (eighteen per group) and by the wide range of respondents ages. The judgments of stressors and indicators of quality of life can be expected to be different depending upon life cycle stage and tasks. The authors noted that the findings should not be generalized. Further limitations included the lack of explanation of statistical procedures for rank ordering of stressors and the inappropriate use of an inferential statistical procedure (ANOVA) with a convenience sample of very small size.

Fuchs and Schreiber (1988) reported on a study of perceived stressors in hemodialysis (n= 30) and CAPD (n=30) patients. The CAPD Stressor Scale was used for CAPD patients and a modified version of the same scale for hemodialysis patients. Fatigue and limited physical
activity received the highest mean intensity score on the Stressor Assessment Scale for CAPD patients and hemodialysis patients, respectively. Limited physical activity ranked number two for CAPD patients and fatigue ranked number six for hemodialysis patients. Unlike the Bihl, Ferrans, and Powers previously described, uncertainty about the future received midlevel mean intensity score for each group, ranking 11th of 21 for CAPD patients and 13th of 21 for hemodialysis patients.

Gurklis and Menke (1988) replicated the 1982 study by Baldree, Murphy and Powers. The sample was larger (n=68) than the 1982 study (n=35) and respondents had been on hemodialysis longer in this study than in the 1982 study. Uncertainty about the future was not ranked in the top five stressors reported by this group, whereas it was ranked in a tie for fourth in the 1982 study.

Brock (1990) explored hemodialysis family members perceptions of their own (i.e., the family member’s, not the patient’s) uncertainty, information needs, and coping effectiveness. Thirty-two of eighty family members completed the mailed survey. Respondents completed three instruments: 1) an Information about Hemodialysis and
Treatment Instrument; 2) the McNett Coping Effectiveness Questionnaire; and 3) the Mishel Uncertainty in Illness - Family Member Form. The findings revealed that there was a negative correlation between knowledge and uncertainty ($r = -.53, p < .001$) and a positive correlation between level of education and coping effectiveness ($r = .39, p < .01$). There were no significant relationships identified between knowledge and coping effectiveness, nor between uncertainty and coping effectiveness. The small sample size is a limitation of this study. Eighty-one percent (n=26) of the respondents were female and racial demographics were not reported, which limit conclusions about how representative the sample was. While five family members, not included in the study, were asked to review the instruments, the instruments were not reviewed by a panel of experts, nor were field test or pilot procedures reported. The alpha reliability coefficient for the Hemodialysis Treatment and Information Instrument was .60, which is at the low end of acceptable according to Nunnally (1968) and below the revised (Nunnally, 1978) acceptable limit of .7-.8 for newly developed instruments.
Treatment Selection and Compliance

Two of the major concerns in care of patients with renal failure are helping the patient to select a treatment modality and assisting the patient to comply or adhere to the requirements of the program. The education of patients prior to the start of dialysis has not been extensively studied or reviewed. Yet, it is the pre-dialysis period during which the decision concerning the choice of renal replacement therapy is made. Compliance with the requirements of the program would seem to be more likely if the patient were involved in the selection process. This section of the review of the literature will address pre-dialysis educational efforts and selected studies of compliance behavior in renal patients.

Pre-Dialysis Education for Treatment Selection

Opinion and program description articles have supported the importance of the pre-dialysis education of patients and/or family members. (Chambers, 1979; Coover & Conlon, 1982; Chambers, 1983) Further, the rules and regulations for Medicare certified ESRD facilities mandates that treatment options be reviewed annually for each patient
enrolled in the program. The importance of these explanations, as well as strategies for discussing treatment options, to promote patient decision-making, have also been discussed. (Ulrich, 1981; Perras, Mattern, & Zappacosta, 1984; Burrows-Hudson, 1985)

In an opinion article, Kimmel (1990) discussed the need to have a developmental view of the patient with end-stage renal disease. This was also characterized as the life cycle of the end-stage renal disease patient. It is of particular interest for this review that the author specifically identified the period of renal insufficiency as an onset stage and called for attention to the tasks of the patient during this period. This included the following: "...confronting the particular realities of a diagnosis of ESRD, and choosing a long-term treatment modality."

Wynne (1981) described a program to orient new patients to the treatment process and environment, review treatment options, and meet members of the nephrology team, but emphasized that meeting the patient in advance of treatment was the ideal situation and seemed to imply that this rarely occurred. This program was based upon a belief in the importance of informing patients about the expectations of
treatment prior to initiating therapy in an effort to reduce anxiety and enhance personal control for participation. The article was limited by the lack of description of specific program details concerning implementation, e.g. the time devoted to various aspects of the program, assessment of patient knowledge, concerns, or preconceived ideas. In addition, there were no evaluative data provided, e.g. number of people who had been through the program, outcome assessments, etc. The potential for cognitive alterations from uremia was not considered in this program description.

Starzomski (1986) described a program developed to provide information prior to decision-making about the treatment options and the initiation of dialysis. The program was offered in two or three sessions over a two or three week period. Some patients participated as early as a few months prior to the start of treatment, but others attended the educational programs only a few days in advance of treatment. Some patients participated in the educational program but had already made a treatment decision or had been prescribed a treatment plan. An evaluation was conducted after the first fifteen months; sixty-three patients went through the educational program during this
Thirty-three patients were identified as a sample to participate in the evaluation. Of those participating prior to making a decision about the type of treatment (n=26), ninety-four percent believed the program was helpful in assisting with decision-making. Of those who participated having already made a decision (n=7), the sessions were judged inadequate, because the decision had already been made. The pre-dialysis group suggested that the information be provided one year prior to starting dialysis. The authors report the decision to participate is made by the nephrologist and the patient/family and that a comprehensive patient/family assessment is conducted by the nurse, dietitian, and social worker. There is no description of a specific assessment tool. Reliability and validity procedures for the post-program evaluation tool were not described. In addition, the author does not describe when, or under what circumstances, the nephrologist may refer the patient and family for the pre-dialysis education program. Patient/family interest in the program is identified as a reason for program participation. The latter acknowledges that patient/family readiness for learning may precede nephrologist identification and referral. It would be
helpful if the author described how the patient and family became aware of the program if nephrologist referral were not a requirement. The program description and patient assessment offer no consideration of potential cognitive alterations of uremia, prior experience, or preconceived ideas.

Nitz and Shayman (1986) described a patient education program funded by the State of Missouri to introduce patients to treatment options in advance of starting therapy. The purposes were to provide information about the variety of treatment options, to decrease anxiety, to control facility bias for a preferred modality when informing patients, and to contain costs. Patients were referred by physicians with the expectation that dialysis would be needed within one year. The educational sessions consisted of one hour a week for seven weeks. The classes were held at night. The educational program was offered in two cities, St. Louis and Kansas City. This report lacks descriptive statistics concerning the number of patients and/or family members participating, nor data concerning how long in advance of starting dialysis individual patients participated. Pre-test and post-test tools are used, but
there is no description of procedures performed to establish reliability and validity. Therefore, confidence in the report that post test scores exceeded pretest scores is limited. The authors reported that most rated the seminars positively and none rated the seminars negatively. A table summarizing treatment selection by program participants was seemingly in contradiction with the narrative description. No other evaluative data were presented and there was no indication of concern about cognitive alterations from uremia.

Geary and Lawry (1988) described an educational program for pre-dialysis patients and their families. The purposes of the program were to "...provide education to patients while they were mentally alert, capable of processing and comprehending information about end-stage renal disease (ESRD) and treatment requirements." (Geary & Lawry, 1988, p.32) A planning survey (Fall, cited in Geary & Lawry, 1982) provided information that many patients reported feeling overwhelmed with the diagnosis of renal failure. The article describes the content of the program and administrative components of its implementation. There was no evaluation of the program, other than a couple patient
quotations indicating that information helped to decrease fears and enhance acceptance.

**Education for Adherence or Compliance**

Watchous, Thurston, and Carter (1980) reported the results of a pilot study with adult hemodialysis patients (n=10) to determine if programmed learning could help patients on dialysis adjust to the reality of renal failure. The method selected involved the administration of a programmed learning instructional unit with six behavioral objectives concerning renal regulation of fluid and sodium, alterations in regulation associated with kidney failure, signs and symptoms, complications, and sources of sodium and fluid intake. This information was provided during a single hemodialysis treatment. When participants were asked if the information would be of helpful to new dialysis patients, each of the ten participants responded positively. The highest gain scores (pre-test to post-test) were obtained by four of the ten who had been receiving treatment less than six weeks. There are several significant limitations to this study: 1) the relationship of the method, i.e. providing factual information the need to restrict fluid and
sodium in renal failure, to the stated purpose of the study, i.e. to help adjust to the reality of renal failure, was not clearly established, as implications for personal behavior were not described or explored; 2) the sample was small; and 3) a discussion of statistical significance implying the generalizability of the results. This study also gave no consideration to cognitive alterations associated with uremia. The investigators (Watchous, Thurston, & Carter, 1980, p.80) further suggested that the first few weeks of dialysis treatment might be "...an optimum learning time." This finding might have been alternatively explained as representative of a lack of pre-dialysis education and a significant desire for this education.

Ulrich (1981) described a study of adherence to the therapeutic regimen in adult dialysis patients (n=46) who had been receiving treatment for at least three months. Adherence criteria were based upon pre-determined expectations for serum potassium, blood urea nitrogen, and serum phosphate levels, a weight gain allowance for fluid accumulation, and presence in the dialysis unit for the prescribed treatment. The data indicated that only four
percent of the patients achieved adherence in each of the areas identified. Further analysis revealed that the majority adhered with presence for treatment (100%), serum potassium level (65%), and weight gain (52%). With regard to the patients' perceptions of adherence, forty-three percent thought they adhered very well and forty-one percent believed they adhered fairly well. The author suggested that adherence to potassium restriction was based upon the educational content provided in teaching patients about the life-threatening consequence of cardiac arrest from increased serum potassium levels. The author also suggested that the subjective symptoms experienced by the patient, such as cramping and shortness of breath, may have accounted for patient adherence to fluid restrictions. The author noted that respondents scored high on the internal locus of control scale, as well as the high on the powerful others scale. The contrast of this finding with that of healthy adults, who if they score high on the internal locus of control scale will tend to score low on the powerful others scale, is suggested to be due to perceived dependence on staff and equipment used necessary for treatment. Study limitations included the following: 1) lack of theoretical
support for derivation of the adherence criteria, as these were generated from twenty experienced nephrology nurses; 2) lack of explanation of procedures to establish reliability and validity of the instruments used; 3) lack of explanation of statistical procedures and partial presentation of statistical data without supporting rationale and/or interpretation; and 4) an overall lack of literature review and theoretical support for the investigation.

Stephenson and Hayes (1982) described a modular education program for dialysis patients new to treatment based upon adult education concepts of self direction and self control, but noted problems in evaluation of program effectiveness. The authors cite a reluctance to use pre-test/post-test measures because of the perceived threat of testing in adults. The authors describe the use by nurses' of a Patient Readiness to Learn Assessment Tool and it is included in the article. The content of the program, modular components of the program, use of dialyzer models, etc. are described. The authors offer no summary statistics concerning how long the program has been operational, how many individuals have been able to receive the program prior
to starting dialysis, and no evaluation of the outcomes of the program. The Patient Readiness to Learn Assessment Tool (Wynne, 1981) only grossly considered patient level of consciousness in the form of the following options: alert, oriented, confused, unresponsive.

Cheek (1982) studied the feelings about illness in a convenience sample of twenty-seven adult hemodialysis patients who had been receiving treatment for at least two months in an attempt to determine factors contributing to compliance or noncompliance. Only one respondent (3%) was determined to be compliant with regard to the three areas of compliance identified for study: potassium level, phosphate level, and between treatment weight gain. Serum phosphate and serum potassium levels were determined to not be reliable predictors of compliance. The authors measured response to illness on a Response to Illness Questionnaire and identified that respondents who were had more positive feelings toward the illness were more compliant in the area of weight gain. Age and marital status were demonstrated to predict compliance with weight gain. The feelings of the compliant group included the following: acceptance of illness, no blame of others, self-responsibility for care,
control of anxiety. The feelings of non-compliant group included the following: illness viewed as enemy or burden resulting in being defenseless or powerless, illness viewed as unjust, and dependency was not resented. Study limitations include the following: 1) small, convenience sample; 2) lack of information on reliability and validity procedures for the instruments used; 3) the use of statistical procedures, i.e. Discriminant Function Analysis, in a small sample, without explanation about how requisite assumptions were met and/or their violation justified. Even with the limitations identified, the data offer some useful insights concerning how feelings about an illness may impact upon behavior. Consequently, this offers support of the need to consider patient perspectives when assessing readiness for learning and planning educational interventions.

Parker and others (1985) described an interventional study of adult hemodialysis patients (n=12) who were screened for participation by a required demonstration of having adequate knowledge for compliance. The nurse intervention consisted of a structured interview/assessment guide in which data are collected (e.g. blood pressure,
weight, lab work, patient perceived problems with medications or diet), goals are determined, and strategies for accomplishment are reviewed. The twenty-five minute intervention session was conducted during each hemodialysis treatment. The investigators reported that it was not possible for the same nurse to work with each patient at each treatment. Eight patients completed the study. Blood pressure dropped during the intervention phase of the study but was not maintained after intervention. No significant changes were noted in weight gain, serum potassium or serum phosphate levels. The elevation of blood urea nitrogen after intervention was explained by the simultaneous occurrence of the Thanksgiving and Christmas holidays. Limitations of the study include the following: 1) very small sample size; 2) lack of information on procedures to determine reliability and validity of data collection tools; 3) lack of information about nurse training to assure reliability and validity of the administration of the treatment intervention; and 4) lack of consideration of patient attitudes and feelings about their situation as factors potentially contributing to lack of compliance or change in behavior.
Summary

From this review of the literature, it can be seen that there is an increasingly positive expression of the belief that individuals have a right and a responsibility to be involved in decision-making concerning treatment for alterations in health. It is also apparent that there is an awareness of the neurological sequelae of uremia and the extraordinary psychosocial stressors of living with kidney failure. While a few programs for pre-dialysis education or education shortly after onset of treatment have been described in the literature, these programs do not offer consideration of the neurological effects of uremia upon cognitive function. Further, the literature generally lacks attention to assessing the knowledge and attitudes of individuals and the systematic planning of education about treatment options when neurological functioning is intact.
CONCEPTUAL FRAMEWORK

The conceptual framework for this investigation was guided by basic premises of the investigator about nursing and education. The investigator believes that education of patients and families is a significant component of nursing practice. Further, the investigator believes that factors within the person, such as attitudes and the meanings that are formulated from one's knowledge and attitudes, may serve to enhance or limit the education of patients. Several theoretical and conceptual perspectives have been selected to demonstrate the proposed relationship of concepts under investigation. These include the following: 1) assessment of the human response in nursing; 2) readiness and the information-processing model in education; and 3) the person-environment interaction model in psychology.

Nursing and Assessment of Human Response

The definition of nursing is centered around the concept of human response and is offered by the American Nurses' Association as follows: "Nursing is the diagnosis and treatment of human responses to actual or potential
health problems." (ANA, 1080, p.9) The phrase 'human response' is meant to reflect a perspective that individuals respond differently to different situations involving health problems. Human response patterns, such as deficiencies in decision-making and self-care limitations, are areas for nursing intervention within the scope of nursing practice and are more than subjective symptoms or disease states. (Gordon, 1987)

The assessment and diagnosis of a human response to an actual or potential health problem includes consideration of the subjective and objective data gathered from the patient. Beyond the subjective and objective data, the human responses reflect how a symptom or disease state (actual or potential) impacts upon the individual. As such, the element of interpretation by the individual of what meaning the response has for the individual is an essential requisite for planning. Emotional and social factors are also integral to understanding and interpreting the human response. The patient's perspective becomes a critical element in guiding the specification of the nature of the nursing diagnosis, as well as guiding the differential selection of the appropriate intervention.
The disciplines of nursing and education each emphasize assessment and diagnosis of their respective target client groups. (Gordon, 1987; Carpenito, 1984; Witkin, 1984; Pennington, 1980; Davis, Hull, & Bouteaugh, 1980) The educative function of nursing is an intervention that is selected for use based upon the assessment and diagnosis of the patient and/or family. The major purpose of the assessment is to assure that accurate, necessary data are collected, the correct problem identified and the appropriate plans for intervention determined. Many educational strategies varying widely in content and method are available for implementation. Thorough assessment of the patient is critical to appropriate planning and implementation. Evaluation through on-going assessment of process, as well as evaluation of outcome, is also integral to both nursing and education. (Gordon, 1987; Gagne, 1985)

Educational Readiness and Information-Processing

The educative function of the nurse requires awareness and understanding of the nature of learning, as well as assessment of needs for and readiness for learning. In patient education, the nurse/educator extends beyond the
actual content that needs to be acquired and the method of presentation and assesses the physiological, psychosocial, and cognitive status of the individual. The physiological alterations, the psychosocial perspective and supports that are available, and the cognitive status of the individual are all components of determining readiness to engage in learning.

Darkenwald and Merriam (1982) described perspectives of adult readiness and orientation to learning. These perspectives have been variably organized according to 1) developmental tasks, 2) milestones, 3) life cycles, and 4) life stages. While each of these offer useful organizing frameworks, the work of Kimmel (1974) is noteworthy for his attention the role of interaction and the acquisition of experience. Kimmel utilizes the concepts of 'situation experience,' 'interaction experience,' and 'self-experience' to describe how events or milestones in a person's life are experienced and interpreted. Kimmel asserts that every experience is interpreted from an interaction perspective and that meanings are obtained from this interaction of the person with various aspects of the environment.
Others in adult education emphasize the effect of experience and the interpretation of experiences as factors influencing the learning and participation in educational activities. (Darkenwald and Merriam, 1982; Cross, 1981) Darkenwald and Merriam (1982) note that the accumulated experiences and interpretations of the experience are key features of the adult and underlie what the adult learner brings to any learning situation. Cross's proposed a model for understanding adult learners considers situational aspects and personal characteristics. For the adult educator, Cross emphasized that assessment and understanding the physical, psychological, and sociocultural characteristics of the adult learner were requisites to assessing readiness for learning and subsequent planning efforts. The assessment of readiness for learning in adult education, as well as the emphasis upon the characteristics of the adult learner, parallels considerations that are similar in conceptualization to those previously described within a nursing framework.

Gagne (1985) described the information-processing model as an integration of memory and learning that is composed of internal processes and external events. According to Gagne
(1988), the significance of this model is that it provides a systematic approach to the design of instruction appropriate for the desired outcomes of learning.

Gagne (1985) described conditions for learning that are essential for the design of instructional activities that will result in learning by the individual. The conditions of learning include both internal processes and external events.

The internal processes of learning include attention (reception), selective perception, semantic encoding, retrieval, response organization, control processes, and expectancies. According to the information-processing model, attentional events occur very quickly as stimuli from the environment are received and sorted for further categorization by selective perception. Palmer (cited in Gagne, 1985) described selective perception as the differential attention to some aspects of stimuli while simultaneously not attending to other features. Semantic encoding is refers to the processes by which an individual meaningfully organizes the information in long-term memory. The organization may be in a variety of forms, such as verbal units of words or sentences or visual images such as
pictures or diagrams. Retrieval from long-term memory requires the ability to search for that which has been stored. Gagne (1985) has described transfer of learning as the ability to use retrieval for recall or reconstruction in order to solve problems in new situations. Response organization deals with the type of response that will be required, such as using one’s hands and fingers to write a response.

Bovy (1981, p. 208) described "...the attention mechanism of a learner with a highly developed cognitive schema (as in the case of a learner with a great deal of prior knowledge or experience with the content)." It was suggested that this experienced learner will be "...very different from that of a naive learner and ...likely to require qualitatively different types of instructional support." (Bovy, 1981, p. 208) Theoretically, these concepts have implications for planning for the selection of educational interventions.

The executive control processes and the expectancies are also considered internal processes by Gagne (1985), but he views them as separate from information-processing and dependent upon prior experiences. Bovy also discusses
metacognition (1981, p. 213) as the "...ability to monitor and adjust consciously one's cognitive processing activity to meet the needs of a learning task." Further, this process incorporates all internal processes, such as attention and memory.

In the design of instruction, Gagne (1988) suggested that externally generated events (i.e., instructor actions) are necessary to achieve the desired learning outcomes. These external events (Gagne, 1988) include 1) stimulation to gain attention; 2) informing about the objectives; 3) reminding about previously learned information; 4) presenting clear material; 5) guiding learning through appropriate semantic encoding; 6) eliciting performance through practice or demonstration; 7) providing feedback about performance; 8) assessing performance with additional feedback; and 9) arranging practice opportunities.

Models of Person-Environment Interaction

A variety of perspectives and theoretical formulations concerning the person, the person's environment and the nature of the interaction have been proposed in the field of psychology. Walsh (1985) described some of the earliest
contributions to the field of person-environment psychology as related to the work 1920’s work of Kantor and the 1930’s work of Lewin. According to Walsh (1985), "Kantor believed that psychology should attend to the person-environment [sic] unit. Lewin’s contribution is described (Walsh, 1985, p. 330) through specific delineation of a belief that "...behavior is a function of the person and the environment."

Lewin’s conceptualization of a ‘life space’ is described by Hill (1977) as being composed of the person, the person’s environment, and everything that influence’s the person’s behavior. The life space conceptualization of Lewin includes the person’s goals, the objects of avoidance, and the barriers that impact on movement toward or away from the goals. According to Hill (1977), Lewin’s conceptualization was essentially a scheme for describing behavior and offered some insights for prediction, but did not extend into a theoretical basis to explain learning.

Endler and Magnusson (1976) also proposed a person-situation interactional model. This model contained four components: 1) behavior; 2) individual; 3) cognitive and motivational factors of the person’s behavior; and 4) the
meaning of situations. This model is represented by an algebraic equation of $B = f(P,E)$. In the equation, $B$ (behavior) is a function of the combined effects of the person and the environment. This is interpreted by Walsh (1985, p. 332) as "...a synthesis of person and environment in which the interaction of the two is the main source of behavior."

It influence of attitudes upon decision-making and attention to the requisites of treatment are believed to be an important component of understanding patients with decreased kidney function. Bandura (1969, p. 595) stated that "... it is widely assumed that attitudes are important determinants of overt actions and consequently any changes brought about in the attitudinal domain will have widespread effects upon subsequent behaviors." The interrelationship between values and attitudes as components of behavior can be further elucidated. Gagne (1985, p. 229) suggests that attitudes be defined as "...the degree of commitment expressed to statements describing choices of personal action ...toward some class of objects, persons, or events. Gagne (1985) suggested this definition for use when measures are by verbal statements. It is clear that knowledge and
attitudes are related to behavior, but this relationship is not necessarily causal. As noted by Eson (1972, p.297), "...in some respects values function independently of cognition and prior to cognition."

Other models have been suggested to explain or predict behavior primarily to achieve the goal of compliance. Becker's Health Belief Model (1976) modified from the work of Rosenstock (cited in Becker, 1976) utilizes concepts of perceived susceptibility, severity, costs and benefits as cues for action. Yet, Becker (1979) clearly notes that the possession of knowledge is not sufficient to explain behavior. Svarstad (1986) offers a health communication model which considers both the cognitive and motivational aspects of the individual but focuses upon the process of communication as most important in obtaining compliance. This model appears to focus upon the strategies and techniques of the provider of information, but Svarstad (1986) emphasizes the feedback loop in the communication process so that the thoughts and perceptions of the patient are understood. These models lack an attention to the role of assessment of the patient/client prior to the implementation of any discussion.
The Endler and Magnusson Model of person-situation interaction is believed most useful for this investigation, because of its emphasis on the person and the person's interpretation of the situation. The model does not appear developmentally to have considered of the role of the practitioner-helper in terms of influencing the behavior side of the equation, but the relationship and importance of the person and the person's interpretation of the environment demonstrate the relationship between variables that are believed relevant to this investigation. Perhaps with further description of the environment or situational component, the role and functions of the nurse adult educator could emerge.

Summary

The information-processing and information-seeking behaviors about renal replacement therapy are viewed as a function of characteristics of the person (knowledge and attitudes) and the situation (uncertainty, prior experience, and experience with a nephrologist). In this study, the cognitive and motivational factors of the person will be explored through measurement of knowledge and attitudes.
The personal meanings of the situation will be explored through measurement of uncertainty, assessment of extent of prior experience with others with kidney failure and time under the care of a nephrologist.

Uncertainty is viewed as a factor potentially influencing the internal process of semantic encoding (assigning meaning), as well as a factor dependent upon situational events dependent upon time and place, i.e. those events external to the person. While not a specific area of investigation in this study, the cognitive alterations of uremia are considered potentially influential to the internal events of information-processing that deal with attending, selective perception, semantic-encoding, retrieval and response. Attitudes, prior experience, and length of time under the care of a nephrologist are considered as influencing the processes of executive control, as well as moderating specific expectancies.

The knowledge, attitudes and uncertainty of adults are considered factors contributing to behavior in adults with decreased kidney function. The interrelationship of these variables for consideration in this investigation have been demonstrated in the previous review of selected concepts and
models within nursing, educational and psychology. While this investigation does not address the overall outcome of treatment selection, the choice of treatment is believed to ultimately impact upon the overall satisfaction of the patient. The knowledge, attitudes, and uncertainty in adults with decreased kidney function are viewed as factors that contribute to treatment selection for renal replacement therapy.
CHAPTER III

METHODOLOGY

The procedures used in the implementation of this exploratory study of the knowledge, attitudes, and uncertainty in patients with decreased kidney function are described in this chapter.

Research Design

An Ex Post Facto (causal-comparative) design was selected for this study. Fraenkel and Wallen (1990, p.305) describe causal-comparative research as seeking to "...determine the cause or consequences of differences that already exist between or among groups." Further, Fraenkel and Wallen (1990) described three potential outcomes of a causal-comparative design: 1) to explore effects caused by group membership, 2) to explore causes of group membership, and 3) to explore the consequences of an intervention or existing characteristic. As the difference between the groups already exists, based upon experience, exposure, or an existing condition, the study is sometimes referred to as ex post facto (after the fact). (Fraenkel & Wallen, 1990)
In this study, the intent was to explore the effects of decreased kidney function in relationship to individual knowledge, attitude, and uncertainty about renal failure. This design seeks to explore "...the consequences of differences that already exist between or among groups of individuals." (Fraenkel & Wallen, 1990) This study is quasi-experimental as no variables are manipulated.

VARIABLES

This study had one main independent variable and three dependent variables. The main independent variable was decrease in kidney function. The three dependent variables were the scores obtained on the Kidney Knowledge Test (KKT), the Kidney Failure Attitude Scale (KFAS), and the Mishel Uncertainty in Illness Scale - Community (MUIS-C). In addition, three extraneous variables were considered. These were level of education, prior experience with kidney failure via friends or family, and length of time under the care of a nephrologist. As this was an exploratory study with a nonprobability sample, demographic data about gender, age, race/ethnicity, religion, marital status,
financial concern, and time under the care of nephrologist were also collected.

Independent Variable

The main independent variable for this study was decrease in kidney function. Two groupings were identified for this variable. Group I refers to patients whose serum creatinine level is 2.4mg/dl or less. Group II refers to patients whose serum creatinine is 2.5mg/dl or more. Group I patients may be described as having renal insufficiency. Group II patients may be described as having chronic renal failure. These are categorical variables.

Constitutive Definition

Luke and Strom define chronic renal failure as "...permanent...significant reduction in glomerular filtration rate... which...leads to the uremic syndrome and end-stage renal disease." (1990, p. 801) Additionally, Luke and Strom define chronic renal failure as having a glomerular filtration rate of <30-40ml/min and a serum creatinine of >2.5mg/dl. (1990, p. 801)
The terms renal insufficiency, renal failure, and uremia should be considered as representing a continuum of types of evidence that decreased kidney function exists. When renal insufficiency exists, the only evidence of this is usually abnormal laboratory data, such as an increased serum creatinine and/or a decreased creatinine clearance. With chronic renal failure, the creatinine clearance is less than 30-40ml/minute, but there may still be few, if any, clinical manifestations. As the patient progresses to end stage renal failure, the term uremia may be applied. Uremia is defined as "...the signs and symptoms associated with the retention of the end products of nitrogen metabolism...." (Luke & Strom, 1990, p. 801)

**Operational Definition**

Kidney function is operationally defined by the reported serum creatinine level. Renal insufficiency is operationally defined as a serum creatinine of less than 2.5mg/dl. Chronic renal failure is operationally defined as a serum creatinine of 2.5mg/dl or greater.
Justification

The serum creatinine level has been selected as the criterion by which to measure kidney function. The overall percentage of kidney function is often initially assessed through collection of a twenty-four hour urine from which creatinine clearance is calculated. The calculation of creatinine clearance is based upon a mathematical formula that compares the quantity of creatinine excreted into the urine with that remaining in the blood; height, weight, and urine volume are additional considerations in the calculation. The collection of urine for a twenty-four hour period is cumbersome and time-consuming and the serum creatinine level is most commonly used to measure serial changes in kidney function over a period of time. (Levey, Madaio, & Perrone, 1991)

While the most informative measurement of renal function is obtained by collecting urine for a twenty-four hour period and calculating a "creatinine clearance," patients referred to a nephrologist may, or may not, have a 24 hour creatinine clearance collected and calculated. In many instances, this information might have been collected by the referring physician. Because this information was
expected to not always be available, the serum creatinine level was used for conduct of this study.

The normal serum creatinine is 0.5-1.5mg/dl. This range of normal reflects variability in adult muscle mass. The potential for measurement error through laboratory procedures is a possibility. The ninety-five percent confidence limit for the reported serum creatinine level, representative of two standard deviations from the mean, is .3mg/dl (± .3mg/dl). (Walker & Mitch, 1988)

During conduct of the Pilot Test, the investigator identified that the serum creatinine levels of some respondents under the care of nephrologist were lower than had been expected. A review of the medical record indicated that these lower than expected serum creatinine levels also included physician progress notes indicating significant renal deterioration. In some cases, a calculated creatinine clearance was reported as less than normal.

Initially, the intent of the study was to require that participating subjects' serum creatinine be 2.5mg% or greater. If this requirement had been maintained, a number of appropriately eligible subjects (i.e. those with decreased kidney function under the care of a nephrologist)
would have been excluded. This observation by the investigator is consistent with comments by Levey, Madaio, and Perrone (1991) who cited prior study deficiencies resulting from the elimination of patients from clinical studies when the serum creatinine was less than 2-3mg%. Therefore, variable decrease in kidney function and the subject eligibility criteria were revised to include individuals who were under the care of a nephrologist with serum creatinine levels less than 2.5mg%, when evidence was available of renal insufficiency of a chronic nature, or the 24 hour creatinine clearance was less than normal.

Dependent Variable 1

The first dependent variable for this study is ability to process information about kidney failure.

Constitutive Definition

Information is defined in Webster's (Neufeldt, 1988, p. 693) as "...3) knowledge acquired in any manner, facts, data; learning, lore...." Process is defined in Webster's (Neufeldt, 1988, p. 1072) as "...4) a particular method of doing something, generally involving a number of steps or
operations...." Many descriptions and models of information processing have also evolved from developments in communication, psychology, and education.

From the communication literature, the Shannon Model describes an information source that transmits a message via a signal to a receiver. (Heinich, Molenda, & Russell, 1986) In addition to the concept of feedback, the Shannon-Schramm Model added the concepts of encoding and field of experience as variables influencing both the sending and reception of the message. (Heinich, Molenda, & Russell, 1986)

Cognitive psychologists have used a framework of information-processing to explain human learning. Bourne, Dominowski, Loftus, and Healy (1986) describe sensory memory, short-term memory and long-term memory as sequential, parallel, and interacting components of information-processing. They also state that behavior is dependent upon information that is available and the processing operations. (1986)

In education, Gagne (1985) described attention (reception), selective perception, semantic encoding, retrieval, response organization, control processes, and expectancies as the internal processes of learning. Gagne
(1985) believed that the internal processes of information-processing may be influenced by the design of specific instructional events to correspond with these internal processes. A taxonomy of educational objectives developed by Bloom, Hastings and Madaus (1971) differentiated the concepts of knowledge (recall), comprehension, application, analysis, synthesis, and evaluation.

In nursing, Roy (1988, p.239) defined information processing as "...human cognitive and emotional activity whereby the person takes in and responds to the environment."

For this study, information-processing is defined as the recall, comprehension, and application of facts concerning kidney function, kidney failure, and treatment options.

Operational Definition

For this study, information-processing ability will be operationally defined as the achievement score on a test of knowledge about kidney function, kidney failure, and treatment options.
Justification

Lovell (1987) described limitations on information-processing abilities encountered when there is excessive amounts of information, when the information is new or unfamiliar, or when the skill level of the person processing the information is marginal. The majority of individuals with kidney failure has minimal prior knowledge and experience with kidney failure and the treatment options. Factors such as anxiety, denial, and the physical symptoms of kidney failure may interfere with knowledge acquisition through information-processing.

Roy (1988) described a variety of investigations in nursing research in which one of three aspects of human information-processing were addressed. Roy (1988) noted that models focused primarily upon 1) input or perceptual processes, 2) memory or storage related activities, or 3) problem-solving or verbal associative learning.

This study explored how one’s knowledge about kidney impairment might influence behaviors or actions concerning treatment, but considers the impact of pathology upon input or perceptual processes and memory/storage processes, as well. Physiological changes associated with kidney failure
impair information input (perceptual) processes, memory (retrieval) processes, and thus may impact upon decision-making or problem solving.

Dependent Variable 2

The second dependent variable for this study was attitude toward kidney disease, as evidenced by feelings about kidney failure, treatment options, and information-seeking.

Constitutive Definition

Attitude is defined in Webster's New World Dictionary (Neufeldt, 1988, p.88) as "2) a manner of action, feeling, or thinking that shows one's disposition, opinion, etc and 3) one's disposition, opinion, mental set, etc."

Mueller (1986, p.3) adopted the following definition for attitude: "Attitude is (1) affect for or against, (2) evaluation of, (3) like or dislike of, or (4) positiveness or negativeness toward a psychological object."

Sudman (1982) identified three components of attitude that could be measured: 1) the affective or evaluative, like or dislike, pro or con, 2) the cognitive, that which is
known or believed to be known, and 3) an action, that which might be done based on the attitude.

Information is defined in Webster's New World Dictionary (Neufeldt, 1988, p. 693) as "...3) knowledge acquired in any manner, facts, data; learning, lore...." Seek, a verb, is defined in Webster's (Neufeldt, 1988, p.1215) as "...3a) to try to get or find out by asking or searching [to seek the answer to a question]...."

**Operational Definition**

For this study, information-seeking behavior about kidney failure will be the mean score on an instrument that measures attitudes about kidney failure, treatment options (dialysis and transplantation) and information-seeking activities.

**Justification**

Emotional or attitudinal components were also believed to be important in the individual's acquisition of knowledge and decisions about treatment.

Information-seeking is a construct used to explore a variety of phenomena. Lazarus (1966) describes five methods
of coping with threatening events; information-seeking is one of these methods. Heisel (1985, p.1) explored the construct of information-seeking in a group of aged black individuals with the intended benefit of assisting individuals to "...cope with their environment and maintain intellectual capacities."

Camp (1986) explored information-seeking and depression in young and older adults using Berlyne's theoretical framework of epistemic curiosity. Camp (1986) defined curiosity as information-seeking and tested Berlyne's two suggested sources of motivation for information-seeking: reduction of uncertainty to decrease conflict and personal needs satisfaction unrelated to the process.

Factors which may contribute to an individual's tendency to seek information may include a determination of personal relevance and value, an assessment of readiness, and whether the individual has the ability to seek and/or use information sources. As previously noted by Bandura (1969), Becker (1979), and Gagne (1985), attitudes are components of behavior and not necessarily dependent upon knowledge.
For this study, the desire for information and the likelihood of acting to seek information were components of attitude about kidney failure and treatment options.

Dependent Variable 3

The third dependent variable for this study was uncertainty in illness.

Constitutive Definition

Uncertainty is defined in Webster’s New World Dictionary (Neufeldt, 1988, p. 1452) as "...lack of certainty; doubt. Uncertain is defined in Webster’s New World Dictionary (Neufeldt, 1988, p. 1452) as "...1 a) not surely or certainly known; questionable; problematic; b) not sure or certain in knowledge; doubtful 2) not definite or determined, vague 3) liable to vary or change; not dependable or reliable; 4) not steady or constant; varying."

Mishel (1981; 1984; 1988; 1990) explored the concept of uncertainty as a factor affecting stress in illness. Mishel cited Budner’s 1962 description of uncertainty as "...a situation is judged as uncertain when it cannot be
adequately structured or categorized because sufficient cues are lacking." (Budner, cited in Mishel, 1981, p. 258)

Mishel (1984, p. 163) stated that "...uncertainty is generated by events characterized as vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information."

Mishel (1988, p.225; 1990, p.1) defined uncertainty as "...the person's inability to determine the meaning of illness related events. It is the cognitive state created when the person cannot adequately structure or categorize an event due to lack of sufficient cues."

**Operational Definition**

For this study, uncertainty is operationally defined as the mean score on the Mishel Uncertainty in Illness Scale (MUIS).

**Justification**

Patients with decreased kidney function live with the knowledge that a chronic disease exists. For patients with renal insufficiency, there is the potential for further deterioration of function and the possibility of kidney
failure. For patients with chronic kidney failure, there is the potential for progression to end-stage, requiring renal replacement therapy to sustain life. In most situations, the temporal course of the progression, or lack thereof, is unknown. Patients with decreased kidney function might be expected to experience some uncertainty about their illness.

Uncertainty may result from one's knowledge or lack of knowledge. One's attitudes derive from beliefs and knowledge and may influence one's behaviors choices and actions. When considering the potential behaviors of persons with decreasing kidney function with regard to actions to increase knowledge, the individual's level of uncertainty may be an influencing variable.

Extraneous Independent Variables

Three extraneous variables were identified that might also contribute to changes in the dependent variables. These were 1) level of education, 2) prior experience via family or friends with kidney failure and/or renal replacement therapy, and 3) length of time under the care of a nephrologist.
Education was expected to be related to one's knowledge about kidney function, failure, and treatment options. It was expected that individuals completing more years of education would have had more exposure to the sciences, either in college or post graduate education, and therefore would have more knowledge of basic human biology/physiology and the technology of dialysis and transplantation.

The expected relationship was that more education would be associated with greater knowledge about kidney function, kidney failure, and treatment options. The influence of education upon attitude about kidney failure, treatment options, and information-seeking is difficult is unclear, as other factors may influence one's attitude. Attitude may also be expected to be influenced by one's education. The level of one's education has been shown to influence the level of uncertainty: studies reported by Mishel (1984) have shown that individuals with less education tend to score higher on the uncertainty scales.

The previous experience of kidney failure and treatment options via relationships with family members and/or friends might be expected to result in differences in one's knowledge, attitudes, and level of uncertainty.
In addition, because this was an exploratory study of a nonprobability, purposive sample, demographic data about gender, age, race/ethnicity, marital status, religion, financial concern, and length of time under the care of a physician for treatment of kidney disease were also collected.

POPULATION AND SAMPLE

Target and Accessible Population

The target population for this study is English-speaking adults over age 18 in the central Ohio area who have been diagnosed with decreased renal function but who have not reached end-stage sufficient to require dialysis and/or transplantation. The accessible population is patients who are under the care of a board-certified nephrologist and identified as potential study participants. There is no formal listing of patients for whom dialysis and/or transplantation might be necessary. Therefore, the size of the target and accessible population was difficult to specify and the development of a frame was not possible.
Sample Size and Methods

Three nephrology practice groups in central Ohio were contacted by the investigator and the purposes of the study were explained. Each practice group is geographically located in a different area of Columbus, serves different hospitals, and thus receives patient referrals from throughout Columbus and counties surrounding central and southern Ohio. These practice groups were believed by the investigator to serve a diverse clientele, in terms of rural/urban locales, racial/ethnic diversity, and socioeconomic status.

A nonprobability, purposive sample of 241 potential study subjects were invited by cooperating nephrologist to request information about participation in the study. (Refer to Appendix: Letter from nephrologist to potential study participants). Following receipt of a request for information about the study, a letter describing the study and a Consent to Participate form were mailed to the potential study participant. These procedures were followed to protect the privacy and confidentiality of patients. These procedures did not allow prior consideration of subject characteristics, as access of the medical record
without consent would have been necessary.

Criteria for participation in the study included: 1) ability to read and speak English, 2) lack of diagnosed neurological impairment (e.g. cva, cortical disease, etc), and 3) absence of diagnosed psychiatric disorder (e.g. schizophrenia). In addition, the investigator requested that nephrologist consider that the potential participant have a decrease in kidney function, evidence of the possibility of progression, and absence of prior or current treatment by dialysis or transplantation. Patients with acute renal failure who had evidence of underlying renal insufficiency were considered appropriate for inclusion.

Frame, Selection, and Sampling Error Control
This is an exploratory study of a population that has not previously been studied. Because of the difficulty in identifying appropriate subjects, a nonprobability purposive sampling plan was selected.

Sampling errors in this study are possible due to an incomplete frame and the potential for selection bias. Frame error is possible, as the completeness of the list of invited participants was dependent upon the participating
nephrologist. As subjects volunteered to participate in the study, there is potential for selection bias.

To control selection error, the investigator met personally with nephrologist, or designated office staff, to explain the purposes of the study and the desired subject characteristics. This information was also communicated in writing. The investigator also carefully reviewed the names of volunteer subjects to assure that duplicate names were eliminated. The investigator anticipated that some patients might visit more than one nephrology practice group in search of a second opinion about the diagnosis of kidney disease.

Fowler (1988, p. 58) emphasized that if nonprobability sampling is used the reader should be clearly advised in advance about potential biases, such as availability, and that "...normal assumptions for calculating sampling errors do not apply." Holm and Llewellyn (1986, p.150) stated that "some would argue that a purposive sample is inherently random" as the "...investigator really has no way of knowing who the people will be who will meet the sample criteria." Kachigan (1986) suggested that when random sampling is not possible or feasible that the investigator
should "...strive for a sampling scheme which is in the spirit of random sampling...." Kachigan (1986) emphasized that one should attempt to have the sample representative of the population based on some logic and that certain segments not be overlooked. Selected demographic characteristics were collected so that respondents could be described.

INSTRUMENTATION

Three instruments were used in this study. These were a Kidney Knowledge Test (KKT), a Kidney Failure Attitude Scale (KFAS), and 3) Mishel's (1984) Uncertainty in Illness Scale - Community Form. The Kidney Knowledge Test and the Kidney Failure Attitude Scale were developed by the investigator. Procedures to establish the reliability and validity of the newly developed instruments (KKT and KFAS) are described below.

Kidney Knowledge Test

The Kidney Knowledge Test (KKT) was developed to assess the basic knowledge of individuals about the functions of the kidneys, the common laboratory tests used to measure
kidney function, the causes of kidney failure, the symptoms associated with kidney failure, and the basic treatment options for kidney failure.

The KKT is a thirty one (31) item multiple choice instrument. (Appendix: Kidney Knowledge Test) The multiple choice questions contain four potential responses.

The domain of content to be tested includes information typically included in physician-patient/family discussions when consultation for kidney disease occurs. The discussion typically includes 1) an explanation of what functions the kidneys perform, 2) an explanation of basic lab tests (i.e. the purpose and the findings), 3) the cause(s) of kidney failure, if known, 4) inquiry re: common symptoms of kidney failure manifestations, and 5) an explanation of treatment options.

The wording of the questions and the responses are designed to minimize threat and promote comfort with two of the options being "unsure" and "I don't know." The items relate to one of three knowledge subscales: kidney function, kidney disease, and treatment options. Scoring of the instrument consisted of summing the correct responses and calculating a percentage correct responses.
Reliability

The reliability of the Kidney Knowledge Test was assessed in a Pilot Study. Twenty-six (26) patients with decreased kidney function who were believed to be similar to the projected study population and met study eligibility criteria volunteered to participate in the Pilot Study.

A measure of internal inconsistency was made to estimate the reliability of the Kidney Knowledge Test. Cronbach’s Alpha was selected to establish an index of inter-item reliability. (Mueller, 1986) Inter-item reliability refers to the extent to which each item is "...measuring the same thing as each other item." (Walsh and Betz, 1985, p.52) Cronbach’s Alpha is a measure of how each item contributes to the overall score; as such, it is a test of internal consistency. Cronbach’s alpha represents an estimate of the true score variance in comparison with the observed score variance. (Mueller, 1986; Walsh and Betz, 1985)

The alpha reliability coefficient for the Kidney Knowledge Test was .8625. (Table I) Nunnally (1978) suggested that a reliability coefficient of .7-.8 is sufficiently high in the early stages of research.
As this instrument sought to assess knowledge about three areas of content, kidney function, kidney disease, and treatment options, alpha reliability coefficients were computed for each subscale of items. The subscale alpha coefficients offer further confirmation that the three content areas were represented and contributed to internal consistency. These subscale alpha reliabilities are reported in Table I.

<table>
<thead>
<tr>
<th></th>
<th>Pilot (n=26)</th>
<th>Study (n=75)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Function Subscale</td>
<td>$\alpha = .67$</td>
<td>$\alpha = .71$</td>
</tr>
<tr>
<td>Kidney Failure Subscale</td>
<td>$\alpha = .76$</td>
<td>$\alpha = .79$</td>
</tr>
<tr>
<td>Treatment Subscale</td>
<td>$\alpha = .87$</td>
<td>$\alpha = .92$</td>
</tr>
<tr>
<td>Total Instrument</td>
<td>$\alpha = .86$</td>
<td>$\alpha = .89$</td>
</tr>
</tbody>
</table>
From Table I, it can be seen that the alpha reliability coefficients for the Kidney Knowledge Test subscales and the entire instrument were higher in the study than those obtained during the Pilot Test.

Validity

Fifteen experts from the fields of medicine (nephrology), nursing (nephrology), nutrition (nephrology), social services (nephrology), education (adult), and measurement/instrumentation responded to a request to participate as a Panel of Experts. These individuals responded to a request to review the Kidney Knowledge Test for content validity. The experts reviewed the questions contained in the instrument to determine whether the questions were appropriate for measurement of knowledge about the functions of the kidneys, the potential causes of kidney failure, the symptoms of kidney failure, and the potential treatment options. In addition, the Panel of Experts was asked to suggest other areas for inclusion and to identify areas that should be deleted. An assessment of appropriateness of wording and clarity was also requested. The Kidney Knowledge Test was revised after consideration of
the suggestions provided. Appendix L lists those individuals contacted who from which responses were obtained.

Following instrument revision, a Field Test of the Kidney Knowledge Test was conducted to further assess content validity and establish face validity.

Field test participants included current dialysis patients for whom the content was familiar and/or relevant. Dialysis patients were considered to have characteristics similar to the proposed study population as they had experienced living with decreased kidney function, as well as the need for renal replacement therapy.

Twenty of twenty-eight questionnaires sent to current hemodialysis (16) and continuous ambulatory peritoneal dialysis (12) patients were returned. Two respondents misunderstood the directions and did not complete the field test evaluations. They believed that since the questionnaires were to be used with pre-dialysis patients that they should not complete the evaluation of the questionnaires. Therefore, eighteen respondents completed the majority of the questions asked on the field test of the instruments. Several offered additional comments.
For the Kidney Knowledge Test, respondents generally indicated that the questions would determine the patient's knowledge about kidney function, causes and symptoms of kidney failure. Three respondents indicated that they did not believe the questions would determine the patient's knowledge about treatment options. As some specific comments were made by respondents, additional questions were added to the instrument to elicit further knowledge about treatment differences. Two comments were made about potential concern for "reading level." Suggestions and comments from the Field Test were incorporated into revision of the Kidney Knowledge Test. Prior to Pilot Testing, the Kidney Knowledge Test was evaluated for reading level. Reading level calculations were made by use of the Rightwriter Software, Version 4.0. Rightwriter measures statistical readability through the Flesch-Kincaid Index, the Flesch Index, and the Fog Index. (Rightwriter User's Manual, 1990)

The Flesch-Kincaid formula for readability is comparable to the Overall Reading Grade Level for the document. (Rightwriter User's Manual, 1990). The Kidney Knowledge Test was calculated to require a fifth grade
reading level.

The Flesch Formula establishes a score of 0-100, with higher scores representative of easier reading and a score of 40 or more as a good value. (Rightwriter User’s Manual, 1990) The Flesch Formula for the Kidney Knowledge Test was 77.912.

The Fog Index analyzes writing samples of 100 or more, based on polysyllabic words and sentence length, with a good range considered to be 8-12. (Rightwriter User’s Manual, 1990) The Fog Index for the Kidney Knowledge Test was 6.489.

Based upon comments received from the Panel of Experts and Field Test, the Kidney Knowledge Test was judged to have content and face validity.

Kidney Failure Attitude Scale

The Kidney Failure Attitude Scale (KFAS) was developed by the investigator. This instrument is designed to measure 1) attitudes about kidney failure and treatment options, 2) feelings about kidney failure and treatment options, and 3) attitudes about information-seeking.

The KFAS consists of a 21 items with a five point
Likert-type scale for responses. The response options are
1) strongly disagree, 2) disagree, 3) undecided, 4) agree,
and 5) strongly agree. The scale is scored as follows:
strongly disagree = 1 point; disagree = 2 points; unsure =
3 points; agree = 4 points; and strongly agree = 5 points.
Scoring of negatively worded items is reversed. The
responses are totaled and a mean score is calculated.

This instrument is scored so that a high score on the
scale indicates that the person has a positive attitude
toward kidney failure and treatment options and information-
seeking or learning about kidney failure and the treatment
options.

Reliability

The reliability of the Kidney Failure Attitude Scale
was assessed in a Pilot Study. Twenty-six (26) patients
with decreased kidney function who were believed to be
similar to the projected study population and met study
eligibility criteria volunteered to participate in the Pilot
Study.

A measure of internal inconsistency was made to
estimate the reliability of the Kidney Failure Attitude
Scale. Cronbach's Alpha was selected to establish an index of inter-item reliability. (Mueller, 1986) Cronbach's Alpha was calculated using the SPSSPC Version 4.0.

The reliability coefficient (alpha) for the Kidney Failure Attitude Scale was .79. Nunnally (1967) suggested that a reliability coefficient of .5-.6 is sufficiently high in the early stages of research.

Alpha reliability coefficients were also computed for each of the subscales. The alpha levels of the subscales offer further support of the internal consistency of the instrument for measuring attitudes toward kidney failure, treatment options and information seeking or learning about kidney failure.
TABLE II

<table>
<thead>
<tr>
<th>SUBSCALES</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Failure</td>
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</tr>
<tr>
<td>Treatment Options</td>
<td>.74</td>
</tr>
<tr>
<td>Information-Seeking</td>
<td>.75</td>
</tr>
<tr>
<td>TOTAL SCALE</td>
<td></td>
</tr>
<tr>
<td>Kidney Failure Attitude Scale</td>
<td>.79</td>
</tr>
</tbody>
</table>

From Table II, it can be seen that the alpha reliability coefficients obtained in the Pilot Test for the subscales in the Kidney Failure Attitude Scale ranged from .74-.87 and that the total instrument alpha reliability coefficient was .79.

The composition of the subscales for the KFAS were realigned for the study. These changes were believed to more clearly separate the two components of attitude that were being measured: attitude toward learning about kidney failure and treatment options and attitude toward kidney
failure and treatment options. The total instrument reliability remained at .79.

<table>
<thead>
<tr>
<th>TABLE III</th>
</tr>
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<tbody>
<tr>
<td>KIDNEY FAILURE ATTITUDE SCALE</td>
</tr>
<tr>
<td>ALPHA RELIABILITY COEFFICIENTS</td>
</tr>
<tr>
<td>STUDY INSTRUMENT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SUBSCALES</th>
<th>n = 75</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning</td>
<td>$\alpha = .85$</td>
</tr>
<tr>
<td>Failure</td>
<td>$\alpha = .68$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TOTAL SCALE</th>
<th>$\alpha = .79$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Failure</td>
<td></td>
</tr>
<tr>
<td>Attitude Scale</td>
<td></td>
</tr>
</tbody>
</table>

From Table III, it can be seen that the alpha reliability coefficients for the Kidney Failure Attitude Scale and subscales calculated from the investigation ranged from $.68 - .85$ for the subscales and was $.79$ for the entire
instrument.

Validity

The content validity of the Attitude Instrument was also assessed by asking a panel of experts to review the instrument to determine if the questions are representative of areas of concern related to kidney failure, treatment options, and information-seeking behaviors. Fifteen experts from the fields of medicine (nephrology), nursing (nephrology), nutrition (nephrology), social services (nephrology), education (adult), and measurement or instrumentation comprised the Panel of Experts.

The Panel of Experts was asked to indicate whether the instrument was believed to measure attitudes about kidney failure, treatment options and information-seeking. Experts were also asked to suggest areas to be added and/or deleted. Suggestions to improve wording or clarify content were also solicited. The responses and comments of the Panel of Experts were reviewed and incorporated when appropriate.

Following instrument revision, a Field Test of the Kidney Failure Attitude Scale was conducted to further assess content validity and establish face validity.
Field test participants were the same as those who reviewed the Kidney Knowledge Test. Eighteen individuals responded with evaluations of the Kidney Failure Attitude Scale. Respondents generally believed that the questions would determine patients' feelings about kidney failure, treatment options, and information-seeking. One respondent questioned if "feelings" and "attitudes" were being used interchangeably. As the directions were already lengthy, this revision was not made. Seven of the respondents indicated other areas of concern that should be explored. The instrument was modified to include concerns regarding finances, an area recommended by several of the respondents. One respondent emphasized the need for the patient to realize that he/she was in "control" and the "most important person in their treatment." A question addressing the concept of control had been included in the knowledge instrument and thus was not included in the attitude scale.

Following revision of the Kidney Failure Attitude Scale based upon comments received in the Field Test, and prior to Pilot Testing, the instrument was analyzed for readability. Reading level calculations were made by use of the Rightwriter Software, Version 4.0.
The Flesch-Kincaid formula for readability is comparable to the Overall Reading Grade Level for the document. (Rightwriter User's Manual, 1990). The Kidney Failure Attitude Scale was calculated to require a sixth grade reading level.

The Flesch Formula establishes a score of 0-100, with higher scores representative of easier reading and a score of 40 or more as a good value. (Rightwriter User's Manual, 1990) The Flesch Formula for the Kidney Failure Attitude Scale was 71.852.

The Fog Index analyzes writing samples of 100 or more, based on polysyllabic words and sentence length, with a good range considered to be 8-12. (Rightwriter User's Manual, 1990) The Fog Index for the Kidney Failure Attitude Scale was 7.367.

Based upon comments received from the Panel of Experts and Field Test, the Kidney Failure Attitude Scale was judged to have content and face validity.

Mishel Uncertainty in Illness Scale - Community

The Mishel Uncertainty in Illness Scale - Community (MUIS-C) evolved from the Mishel Uncertainty in Illness
Scale - Adult Form (MUIS). (Mishel, 1990) The MUIS was initially developed to measure uncertainty in illness in hospitalized adults. Several versions of the form are available, depending upon the target population. The Mishel Uncertainty in Illness Scale - Community (MUIS-C) developed for chronically ill individuals who are not hospitalized was selected for the study. (Mishel, 1990)

The MUIS-C consists of 23 items with a five point Likert-type scale for responses. The response options are 1) strongly disagree, 2) disagree, 3) undecided, 4) agree, and 5) strongly agree. The scale is scored as follows: strongly disagree = 1 point; disagree = 2 points; unsure = 3 points; agree = 4 points; and strongly agree = 5 points. Scoring of negatively worded items are reversed. The responses are summed and a raw score is calculated. Scores on the instrument can range from 23-115. A higher score indicates greater uncertainty.

Reliability

Mishel (1990) reported normative data from eight samples and representing eight different studies. A variety of chronic illness populations, such as rheumatoid
arthritis, mixed cancer diagnoses, multiple sclerosis, and heart disease (total N = 396) was included. The alpha reliability coefficients for these studies ranged from .75-.90 with a mean score was 60 and a standard deviation of 17.1. (Mishel, 1990)

The reliability of the Mishel Uncertainty in Illness Scale - Community form was further assessed in a Pilot Study. Twenty-six (26) patients with decreased kidney function who were believed to be similar to the projected study population and met study eligibility criteria completed the MUIS-C.

A measure of internal inconsistency was made to estimate the reliability of the MUIS-C. Cronbach’s Alpha was selected to establish an index of inter-item reliability. (Mueller, 1986) Cronbach’s Alpha was calculated using the SPSSPC Version 4.0. The reliability coefficient (alpha) for the MUIS-C was .93 in the sample and .88 (n=72) in the study.
Validity

The original reports on the validity of the MUIS were reported by Mishel (1981). For this study, content validity of the MUIS-C was established through review by a Panel of Experts. The characteristics of the Panel of Experts have been described previously. The Panel of Experts judged the content of this instrument appropriate for use with patients with decreased kidney function. Wording was judged appropriate and questions clearly written.

A Field Test of the Uncertainty Instrument was also conducted to establish content and face validity. Field Test participants were previously described. Respondents to the Field Test of the MUIS-C generally believed that uncertainty was experienced by patients with decreased kidney function who have not started dialysis and that the questions were appropriate. A substantial majority of respondents indicated that these questions were appropriate to ask; two of thirteen did not think they were appropriate. The questions were assessed as clear with appropriate wording. No changes in the instrument were made.

Following completion of the review by the Panel of Experts and the Field Test, the MUIS-C was judged to have
content and face validity. The instrument was then Pilot Tested.

DATA COLLECTION

Data were collected for this study by mailed questionnaire and by investigator review of medical records. Dillman (1978) described a "total design method" which is theoretically based upon a premise that respondent and surveyor have a social exchange. Dillman (1978) suggested that three conditions were necessary to have maximum response rates: 1) minimize costs of responding, 2) maximize rewards for doing so, and 3) establish trust that the rewards will be obtained.

In this study, costs to the participant were minimized by providing postage and preparing materials to minimize time required for completion. The potential value of the study in helping to identify educational needs and concerns of persons with decreased kidney failure was emphasized as the reward for participation. The investigator attempted to develop trust through the use of clear, precise communications and the offer to provide a summary of the
study to participants. The introductory letter by the nephrologist and study approval statements also were believed to contribute to building trust.

In addition, many of the procedures suggested by Dillman (1978) and Sudman (1982) for questionnaire construction, formatting, printing, and implementation of a mailed survey were followed. A detailed description of these procedures follows.

Questionnaire Construction and Formatting

The questionnaire booklet consisted of four sections. These included the Kidney Knowledge Test, the Kidney Failure Attitude Scale, the Mishel Uncertainty in Illness Scale, and a section on Demographic Data. As suggested by Dillman (1978) and Sudman (1982) the order of section placement was from least to most sensitive.

Directions were simple and without skip instructions and there were no open-ended questions. (Sudman, 1982) For each of the instruments, an example followed the instructions for completion. The Kidney Knowledge Test and the Demographic Data section were formatted with the stem of the question in lowercase letters and the responses in
uppercase letters, as recommended by Dillman (1978). The Kidney Failure Attitude Scale and the Mishel Uncertainty in Illness Scale were formatted in two columns, with the question statement in the left column and the Likert-type scale responses bracketed by a "hat" (Dillman, 1978) in the right column.

Responses to the Kidney Knowledge Test were designed to offer minimal threat if the answer was not known. For example, for the majority of the questions, responses included an "unsure" and an "I don't know" option. Sudman (1982) described this technique to enhance response when respondents might be concerned about lacking knowledge about the item in question. Responses to the Kidney Failure Attitude Scale and the Mishel Uncertainty in Illness Scale were ordered from the least to the most socially desirable response. Because it is socially desirable to agree, the strongly disagree and disagree responses preceded the undecided, agree and strongly agree responses. This sequencing of responses is recommended by Sudman (1982). Minimizing threat and potential embarrassment are considered by Dillman (1978) as decreasing respondents costs.

The pages of the instruments were formatted to
establish a vertical flow (Dillman, 1978) and Sudman (1982). Careful attention was given to spacing of words and the break-up of phrases were made, so that reading would be facilitated by logical breaks. For example, if the stem of the question required two lines, the second line of the stem would contain a phrase, rather than only a single word. Also, questions and responses were all formatted onto the same page; no questions were separated from the corresponding responses. These considerations were consistent with the spacing and formatting suggestions by Dillman (1978) and Sudman (1982) were followed.

Booklet Design and Printing

Several design considerations were made about the appearance of the questionnaire booklet. Dillman (1978) recommended that the booklet size be 6 1/8" x 8 1/4" and that 12 point (elite) type, reduced by 79% to fit the booklet size be used. This recommendation was not followed as the investigator expected that many of the respondents would have a visual impairment. The booklet was designed and printed with the following: 1) 12 point type size, 2) the use of Bookman font, because of its familiarity, and 3)
the liberal use of white or blank space. The use of white or blank space is recommended by Dillman (1978) and Sudman (1982) so that the questions would appear easier and completion of the survey would appear uncomplicated.

The final copy was prepared by Macintosh laser typesetting techniques. The booklet was professionally printed on white, non glossy paper with black ink. This was used to enhance contrast and minimize glare. The working title of the study placed was on the front cover. A simple double line border was selected in lieu of a graphic, as no graphic seemed appropriate.

The booklet was printed onto folded and stapled 11" x 17" pages, with final dimensions of 8 1/2" x 11." The larger size was deemed appropriate to accommodate the larger font size and to achieve an appearance of simplicity through adequate white space. Questions were printed on both sides; no questions were on the inside front or back cover, or on the back side of the cover letter, as per Dillman (1978) recommendations.

The cover letter was inside the booklet. As recommended by Dillman (1978), it expressed appreciation for participation, assured confidentiality, explained the
purpose of the Code Number, offered to supply a summary of
the study and was signed personally by the investigator. As
suggested by Dillman (1978), prior communications had
emphasized the regard for the respondents contributions,
identified the investigator's affiliation with The Ohio
State University as a student, identified the investigator's
background as a registered nurse but did not identify the
investigator's employment affiliation, and offered to
provide additional information about the study upon request.

Implementation of the Mailed Questionnaire

Following receipt of a signed and witnessed Consent to
Participate form, materials were mailed to the study
participant. These materials consisted of a questionnaire
booklet, self-addressed stamped return envelope, and stamped
postcard to request a study summary.

A flat, brown 9 x 12 manila envelope was used to mail
the booklet to participants and for return of the booklet to
the investigator. Commemorative stamps were used for both
mailing envelopes. Dillman (1978) recommends personal
signatures and commemorative stamps as appropriate to
maximize the return rate. The packet also contained a self-
addressed, stamped postcard for use by participants who wished to receive a summary of the study findings. The provision of summary data about the study was a method of expressing appreciation by the investigator to the respondents.

A second questionnaire packet was mailed if a completed questionnaire was not returned within 10-14 days of its having been mailed. Participants were determined to be a non-respondent if the questionnaire was not received by the date established for completion of data collection.

During the data collection phase, several decisions were made concerning individual respondents. One respondent included a note describing some personal experiences. This experience included a couple weeks of dialysis treatments. As the respondent indicated a lack of knowledge about what type of dialysis had been received, the respondent was judged sufficiently inexperienced and the questionnaire was retained for data analysis. Two respondents wrote notes indicating that they did not believe they knew enough about their kidney problem or its treatment to be helpful in responding. The investigator responded with individualized letters clarifying the purposes of the study and emphasizing
how helpful their responses would be for the study. A response from one of these was received.

Incomplete Data

Several decisions about dealing with incomplete data were made based upon experiences with the Pilot Test. For the KKT, an unanswered item was scored as an "I don't know" response. This would constitute a wrong response in the overall calculations. For the KFAS and MUIS-C, a missing item was scored as an "undecided" response. These decisions about how to handle missing data were made during conduct of the Pilot Test and were consistent with recommendations by Van Tilburg. (1989) Three instruments were received in which two or more pages of questions in succession were not completed. The instruments for these respondents were not scored.

Calculation of Response Rate

Response rate was calculated by two methods. The first method of response rate calculation is as follows: response rate = number of responses(75) / potential in sample (241) x 100. The response rate was 31% with this method of
calculation. According to Dillman (1978), this method demonstrates how well all potential respondents have been reached. While this response rate was calculated, it is inappropriate for this study for the following reasons: 1) anyone who did not sign a Consent to Participate form was ineligible for participation; 2) some patients were reported to have expired by a family member; 3) some potential participants could not be contacted because of lack of forwarding or known address; and 4) some who initially sought information did not complete a consent to participate form.

The second method of response rate calculation suggested by Dillman (1978) which was as follows: response rate = number returned/number in sample - (noneligible + nonreachable) x 100. For this study, noneligible was defined to include all those for whom a signed consent to participate was not received and those who had started dialysis prior to completing the instrument. Nonreachable was defined to include all those who died or those for whom no forwarding address was available. Given these considerations, the response rate was calculated as follows:
Response Rate = \( \frac{75}{241 - 151} = \frac{75}{90} = 0.833 \times 100\% = 83\% \).

Controls for Nonresponse Error

Nonrespondents in this study were defined as those returning a signed Consent to Participate form, but not returning the completed questionnaire. Given the high response rate and the concern about provoking undue stress in individuals who had not returned the questionnaire, no further follow-up procedures were implemented. Some data about the characteristics of non-respondents were available from the medical record and these data are presented in Chapter IV.

Medical Record Review

The receipt of a signed consent to participate preceded medical record review. The medical record was reviewed by the investigator to obtain information concerning 1) serum creatinine and 2) length of time under the care of a nephrologist. For several respondents, one or two items in the demographic data section were omitted. The investigator reviewed the medical record in an attempt to supply the missing information. The most recently recorded serum
creatinine level was obtained for each patient. All values were within at least twelve months of the time of questionnaire completion.

DATA ANALYSIS

The data for this study consist of descriptive statistics and measures of association. Respondent characteristics are described in terms of frequencies and percentages. Chi square analyses and crossbreak tabulations of respondent characteristics according to Group I or Group II were also calculated. The chi square analyses were not used to make inferences to a larger population, but rather the chi square was used to help interpret the practical significance of the associations. Pearson product moment correlation coefficients were calculated to determine whether relationships existed between level of serum creatinine and the mean scores on the KKT, KFAS, and MUIS-C.
SUMMARY

Chapter III contains information about the research design of the study and procedures followed for implementation. A mailed survey was conducted to measure the knowledge, attitudes, and uncertainty in patients with decreased kidney function who have not started renal replacement therapy. The results from this study are presented in Chapter IV.
CHAPTER IV
PRESENTATION AND ANALYSIS OF DATA

The presentation and analysis of data for this study consists of three sections: 1) calculation of response rate and respondent characteristics; 2) descriptive statistics; and 3) measures of association.

Response Rate

A purposive, nonprobability sample (n = 241) was identified by nephrologists from three practice groups in Columbus, Ohio. Following receipt of a signed consent to participate including review of the medical record, ninety (90) eligible subjects were mailed questionnaires; 75 completed questionnaires were returned. This represents a response rate of 83%, utilizing previously described procedures for calculation.
Descriptive Statistics

Characteristics of Respondents

37 females (50%) and 37 males (50%) who met study eligibility criteria responded. One respondent did not select a gender category. Ages ranged from 18-29 to 65 or more. Only one respondent selected the 18-29 year category and the 80 or more category, respectively. The 80 or more years category was collapsed for analysis purposes with the 65-79 year category, forming a 65 or more years category. The 18-29 year category was not merged with the 30-49 year old grouping. Except for the 18-29 year old group (n=1), the other three categories were relatively evenly divided. Respondents were primarily white (n=66; 90%).
<table>
<thead>
<tr>
<th></th>
<th>FREQUENCY</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENDER*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>n = 37</td>
<td>50%</td>
</tr>
<tr>
<td>female</td>
<td>n = 37</td>
<td>50%</td>
</tr>
<tr>
<td>AGE**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29 years</td>
<td>n = 1</td>
<td>4%</td>
</tr>
<tr>
<td>30-49 years</td>
<td>n = 23</td>
<td>30.7%</td>
</tr>
<tr>
<td>50-54 years</td>
<td>n = 23</td>
<td>30.7%</td>
</tr>
<tr>
<td>65 or more years</td>
<td>n = 26</td>
<td>34.7%</td>
</tr>
<tr>
<td>RACE/ETHNICITY***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>white</td>
<td>n = 66</td>
<td>90%</td>
</tr>
<tr>
<td>non-white</td>
<td>n = 7</td>
<td>10%</td>
</tr>
</tbody>
</table>

*One respondent did not select a gender category.
**Two respondents did not identify their age.
***Two respondents did not identify race/ethnicity.

Table IV contains the gender, age, and race/ethnicity reported by respondents.

The majority of respondents were married (n=54; 72%) and Protestant (n=49; 66%). Respondents reported educational levels of 0 years to graduate (seventeen or more years). These categories were collapsed into two
categories for data analysis purposes. The majority of respondents (n=42; 58%) had some college or more and the remaining respondents (n=38; 42%) had a high school diploma or less.

<table>
<thead>
<tr>
<th>TABLE V</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MARITAL STATUS, RELIGION AND</strong></td>
</tr>
<tr>
<td><strong>EDUCATIONAL LEVEL OF RESPONDENTS</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>MARITAL STATUS</strong></td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Single/never married</td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
</tr>
<tr>
<td><strong>RELIGION</strong></td>
</tr>
<tr>
<td>Protestant</td>
</tr>
<tr>
<td>Non-Protestant</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td><strong>EDUCATIONAL LEVEL</strong></td>
</tr>
<tr>
<td>High School or less</td>
</tr>
<tr>
<td>College or more</td>
</tr>
</tbody>
</table>

*One respondent did not identify a religion.**Three respondents did not indicate educational preparation.
Table V contains the frequencies and percentages of respondents according to marital status, religion, and educational level.

Renal-related characteristics of respondents included level of kidney failure, prior experience in knowing someone with kidney failure, concern with financial aspects of kidney failure, and time under the care of a nephrologist. 59% (n=44) had a serum creatinine of 2.4mg/dl or less and were categorized as having renal insufficiency. Slightly more than one third of the respondents (n=29; 38.7%) reported that they had known no one with kidney failure. The remaining respondents were evenly distributed (n=23; 30.7%) between known of someone with kidney failure and having known a close family member or friend with kidney failure.

In response to the question about financial concern, the majority of respondents (n=37; 49%) indicated they were "extremely or very concerned," whereas (n=29; 37%) respondents indicated "somewhat" of a concern with the financial aspects of kidney failure. The majority of respondents (n=47; 64%) had been under the care of a nephrologist for 13 or more months.
<table>
<thead>
<tr>
<th>TABLE VI</th>
</tr>
</thead>
<tbody>
<tr>
<td>RESPONDENT CHARACTERISTICS AND</td>
</tr>
<tr>
<td>SELECTED RENAL-RELATED PHENOMENA</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LEVEL OF KIDNEY FAILURE</th>
<th>FREQUENCY</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum creatinine</td>
<td>n=44</td>
<td>59%</td>
</tr>
<tr>
<td>(2.4mg/dl or less)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Serum creatinine</td>
<td>n=31</td>
<td>41%</td>
</tr>
<tr>
<td>(2.5mg/dl or more)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| PRIOR EXPERIENCE WITH     |
| KIDNEY FAILURE IN         |
| OTHERS                    |
| None                     | n=29      | 38.7%      |
| Known of Someone         | n=23      | 30.7%      |
| Close Family/friend      | n=23      | 30.7%      |

<table>
<thead>
<tr>
<th>FINANCIAL CONCERN</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Somewhat</td>
</tr>
<tr>
<td>Extremely/very</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME WITH NEPHROLOGIST*</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 months or less</td>
</tr>
<tr>
<td>13 months or more</td>
</tr>
</tbody>
</table>

*Information not available for one respondent.
Table VI contains the renal-related characteristics, financial concern with kidney failure, prior experience by knowing someone with kidney failure, and length of time under the care of a nephrologist by level of kidney failure by group.

**Characteristics of Nonrespondents**

There were fifteen (17%) nonrespondents in this study. Of these fifteen, 9 were male and 6 were female. Of these nonrespondents, data on level of renal function were available for 14 of the 15. Nonrespondents (n=8; 57%) had a serum creatinine of 2.4mg/dl or less; the remaining nonrespondents (n=6; 43%) had a serum creatinine of 2.5mg/dl or more. Thirteen of the nonrespondents had been under the care of a nephrologist for 13 months or more. Data were not available for the other one and two nonrespondents, respectively.

**Independent Variable**

Decrease in kidney function was the main independent variable. Serum creatinine was coded both as a categorical and as a metric variable so that more diverse analyses could
be performed. As a categorical variable, the serum creatinine level functioned to establish two groups.

In Group I, those with renal insufficiency, fifty-nine percent (n=44) had a serum creatinine of 2.4mg/dl or less. In Group II, those with chronic renal failure, forty-one percent (n=31) had a serum creatinine of 2.5mg/dl or more. Chi square analyses of gender, age, and race/ethnicity were performed. The groups were generally similar for these characteristics.
**TABLE VII**

<table>
<thead>
<tr>
<th>KIDNEY FUNCTION</th>
<th>Group I</th>
<th>Group II</th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENDER</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>n=21</td>
<td>n=16</td>
<td>0.0</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Female</td>
<td>n=22</td>
<td>n=15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29 years</td>
<td>n=2</td>
<td>n=1</td>
<td>0.90</td>
<td>3</td>
<td>0.82</td>
</tr>
<tr>
<td>30-49 years</td>
<td>n=12</td>
<td>n=11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-64 years</td>
<td>n=15</td>
<td>n=8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 or more</td>
<td>n=15</td>
<td>n=11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RACE/ETHNICITY</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>n=37</td>
<td>n=29</td>
<td>0.14</td>
<td>1</td>
<td>0.70</td>
</tr>
<tr>
<td>Non-white</td>
<td>n=5</td>
<td>n=2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table VII contains the frequencies and chi square analyses for respondent gender, age, and race/ethnicity according to Group I or Group II.
Chi square analyses were also performed for marital status, religion, and educational level. The groups were generally similar with respect to these characteristics. Table VIII contains the frequencies and chi square analyses for marital status, religion, and educational level according to group.
<table>
<thead>
<tr>
<th>KIDNEY FUNCTION</th>
<th>Group I</th>
<th>Group II</th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MARITAL STATUS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>n=32</td>
<td>n=22</td>
<td>0.18</td>
<td>2</td>
<td>.91</td>
</tr>
<tr>
<td>Single/never married</td>
<td>n=5</td>
<td>n=3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>n=7</td>
<td>n=6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>RELIGION</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>n=30</td>
<td>n=19</td>
<td>1.54</td>
<td>2</td>
<td>.46</td>
</tr>
<tr>
<td>Non-Protestant</td>
<td>n=14</td>
<td>n=10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>n=0</td>
<td>n=1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EDUCATIONAL LEVEL</strong></td>
<td></td>
<td></td>
<td>.24</td>
<td>1</td>
<td>.63</td>
</tr>
<tr>
<td>High School or less</td>
<td>n=19</td>
<td>n=11</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College or more</td>
<td>n=23</td>
<td>n=19</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table VIII contains the chi square analyses for marital status, religion, and educational level for group (level of kidney failure).

Renal-related phenomena according to group were also calculated by chi square procedures. Table IX contains the frequencies and chi square analyses for financial concern about kidney failure, prior experience in knowing someone with kidney failure, and length of time under the care of a nephrologist according to group. The groups were generally similar with respect to these characteristics.
### TABLE IX

**CHI SQUARE FOR FINANCIAL CONCERN, PRIOR EXPERIENCE AND TIME WITH NEPHROLOGIST BY GROUP (LEVEL OF KIDNEY FUNCTION)**

<table>
<thead>
<tr>
<th>KIDNEY FUNCTION</th>
<th>Group I</th>
<th>Group II</th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FINANCIAL CONCERN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely/very</td>
<td>n=17</td>
<td>n=12</td>
<td>.29</td>
<td>2</td>
<td>.86</td>
</tr>
<tr>
<td>Somewhat</td>
<td>n=21</td>
<td>n=16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>n=6</td>
<td>n=3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRIOR EXPERIENCE</td>
<td></td>
<td></td>
<td>2.11</td>
<td>2</td>
<td>.35</td>
</tr>
<tr>
<td>WITH KIDNEY FAILURE IN OTHERS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>n=14</td>
<td>n=15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Known of Someone</td>
<td>n=15</td>
<td>n=8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Close Family/friend</td>
<td>n=15</td>
<td>n=8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TIME WITH NEPHROLOGIST</td>
<td></td>
<td></td>
<td>.34</td>
<td>1</td>
<td>.56</td>
</tr>
<tr>
<td>12 months or less</td>
<td>n=14</td>
<td>n=13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 months or more</td>
<td>n=29</td>
<td>n=18</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table IX contains the chi square analyses for renal-related phenomena according to group.
Dependent Variables

Respondents were measured on three instruments: the Kidney Knowledge Test (KKT), the Kidney Failure Attitude Scale (KFAS), and the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C). Table X contains the range, mean score, standard deviation and alpha reliability coefficient for the three dependent measures.

Kidney Knowledge Test

The alpha reliability coefficient for the Kidney Knowledge Test (KKT) was computed ($\alpha = .89$) (Table X). There were thirty one questions on the KKT and scores could have ranged from 1-31. The mean score for respondents ($n=75$) on the KKT was 15.85, range 3-30, S.D. 6.79.

Kidney Failure Attitude Scale

The alpha reliability coefficient for the Kidney Failure Attitude Scale (KFAS) was computed ($\alpha = .79$). (Table X) The KFAS contains two subscales: 1) attitude toward learning and 2) attitude toward kidney failure and methods of treatment. The alpha reliability coefficient for the LEARN subscale was $\alpha = .85$ (standardized $\alpha = .87$);
the alpha reliability coefficient for the FAILURE subscale was $\alpha = .68$ (standardized $\alpha = .65$). The KFAS contains twenty-one questions; mean scores could range from 1-5. The mean score for respondents (n=75) on the KFAS was 3.57, range 2.48-4.33, and S.D. .399.

**Mishel Uncertainty in Illness Scale - Community Form**

The alpha reliability coefficient for the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C) was computed ($\alpha = .88$; standardized $\alpha = .89$). (Table X) The mean score for respondents (n=72) was 62, range 26-91, S.D. 13.24. There are thirty-one questions on the MUIS-C. Scores could range from 23-115. For the normative data available from prior studies, the mean score is 60 with a standard deviation of 17.1. (Mishel, 1990) Three respondents skipped several pages of questions in the MUIS-C and were omitted from the analysis.
### TABLE X

**MEASURES OF DISPERSION, CENTRAL TENDENCY, VARIATION, AND RELIABILITY OF DEPENDENT MEASURES FOR RESPONDENTS**

<table>
<thead>
<tr>
<th>n</th>
<th>K</th>
<th>Scale</th>
<th>Range</th>
<th>Mean</th>
<th>SD</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>KKT</td>
<td>75</td>
<td>31 1-31</td>
<td>3-30</td>
<td>15.85</td>
<td>6.79</td>
<td>.89</td>
</tr>
<tr>
<td>KFAS</td>
<td>75</td>
<td>21 1-5</td>
<td>2.48-4.33</td>
<td>3.57</td>
<td>.399</td>
<td>.79</td>
</tr>
</tbody>
</table>

Table X demonstrates the number of respondents, number of items, scale, range, mean, standard deviation, and alpha reliability coefficients of the dependent measures, Kidney Knowledge Test, Kidney Failure Attitude Scale, and the Mishel Uncertainty in Illness Scale - Community.

**Measures of Association**

This exploratory study sought to identify for potential relationships among the main independent variable, level of kidney function, and three dependent measures, KKT, KFAS,
MUIS-C. In addition, three extraneous independent variables, educational level, prior experience with another person with kidney failure, and length of time under the care of a nephrologist, were examined.

Statistical procedures were performed with SPSS X Release 3.0 for IBM OS/MVS. Conventions offered by Davis (1971) for interpreting the strength of the association will be followed. These are as follows: .70 or higher = very strong association; .50-.69 = substantial association; .30-.49 = moderate association; .10-.29 = low association; .01-.09 = negligible association.

The research questions for this exploratory study were as follows:

1. What is the nature of the relationship between a decrease in kidney function and achievement on a test of knowledge about kidney failure?

2. What is the nature of the relationship between a decrease in kidney function and attitudes toward kidney failure and treatment options?

3. What is nature of the relationship between a decrease in kidney function and uncertainty in illness?

In addition to the main questions of association, several subquestions concerning three respondent characteristics were explored. The main question of
association between independent and dependent variables is presented initially. Sub-questions concerning each of the extraneous independent variables follows each main question.

Research Question 1

1. What is the nature of the relationship between a decrease in kidney function and achievement on a test of knowledge about kidney failure?

A Pearson Product Moment correlation coefficient comparing the mean score on the Kidney Knowledge Test with the reported serum creatinine level of each respondent was calculated (r = .31, n=74). (Table XI). This demonstrates a moderate, positive association between the mean score on the KKT and the level of kidney failure. This moderate positive relationship indicates that as kidney failure increases, so does knowledge. By squaring the correlation coefficient demonstrating the relationship between the mean score on the KKT and decrease in kidney function, as measured by increasing serum creatinine level, it can be seen that about 10% of the variance in KKT scores can be explained by worsening kidney function.
Sub Question #1.1

1.1. Is there a relationship between a decrease in kidney function and the mean score on the Kidney Knowledge Test when analyzed according to educational level?

The seventy-five respondents were divided into two groups: those with high school or less education and those with some college or more education. For respondents with high school or less education, a Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was calculated \( r = .37, n=29 \). (Table XI) This demonstrates a moderate, positive association. For the group of individuals with high school or less education, about 14% of the variance in the mean score on the KKT was explained by worsening kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was also calculated for respondents with college or greater \( r = .24, n=42 \). (Table XI) This demonstrates a low, positive association. For the group of individuals with some college education or more, about 6% of the variance in the KKT score was explained by worsening kidney function.
Sub Question # 1.2

1.2. Is there a relationship between a decrease in kidney function and the mean score on the Kidney Knowledge Test when analyzed according to prior experience with a person with kidney failure?

The seventy-five respondents were assigned to one of three groups depending upon prior experience with kidney failure. Respondents selected which level of prior experience was most descriptive. The choices were as follows: 1) having known no one with kidney failure; 2) having known of someone with kidney failure; or 3) having a close friend or family member with kidney failure.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was calculated for respondents with no prior experience with someone with kidney failure ($r = .14, n=28$). (Table XI) This demonstrates a low, positive association. For individuals with no prior experience with others with kidney failure, about 2% of the variance in the KKT score was explained by worsening kidney function. This is essentially no relationship.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum
creatinine level of each respondent was calculated for respondents who had known of someone with kidney failure \((r = .37, n=23)\). (Table XI) This demonstrates a moderate, positive association. For the group of individuals who had known of someone with kidney failure, about 14\% of the variance in the KKT score was explained by worsening kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was calculated also for respondents who had known a close family member or friend with kidney failure \((r = .43, n=23)\). (Table XI) This demonstrates a moderate, positive association. For the group of individuals with experience with kidney failure through a close friend or family member, about 18\% of the variance in the KKT can be explained by worsening kidney function.
Sub Question 1.3

1.3. Is there a relationship between a decrease in kidney function and the mean score on the KKT when analyzed according to the length of time under the care of a nephrologist?

The records of the seventy-five respondents were reviewed to determine the length of time each had been under the care of a nephrologist. Respondents were categorized as either having twelve months or less experience, or thirteen months or more experience under the care of a nephrologist.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was calculated for respondents having twelve months or less under the care of a nephrologist \( (r = .50, n=27) \). (Table XI) This demonstrates a substantial, positive association. For the group of individuals with twelve months or less time under the care of a nephrologist, about 25% of the variance in the KKT can be explained by worsening kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KKT with the reported serum creatinine level of each respondent was calculated also for respondents who had been under the care of a nephrologist for thirteen months or more \( (r = .25; n=46) \). (Table XI)
This demonstrates a low, positive association. For the group of individuals with thirteen months or more experience under the care of a nephrologist, about 6% of the variance in the KKT can be explained by worsening kidney function (increased serum creatinine level).
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<th></th>
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<td>.50</td>
<td>&lt;.004</td>
</tr>
<tr>
<td>13 months or more</td>
<td>46</td>
<td>.25</td>
<td>&lt;.049</td>
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</table>

Table XI contains the Pearson Correlation Coefficients for respondents comparing mean score on the KKT with serum creatinine level, educational level, prior experience and length of time under the care of a nephrologist.
Research Question 2

2. What is the nature of the relationship between a decrease in kidney function and attitudes toward kidney failure and treatment options?

A Pearson Product Moment correlation coefficient comparing the mean score on the Kidney Failure Attitude Scale (KFAS) with the reported serum creatinine level of each respondent calculated \((r = -0.09; n=74)\). (Table XII) This demonstrates a negligible, negative association, or essentially no relationship between the variables. This means that none of the variance in the KFAS can be explained by worsening kidney function, as measured by increasing serum creatinine levels.

There was a low, negative association \((r = -0.18)\) between the subscale FAILURE and decrease in kidney function. While suggesting that as kidney function deteriorated, attitudes toward kidney failure worsened, essentially none of the variation in the KFAS subscale FAILURE was explained by decreasing kidney function.

There was a negligible, positive association \((r = 0.04)\) between the subscale LEARN and decrease in kidney function. Essentially no variation in the KFAS subscale LEARN or FAILURE was explained by decreasing kidney function.
Sub Question # 2.1.

2.1. Is there a relationship between a decrease in kidney function and the mean score on the Kidney Failure Attitude Scale when analyzed according to educational level?

The seventy-five respondents were divided into two groups: those with high school or less education and those with some college or more education. For respondents with high school or less education, a Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for those with high school education or less \( (r = -0.06; n=29) \). (Table XII) This demonstrates a negligible, negative association. For the group of individuals with high school or less education, essentially none of the variance in the KFAS can be explained by worsening kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for respondents with college or greater \( (r = .12; n=42) \). (Table XII) This demonstrates a negligible, positive association. For the group of individuals with some college or more education, essentially none of the variance in the
KFAS can be explained by worsening kidney function, e.i. increasing serum creatinine levels.

Consideration of the subscales of the KFAS revealed additional information. For those with high school or less education, there was a negligible, negative association ($r = -.09$) between the subscale FAILURE and decrease in kidney function and a negligible, negative association ($r = -.01$) between the subscale LEARN and decrease in kidney function. For those with college or more education, there was a low, negative association ($r = -.22$) between the subscale FAILURE and decrease in kidney function and a negligible, positive association ($r = .02$) between the subscale LEARN and decrease in kidney function.

**Sub Question # 2.2**

2.2. Is there a relationship between a decrease in kidney function and the mean score on KFAS when analyzed according to prior experience with a person with kidney failure?

The seventy-five respondents were assigned to one of three groups depending upon prior experience with kidney failure. Respondents selected which level of prior experience was most descriptive. The choices were as follows: 1) having known no one with kidney failure; 2)
having known of someone with kidney failure; or 3) having a close friend or family member with kidney failure.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for respondents with no prior experience with someone with kidney failure \((r = -.25; n=28)\). (Table XII) This demonstrates a low, negative association. For the group of individuals with no prior experience in knowing someone with kidney failure, about 6% of the variance in the KFAS could be explained by worsening kidney function, as measured by increasing serum creatinine level.

Subscale analyses revealed additional information. For the group of respondents with no prior experience with kidney failure through others, there was a low, negative correlation \((r = -.29)\) between the subscale FAILURE and decrease in kidney function and a low, negative correlation \((r = -.11)\) between the subscale LEARN and decrease in kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for
respondents having known of someone with kidney failure $(r = -0.02; n=23)$. (Table XII) This demonstrates a negligible, negative association. For the group of individuals with some prior experience by knowing of someone with kidney failure, none of the variance in the KFAS was explained by worsening kidney function.

Further information was obtained with subscale analysis. For the group of respondents with some prior experience by knowing of someone with kidney failure, there was a negligible, negative correlation $(r = -0.05)$ association between the subscale FAILURE and decrease in kidney function and a negligible, positive correlation $(r = 0.02)$ between the subscale LEARN and decrease in kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for respondents who had known a close family member or friend with kidney failure $(r = 0.15; n=23)$. (Table XII) This demonstrates a low, positive association. For the group of individuals with prior experience with kidney failure through a close family member or friend, essentially no
variance in the KFAS could be explained by worsening kidney function, as measured by increasing serum creatinine level. Additional information was obtained with subscale analysis. For the group of respondents with prior experience by knowing a family member or close friend with kidney failure, there was a negligible, negative correlation \( r = -0.07 \) between the subscale FAILURE and decrease in kidney function and a moderate, positive correlation \( r = 0.33 \) between the subscale LEARN and decrease in kidney function.

**Sub Question 2.3**

2.3. Is there a relationship between a decrease in kidney function and the mean score on the KFAS when analyzed according to the length of time under the care of a nephrologist?

The records of the seventy-five respondents were reviewed to determine the length of time each had been under the care of a nephrologist. Respondents were categorized as either having twelve months or less experience, or thirteen months or more experience under the care of a nephrologist.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for
respondents having twelve months or less under the care of a nephrologist \((r = -0.19; \ n=27)\). (Table XII) This demonstrates a low, negative association. For the group of individuals with twelve months or less experience under the care of a nephrologist, about 4% of the variance in the KFAS could be explained by worsening kidney function.

Consideration of the FAILURE and LEARN subscales of the KFAS provided additional information when analyzed according to the length of time the person had been under the care of a nephrologist. For those respondents with twelve months or less experience with a nephrologist, there was a moderate, negative correlation \((r = -0.43)\) between the subscale FAILURE and decrease in kidney function and a negligible, positive correlation \((r = 0.12)\) between the subscale LEARN and decrease in kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the KFAS with the reported serum creatinine level of each respondent was calculated for respondents having had thirteen months or more under the care of a nephrologist \((r = -0.08; \ n=46)\). (Table XII) This demonstrates a negligible, negative association. For the group of individuals with thirteen months or more experience
under the care of a nephrologist, none of the variance in the KFAS could be explained by worsening kidney function, as measured by increasing serum creatinine level.

For those respondents with thirteen months or more experience with a nephrologist, there was a low, negative correlation ($r = -.11$) between the subscale FAILURE and decrease in kidney function and a negligible, negative correlation ($r = -.03$) between the subscale LEARN and decrease in kidney function.
TABLE XII

PEARSON CORRELATION COEFFICIENTS FOR MEAN SCORE ON KFAS COMPARED WITH SERUM CREATININE AND SELECTED RESPONDENT CHARACTERISTICS

<table>
<thead>
<tr>
<th></th>
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<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum Creatinine Level</td>
<td>74</td>
<td>-.09</td>
<td>&lt;.225</td>
</tr>
<tr>
<td>Educational Level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or Less</td>
<td>29</td>
<td>-.06</td>
<td>&lt;.369</td>
</tr>
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<td>College or More</td>
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<td>.12</td>
<td>&lt;.227</td>
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<td></td>
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<tr>
<td>13 months or more</td>
<td>46</td>
<td>-.08</td>
<td>&lt;.293</td>
</tr>
</tbody>
</table>

Table XII contains the Pearson Correlation Coefficients for respondents' mean score on the KFAS with serum creatinine level, educational level, prior experience and length of time under the care of a nephrologist.
Research Question 3

3. Is there a relationship between a decrease in kidney function and uncertainty in illness?

A Pearson Product Moment correlation coefficient comparing the mean score on the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C) with the reported serum creatinine level of each respondent was calculated ($r = -0.10$, $n=74$). (Table XIII) This indicates a low, negative association. This means that none of the variance in the MUIS-C scores was explained by decreasing renal function, as measured by increasing serum creatinine level.

Sub Question # 3.1

3.1. Is there a relationship between a decrease in kidney function and the mean score on the Mishel Uncertainty in Illness Scale - Community Form when analyzed according to educational level?

The seventy-five respondents were divided into two groups: those with high school or less education and those with some college or more education. A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents with a high school education or less ($r = -0.24$; $n=29$). (Table XIII) This
demonstrates a low, negative association. For the group of individuals with some high school education or less, about 6% of the variance in the MUIS-C could be explained by decreasing kidney function, as measured by increasing serum creatinine level.

A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents with college or greater \( r = .04; n=42 \). (Table XIII) This demonstrates a negligible, positive association. For the group of individuals with some college or more education, essentially none of the variance in the MUIS-C could be explained by worsening kidney function, as measured by increasing serum creatinine level.

Sub Question # 3.2

3.2. Is there a relationship between a decrease in kidney function and the mean score on the Mishel Uncertainty in Illness Scale - Community Form when analyzed according to prior experience with a person with kidney failure?

The seventy-five respondents were assigned to one of three groups depending upon prior experience with kidney failure. Respondents selected one of the following levels which was most descriptive: 1) having known no one with
kidney failure; 2) having known of someone with kidney failure; or 3) having a close friend or family member with kidney failure.

A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents with no prior experience with someone with kidney failure ($r = .19; n=28$). (Table XIII) This demonstrates a low, positive association. For the group of individuals with no prior experience with kidney failure, about 4% of the variance in the MUIS-C could be explained by decreasing kidney function.

A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents having known of someone with kidney failure ($r = -.17; n=23$). (Table XIII) This demonstrates a low, negative association. For the group of individuals with some prior experience by knowing of someone with kidney failure, less than 3% of the variance in the MUIS-C was explained by decreasing kidney function, as measured by increasing serum creatinine level.
A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents who had known a close family member or friend with kidney failure \((r = -.32; n=23)\). (Table XIII) This demonstrates a moderate, negative association. For the group of individuals with prior experience with kidney failure through a close family member or friend, about 10% of the variance in the MUIS-C could be explained by decreasing kidney function, as measured by increasing serum creatinine level.

Sub Question 3.3

3.3. Is there a relationship between a decrease in kidney function and the mean score on the MUIS-C when analyzed according to the length of time under the care of a nephrologist?

The records of the seventy-five respondents were reviewed to determine the length of time each had been under the care of a nephrologist. Respondents were categorized as either having twelve months or less experience, or thirteen months or more experience under the care of a nephrologist.

A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported
serum creatinine level of each respondent was calculated for respondents having twelve months or less under the care of a nephrologist \( (r = -0.06; n=28) \). (Table XIII) This demonstrates a negligible, negative association. For the group of individuals who had been under the care of a nephrologist for twelve months or less, essentially none of the variance in the MUIS-C could be explained by decreasing kidney function, as measured by increasing serum creatinine.

A Pearson Product Moment correlation coefficient comparing the mean score on the MUIS-C with the reported serum creatinine level of each respondent was calculated for respondents having had thirteen months or more under the care of a nephrologist \( (r = -0.10; n=46) \). (Table XIII) This demonstrates a low, negative association. For the group of individuals who had been under the care of a nephrologist for thirteen months or more, none of the variance in the MUIS-C could be explained by worsening kidney function, as measured by increasing serum creatinine level.
### TABLE XIII

PEARSON CORRELATION COEFFICIENTS FOR MEAN SCORE ON MUIS-C COMPARED WITH SERUM CREATININE AND SELECTED RESPONDENT CHARACTERISTICS

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<td>&lt;.197</td>
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<td>Nephrologist</td>
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<td>13 months or more</td>
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<td>-.10</td>
<td>&lt;.263</td>
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</table>

Table XIII contains the Pearson Correlation Coefficients for respondents' mean score on the MUIS-C with serum creatinine level, educational level, prior experience and length of time under the care of a nephrologist.
SUMMARY

The data obtained from the mailed survey of patients with decreased kidney function have been presented in this chapter. These data have been described with measures of central tendency, variation, and measures of association. In addition, several variables were explored to determine if relationships existed.
CHAPTER V
RESULTS AND RECOMMENDATIONS

SUMMARY

This study has explored the knowledge, attitudes, and uncertainty in patients with decreased kidney function who have not started renal replacement therapy. Respondent characteristics such as educational level, prior experience in knowing someone with kidney failure, and length of time under the care of a nephrologist were all considered as potentially influential in the scores obtained on the Kidney Knowledge Test, the Kidney Failure Attitude Scale, and the Mishel Uncertainty in Illness Scale - Community form.

The elusivity of potential participants complicated the conduct of the research. Yet, the high response rate (n=75; 83%) of those who did choose to participate suggests that participants are concerned about their kidney disease and treatment options and efforts to improve patient education.

Respondents were asked to complete three questionnaires measuring knowledge, attitudes, and uncertainty about one’s illness. These scores were then correlated with the
individual's level of kidney function, as measured by the serum creatinine level.

CONCLUSIONS

The descriptive statistics concerning the characteristics of respondents and the measures of association provide an opportunity for additional comments. It would be premature to generalize to other populations on the basis of data obtained from this study, but there are several interesting conclusions to be made.

Respondent Characteristics

Males and females responded almost equally. The ages of respondents were primarily 30 and over. While only one respondent (n=1; 4%) was in the 18-29 year old category, the other three categories (30-49; 50-64; and 65 or more) were almost equally divided (n=23; n=23 and n=26), respectively. The relatively large number in the 65 and older group is consistent with the aging national population as well as the increase in the numbers of older individuals beginning renal replacement therapy. The age range of
participants was similar to those reported in the pre-
dialysis educational groups by Nitz and Shayman (1986) and
by the post-treatment groups reported by Fuchs and Schrieber
(1988) and Bihl, Ferrans, and Powers (1988). As in these
other studies, adults between the ages of 18-29 or 30 are
less represented and more respondent/participants are in the
upper age ranges.

The majority (n=66; 90%) of the respondents were white.
African-Americans comprise about 28% of the end-stage renal
disease population, but they comprise only about 13% of the
national population. The lack of response by non-whites
(n=7; 10%) to this investigation is an important
consideration, particularly when considering the
disproportionate number of African-Americans with end-stage
renal disease. This demographic response is consistent
with those reported in other studies. Higher percentages of
white participants were also reported in studies conducted
by 1) Nitz and Shayman (71% and 75% for St. Louis and Kansas
City, respectively) (1986); 2) Fuchs and Schreiber (75%) (1988);
2) Bihl, Ferrans and Powers (65%) (1988) While it
is possible that African-Americans were not proportionately
represented in the original invitation to participate in
this study by the nephrologists, there is no particular reason to believe that this was the situation. The three nephrology practice groups included are known to serve a diverse population of patients and hospitals representative of diverse racial and ethnic backgrounds. It is possible that other factors contributed to the apparent lack of interest or response by African-Americans. These factors might have included: 1) fear of potential embarrassment associated with lack of education or knowledge about the subject; 2) lack of interest in participating; and 3) lack of belief or value about the potential or relative importance of research, especially if personal priorities were focused upon the concerns of day-to-day existence.

The majority of respondents (n=42; 58%) had some college or graduate education. Respondents or participants in other studies (Nitz & Shayman, 1986; Fuchs & Schrieber, 1988; Brock, 1990) were also fairly well educated.

Kidney Function and Knowledge

What conclusions can be drawn about the relationship between decrease in kidney function and knowledge about kidney function, kidney failure, and treatment options?
The mean score on the KKT was 15.85, range 3-30 (possible range 1-31), with a standard deviation of 6.79. The wide range of scores on the KKT suggests considerable variation in knowledge among respondents. As respondents freely used the response options of "Unsure" and "I don't know," more confidence can be placed in the assumption of the honesty of the respondents responses. In addition, this supports a level of confidence in the instrument's ability to measure knowledge. Kidney deterioration was moderately, positively correlated ($r = .31$) with scores on the KKT. About 10% of the variance in the KKT could be explained by worsening kidney function.

The findings of this study support those of Nitz and Shayman (1986) that there is considerable potential for increasing knowledge about treatment options in pre-dialysis patients. Nitz and Shayman (1986) found that mean pre-test scores increased from 69.5% ($\pm 2.4\%$) to 90.2% ($\pm 1.3\%$) on post-test scores following a seven week course on treatment options for pre-dialysis patients. The mean score on the KKT of 15.85 (16) or about 52%. This midlevel knowledge score suggests potential for increasing the knowledge level of adults with decreased kidney function.
When the educational level of respondents (high school or less) was considered, a moderate, positive correlation \( r = .37 \) of KKT and level of kidney function explained about 14% of the variance in this group. Only 6% of the variance in the KKT was explained by decreasing kidney function in the group of individuals with some college or more education. The low, positive association \( r = .24 \) for those with some college education might reflect greater homogeneity of subjects within the more educated group.

The effect of prior experience in moderating the scores on the KKT with decrease in kidney function provided some interesting findings. For those with experience in knowing about someone with kidney failure, the correlation \( r = .37 \) was moderately, positive between a decrease in kidney function and score on knowledge. For those who had known a close friend or relative with kidney failure, there was also a moderate, positive correlation \( r = .42 \) between decrease in kidney function and the score on knowledge. For those with no prior experience, there was a low, positive correlation with knowledge \( r = .14 \). This was essentially no variation between the variables. In the group of individuals with no prior experience, this finding
may be explained by a relatively greater homogeneity of this
less experienced group. The finding that knowledge
increased for those with some, or a lot of experience,
with others with kidney failure suggests the need to explore
further about the concept of prior experience, as has been

When the length of time under the care of a
nephrologist was considered, respondents with twelve months
or less time had a substantial, positive correlation
\( r = .50 \) and indicates that 25\% of the variance in the KKT
was explained by decreasing kidney function. For
respondents with thirteen or more months experience, there
was a low, positive correlation \( r = .24 \) which indicates
that only about 6\% of the variance in the KKT was explained
by decreasing kidney function. From this findings, one can
conclude that the first twelve months of time that the
person is under the care of a nephrologist seems to explain
something about knowledge as kidney function decreases.
Several factors might influence this finding. The
nephrologist might be more likely to allow more time in the
initial visit with the patient. Nurses or other health
professionals, such as dietitians or social workers, might
also spend more time with the new patient. Similarly, the patient may be motivated to learn more, or know so little, that knowledge gain scores in the first year seem more impressive than in subsequent years. The study by Watchous, Thurston and Carter (1980) also found that pre-test to post-test gain scores were higher in patients who had only been receiving treatment for several weeks. While this study did not examine the presence or degree of altered cognitive functioning in respondents, it is possible that even though kidney function decreased the opportunity for increased knowledge through greater time with the nephrologists was moderated by uremic effects upon cognitive processing.

Kidney Function and Attitude

What conclusions can be drawn about the relationship between decrease in kidney function and attitude toward kidney failure and learning about treatment options?

The mean score on the Kidney Failure Attitude Scale (KFAS) was 3.57, with a range of 2.48 to 4.33 (possible range 1-5), with a standard deviation of .399. The mean score of the KFAS suggests that respondents held attitudes that were more positive than neutral or negative toward
kidney failure, treatment options, and information-seeking.

While the negligible, negative association ($r = -0.09$) indicates essentially no relationship between decrease in kidney function and mean score on the KFAS and explains none of the variance in the KFAS, the findings on the subscales of the KFAS offer somewhat more insight. The low, negative association ($r = -0.18$) between the subscale FAILURE and decrease in kidney function suggests that as kidney function deteriorated, attitudes toward kidney failure worsened. There was a negligible, positive association ($r = 0.04$) between the subscale LEARN and decrease in kidney function. While essentially none of the variation in the KFAS subscales LEARN or FAILURE was explained by decreasing kidney function, it is of interest that attitude toward kidney failure decreased as kidney function worsened; whereas, attitude toward learning about kidney failure essentially did not change with worsening kidney function.

The variable of education, high school or less versus college or more offered little in the explanation of attitude in association with decrease in kidney function. When the KFAS subscales were considered, there was a low, negative association ($r = -0.22$) between attitude and
decrease in kidney function for the group of individuals with some college or more education.

The findings about the effect of the variable of prior experience offered some interesting insights. The midrange of level of experience represented by those who had known of someone with kidney failure offered essentially no information about the relationship between attitude and decrease in kidney failure. But, for those with no prior experience, attitudes toward learning about kidney failure were negatively associated with decrease in kidney failure ($r = -.11$) and attitudes toward kidney failure were also negatively associated ($r = -.29$) with decrease in kidney failure. Finally, for those with the highest level of experience with kidney failure through a family member or close friend, there was still a low, negative association between attitude toward kidney failure and decrease in kidney function ($r = -.07$), but a moderate, positive association between attitude toward learning about kidney failure and decrease in kidney function.

The findings surrounding the variable of length of time under the care of a nephrologist also offered some interesting conclusions. While there were low negative
(r = -.19) and negligible negative (r = -.08) correlations between the KFAS and decrease in kidney function for those with twelve months or less and thirteen months or more, respectively, these findings are of most interest when the results of subscale analyses are considered. For individuals with twelve months or less experience, there was a moderate, negative correlation (r = -.43) for attitude toward kidney failure and decrease in kidney function and a low, positive correlation (r = .12) for attitude toward learning about kidney failure and decrease in kidney function. For individuals with thirteen months or more under the care of a nephrologist, there was a low, negative association (r = -.11) for attitude toward kidney failure and a negligible, negative association (r = -.03) for attitude about learning about kidney failure and decrease in kidney function, respectively.

The overall lack of variation in attitude as kidney function worsened was an unexpected finding. In this study, the respondents might not have known the extent of their kidney deterioration. In addition, respondents might not have been aware of how the disease process was expected to proceed, or over what time period.
Because the KFAS measured two constructs, attitude toward kidney failure and attitude toward learning about kidney failure, some clarification of this unexpected finding was achieved when the subscale correlations were reviewed. From the findings, it would appear that the KFAS did indeed measure two constructs: attitude toward kidney failure and attitude toward learning about kidney failure.

It is important to note that for persons with no prior experience, as kidney function worsened, attitudes toward kidney failure decreased as well as attitudes toward learning about kidney failure. But, in the group with prior experience with a close family member or friend with kidney failure, attitudes toward learning about kidney failure increased as kidney function worsened, even though there was essentially no change in attitude toward kidney failure as kidney function worsened.

When the respondent characteristic concerning the length of time with the nephrologist was analyzed, further insights into the KFAS subscale correlations were also obtained. In the group of respondents with twelve months or less experience with kidney failure, as kidney failure worsened attitudes about kidney failure also worsened. But,
for the group of respondents with thirteen months or more experience, there was less moderation of attitude toward kidney failure by decrease in kidney function. This suggests that the first twelve months under the care of a nephrologist may be an important time period in influencing attitudes of persons with decreased kidney function.

Kidney Function and Uncertainty

What conclusions can be drawn about the relationship between decrease in kidney function and score on the MUIS-C?

The mean score on the MUIS-C was 62, range 26-91 (possible range 23-115), with a standard deviation of 13.25. The wide range of scores on the MUIS-C suggests considerable variation among the respondents on the variable of uncertainty about the illness. There is a low negative association ($r = -.10$) between decrease in kidney function and mean score on the MUIS-C. This indicates that there is essentially no relationship between decrease in kidney function and level of uncertainty and that none of the variance in the uncertainty score could be explained by decreasing kidney function. While relationships between the variables were not predicted in advance, this was an
unexpected finding based upon the review of the literature.

The variable of uncertainty about the future had been identified as a factor of considerable concern by Murphy, Baldree, and Powers (1982) and Bihl, Ferrans, and Powers (1988). The factor of uncertainty had been identified as one of midlevel concern by Fuchs and Schrieber (1988). Only the Gurklis and Menke study (1988) did not identify uncertainty as a high or midlevel factor of concern.

Consideration of the effect of the variable of level of education offers additional insight into the relationship between score on the MUIS-C and decrease in kidney function. When the educational level of respondents was considered, a low, negative correlation \((r = -.24)\) was found for those with high school or less education. For those with some college education or more, a negligible, positive correlation \((r = .04)\) was found. While little or none of the variation in the MUIS-C in relationship to decrease in kidney function was explained by the educational level, it is interesting to note that as kidney function decreased, uncertainty decreased. Brock (1990) found a negative correlation \((r = -.13)\) between level of education and uncertainty in spouses of dialysis patients. If educational
level had been measured as a continuous variable in this study, as was done by Brock, an alternate finding might have been obtained. These findings indicate that essentially none of the variation in the MUIS-C is explained by decreasing kidney function when level of education is considered.

When the variable of prior experience with another person with kidney failure is considered in analyzing the effect of decrease in kidney function with level of uncertainty, other conclusions can be drawn. For those respondents who reported an absence of prior experience with others with kidney failure, uncertainty increased as kidney failure worsened \((r = .19)\). But, uncertainty decreased as kidney failure worsened in persons reporting knowing of someone with kidney failure \((r = -.17)\) and those persons reporting knowing a close family member or friend with kidney failure \((r = -.32)\). From these findings, it is possible to conclude that prior experience with kidney failure through a close friend or family member explains about ten percent of the variance in uncertainty scores.

The variable of length of time under the care of a nephrologist did little in this study to explain level of
uncertainty. When the length of time under the care of a nephrologist is considered, a negligible, negative correlation ($r = -0.06$) was found for respondents with twelve months or less experience with a nephrologist. For those with thirteen or more months of experience, a low, negative correlation ($r = -0.10$) was found. These data indicate that there was essentially no relationship between the uncertainty score and decrease in kidney function. These findings might also be explained by considering that the respondent might not know the extent of his/her renal deterioration, nor the possible/probable outcome of the deterioration. The lack of awareness of a projected time frame may also have contributed to these findings.
IMPLICATIONS FOR PRACTICE

The findings from this study suggest several implications for nursing practice involving the care of adult patients with decreased kidney function. The discussion of these implications are organized within a framework of the nursing process.

Assessment

Methods for systematic assessment of the knowledge of pre-dialysis patients have not been previously reported. Methods of assessment of knowledge used in previous studies have not been well described (Wynne, 1981; Nitz and Shayman, 1986; Starzomski, 1986) or have lacked procedures to establish the reliability and validity of the tool developed. (Stephenson and Hayes, 1982)

No prior studies have been identified which have attempted to assess the attitudes of patients with decreased kidney function about kidney failure or information seeking. Chambers (1983) reported that staff nurses frequently identified nursing diagnoses related to psychosocial concerns of hospitalized dialysis patients, but these renal
staff nurse perceptions were not validated with empirical testing. As with other studies (Baldree, Murphy, Powers, 1982; Bihl, Ferrans, and Powers, 1988; Fuchs and Schrieber, 1988; Gurklis and Menke, 1988), attempts have been made to identify the concerns of current dialysis patients. But, the concerns of hospitalized patients or those receiving outpatient renal replacement therapy are not necessarily reflective of the attitudes of adults with decreased kidney function.

The Kidney Failure Knowledge (KKT) instrument is an instrument developed to measure knowledge about kidney function, causes of kidney failure, and kidney failure treatment options in adults with decreased kidney function. The Kidney Failure Attitude Scale (KFAS) is an instrument developed to measure attitude toward kidney failure and treatment options, as well as attitude toward learning about kidney failure through information-seeking. The reliability and validity of each instrument has been established.

Nurses in a variety of clinical practice settings might use the KKT to assess the knowledge and the KFAS to assess attitudes in adults with decreased kidney function. These practice settings might include nephrology patients in the
physician's office or clinic, acute medical units in hospitals, extended care facilities addressing the skilled care needs of persons with complications of chronic illnesses, and home health care or community health settings providing on-going care to adults with decreased kidney function.

The KKT and KFAS might also be of utility in general medical and nursing practice settings where adults with decreased kidney function are receiving care for primary conditions perhaps unrelated to the decreased kidney function. These practice settings might focus upon family or primary care, general internal medicine, or sub-specialty areas such as cardiology or diabetology. The use of the KKT with patients in these settings could also provide a baseline assessment of knowledge.

In addition, the KKT and KFAS might be used in general and specific health screening events. The KKT would be particularly appropriate for use with populations at high risk for the development of kidney failure, such as those with diabetes mellitus and/or high blood pressure (hypertension). The KFAS would be particularly appropriate for use in patients newly diagnosed with end-stage renal
failure with an expected need for imminent renal replacement therapy.

As many patients with decreased kidney function are unaware of their condition, the practitioner is advised to proceed cautiously in the use of these assessment tools. For example, the utility of the KKT might be enhanced through separate administration of the subscales. While alpha reliability coefficients of the subscales of knowledge about kidney function, kidney failure, and treatment options have been established within the context of the entire instrument, the reliability of each subscale when administered separately has not been established. This might be a next step in enhancing the clinical utility of the instrument. The administration of either assessment tool, the KKT or the KFAS, without knowledgeable support for follow-up could have untoward effects of increasing stress and concern.

Diagnosis and Planning

Accurate diagnosis presumes adequacy and accuracy of data collection for assessment. The development of an appropriate plan for educational intervention requires
consideration of need, perceived or awareness of need, readiness, prior education and experience, and attitude. The findings concerning cognitive functioning difficulties experienced by patients receiving hemodialysis treatment identified by Smith and Winslow (1990) require consideration when planning to provide educational interventions.

The findings from this study concerning the influence of prior experience and time under the care of a nephrologist suggest some implications for diagnosis and planning of interventions. The prior experience of the patient was shown to be a potential moderating variable in influencing knowledge, attitude, and uncertainty. It is important to identify patients who have had prior experience with kidney failure through a close family member or friend when assessing knowledge needs. With regard to attitude, it appears that those persons with no prior experience in knowing a person with kidney failure might be expected to have a more negative attitude. The nature of the individual’s prior experience needs to be explored, to determine whether it was positive or negative, to determine if any myths or misconceptions exist, and to further refine the assessment.
It is also important for nephrology nurses and other health care providers to be aware that attitudes toward kidney failure and treatment may differ from attitude toward learning about kidney failure and treatment. This was an important finding from this study that was demonstrated most clearly when the variable of prior experience was examined. The finding that patients with prior experience in knowing a close family member or friend with kidney failure tended to have a slightly negative attitude as kidney failure worsened is not necessarily surprising, when one considers the consequences of kidney failure that might have been observed. Yet, when the subscale of attitude toward learning about kidney failure was considered, attitude toward learning about kidney failure increased as kidney failure decreased. This has potentially important diagnostic and planning implications for nursing practice in that one cannot assume that the very experienced person has adequate or satisfactory information. Similarly, it is important for health care providers working with patients with decreased kidney function to not assume that further information is not desired or not needed. Indeed, the informational and educational needs may be even greater in
this experienced patient group.

The other variable with particularly important implications for nursing practice concerns the length of time the patient has been under the care of a nephrologist. For persons with twelve months or less experience with a nephrologist, there was a substantial, positive effect on knowledge in patients as kidney function decreased and a low, positive effect on knowledge in patients with thirteen months or more as kidney function decreased. These findings suggest that patients who have been seeing a nephrologist a relatively short period of time might be more interested or motivated in learning about kidney failure and treatment options. With regard to attitude, persons under the care of a nephrologist for twelve months or less tend to have more negative attitudes toward kidney failure in general, but there is some evidence of interest in learning about kidney failure in this group.

Implementation

While the previous discussion has focused upon the findings of this study in terms of the assessment and planning for interventions with patients, this section will
address implications of the study for assuring that the provider is adequately prepared to deliver the interventions. The particular area of emphasis will vary depending upon the patient’s point of entry into the health care system, as well as the point of provider contact within the health care system.

This findings of this study suggest that there is a general lack of knowledge, and a worsening of attitude, that is associated with decrease in kidney function. The study findings also suggest that prior experience can influence knowledge and attitude. The implication of these findings for practitioners concerns the adequacy of the preparation needed for those that educate and counsel patients with decreased kidney function. The importance of practitioner preparation can be appreciated when one considers the numerous areas of content expertise that are required. General topical areas include, but are not limited, to the following: the roles and functions of the kidneys, the effects of kidney failure, the causes of kidney failure, the methods of measurement and interpretation of function, the treatment functions of medications and nutritional modification, the diversity, routines, and
requirements of various treatment options including relative advantages and limitations, the concerns of living with a chronic disease that is fatal without treatment, and the diversity of systemic involvements and psychosocial stressors.

The nature of the patient's concern might be expected to vary depending with the point of entry into the system, as well as with the patient's understanding about the nature of his/her kidney problem. The selection of educational materials, utilization of resource specialists, and the implementation of an educational plan should be dependent upon consideration the patient's assessment, as well as an assessment of personal adequacy to implement the intervention.

The naive practitioner might view the intervention as merely the delivery of information. The indiscriminate distribution of pamphlets, videotapes, or other educational materials is not recommended. The prepared practitioner must be familiar with the breadth and depth of these materials in order to select that which is appropriate, as well as avoid that which is not appropriate, for the specific patient situation. As the findings of this study
suggest, prior experience can be an important intervening variable. There is a need for further study of the phenomenon of prior experience.

This study seems to support an interest in learning about kidney failure and its treatment options. The relatively high response rate also supports an interest in efforts to promote patient education. While these implications are important for all practitioners involved in the care of patients with decreased renal function, but they are especially pertinent to nephrology practitioners. Educational materials, resources, and programs that seek to influence attitudes toward kidney failure and treatment options are necessary to support practitioner efforts.

Evaluation

The evaluation of the effectiveness and/or appropriateness of the intervention is a necessary component of the nursing process. While sequentially identified as the final phase of the nursing process, it actually includes both formative and summative components. The formative component is reflected the practitioners on-going
evaluation of educational interventions so that revisions in the original plan may be made. Evaluative data might include consideration of questions asked or not asked, behaviors demonstrated or not, as well as by feelings stated or withheld. The summative evaluative component may be noted as patient outcomes for such factors as adequacy of treatment, complication and/or readmission rates, quality of life measurements or patient satisfaction indices.

The findings of this exploratory study suggest that knowledge, attitude, and uncertainty in adults with decreased kidney function are important considerations within the context of health care planning. Additional studies are needed from which the evaluative components may be more thoroughly investigated.
SUGGESTIONS FOR FUTURE RESEARCH

Suggestions for future research include the following: 1) the design of longitudinal studies to describe, explore, and objectively measure the cognitive alterations that patients experience with the development of uremia; 2) the investigation of mechanisms to guide decision-making processes about therapy selection for patients with and without prior knowledge of the diagnosis of chronic kidney failure; 3) the need for nephrology and other health care providers to develop educational programs for pre-end stage renal failure patients that offer consideration of the variety of health system entry points and the temporal effects of knowledge of one's diagnosis; 4) an investigation of the ethics of informed consent in uremic individuals and about treatment options influences personal satisfaction, quality of life, and financial consequences of treatment; and 5) development and implementation of educational interventions with high risk populations for the development of end-stage renal disease; and 6) further development and testing of the Kidney Knowledge Test and the Kidney Failure Attitude Scale.
Cognitive Alterations

The entire field of alterations in cognitive functioning as a result of the neurological effects of uremia deserves more attention. The study by Souheaver (1982) revealed that uremic patients experienced difficulty with new problem-solving tasks and with the assimilation of two or more pieces of information simultaneously. In this study, the findings indicated a moderate, positive association (r = .31) between decrease in kidney function and knowledge about kidney function, kidney failure, and treatment options. While this only explained about 10% of the variance between knowledge and decrease in kidney function, this finding may be influenced by the degree of uremia present in respondents and by altered cognitive functioning affecting performance on the KKT.

As cognitive alterations are rarely evaluated by objective measures in day to day clinical practice, there is a need to develop simple measurements that sensitively and reliably identify alterations in cognitive functioning particularly in pre-end stage renal failure patients with worsening azotemia. The specific alterations in cognitive functioning need to be identified.
specific cognitive alterations would allow individualization of the teaching process and perhaps maximize the learning. Educational materials could be developed with consideration of the types of cognitive deficits typically experienced in uremia. Decisions about how, when and where to implement educational efforts could be guided by this information and facilitated by these resources.

Decision-Making and Treatment Selection

Selection of a preferred means of renal replacement therapy requires considerable forethought and knowledge about one's personal physical, psychological, social strengths and limitations. There are substantial personal and financial costs associated with starting with one treatment modality, only to decide that another option would be better. Personal costs include time for hospitalization, lost work hours for employed patients, discomforts associated with preparatory procedures, alterations in body image from invasive and/or surgical procedures that in retrospect were unnecessary, and risks of infection or other complications associated with the modality initially chosen. Most of these personal costs also have a financial component
in the form of medical, surgical and hospital charges, lost income of both patient and family from being off work, and employer costs from lost productivity of ill employees. In this study, almost half (49%) of the respondents indicated that they were "extremely" or "very" concerned about the potential financial impact of renal disease. This suggests that even patients who are not end-stage have serious concerns about the financial implications.

Health Care Providers and Pre-dialysis Education

The point of entry into the health care system for treatment of kidney failure varies widely for individual patients. The attitude of the patient, as well as the health care provider, may influence how and when pre-dialysis education is initiated. In this study, there was essentially no relationship between decrease in kidney function and attitude toward kidney failure, treatment options, and information-seeking. But, when the data were analyzed with consideration of the extraneous variable of prior experience, there was low, negative correlation between decrease in kidney function and attitude in the group with no prior experience. This suggests that among
individuals with a lack of prior experience, that decrease in kidney function accounts for about 6% of the variance in attitude.

Non-nephrology health care providers, specialists in general practice or in other medical and nursing subspecialties, may delay or overlook the need to inform the patient about the deteriorating kidney function. (Friedman, 1978) Non-nephrology specialists may view progression to end-stage renal failure as a personal failure of the prescribed treatment plan, rather than the consequences of a disease process for which the prescribed treatment may prevent the development of end-stage renal disease. Alternatively, health care professionals may view the renal failure as an avoidable consequence, if only the medical advice had been followed. Consequently, further educational efforts may seem futile.

Nephrology health care specialists are generally aware of the need for preparatory educational efforts to facilitate decision-making and acceptance of the treatment requirements. The lack of screening methods to detect early kidney impairment and the delay of referrals from non-nephrology specialists further complicate these issues.
Health care providers in all disciplines, but especially medicine, nursing, nutrition, and social work, need to collaborate in the development and implementation of educational programs for patients with pre-end stage renal failure. The importance of pre-dialysis or pre-end stage renal failure education should also be a topic of education efforts with non-nephrology health care providers.

Ethics of Informed Consent in Uremic Patients

There are important ethical implications concerning decision-making and personal choice about medical treatment. These ethical considerations may be complicated by the altered cognitive processing that occurs in uremic individuals. It is important to consider the consequences of uninformed decision-making upon any of the following: 1) personal discomforts from invasive or surgical procedures that may prove not to be necessary; 2) the potential for complications arising from procedures that might not have been necessary; and 3) the excessive financial burden to the individual and to society.
High Risk Populations

The rapid increase of diabetes mellitus and hypertension as the two leading causes of end-stage renal disease in all persons is contributing to several high risk populations. The rates of increase of diabetes mellitus in the Native American population, as well as the lack of hypertension and diabetes mellitus control in African-Americans suggest the need for targeting of these high risk populations. (USRDS 1990 Annual Data Report) Hispanic Americans and Asian Americans are also demonstrating increases in problems with hypertension and diabetes mellitus. (USRDS 1990 Annual Data Report) These health trends suggest that there is a need for broad-based planning and funding efforts to reach these populations with preventive health strategies and methods of controlling the effects of various chronic diseases.

While a variety of socioeconomic factors contribute to a lack of adequate health care for many individuals in these and other populations, low literacy skills, lack of educational materials that are culturally appropriate, a general lack of cultural awareness by the predominantly white health care providers further complicate the education
of patients about how to live with and/or control the effects of chronic health problems that can result in chronic renal failure.

Instrument Development

The Kidney Knowledge Test and the Kidney Failure Attitude Scale represent a beginning effort to measure knowledge and attitudes about kidney disease. Further development and testing of these instruments are necessary to strengthen their reliability and validity. The subscale of the Kidney Knowledge Test should be tested for reliability and validity when administered separately. This could potentially enhance the instrument’s clinical utility. The constructs of attitude toward learning about kidney failure and treatment and attitudes about kidney failure and treatment require further development and validation.

The instruments should be tested for reliability and validity with other populations. The instruments should be administered to healthy adults, adults with other chronic illnesses, current hemodialysis, peritoneal dialysis, or transplant patients, older adults, adults representing racial and ethnic diversity, and adults with varying
literacy skills. It would be appropriate to test the instruments with alternate methods of administration. The instruments might be read by a health care provider or a family member to persons with low literacy skills, lack of English language skills, or impaired vision. Persons with these learning limitations might be expected to encounter difficulty or be unable to complete the instrument as it is currently designed.

RECOMMENDATIONS

This research has explored the knowledge, attitudes, and uncertainty in adults with decreased kidney function who have not started renal replacement therapy. As a result of this investigation, the following recommendations for future research are made.

1. Subjects who participated in this study should be invited to complete the instruments again immediately prior to starting renal replacement therapy.
2. Subjects who have not participated in this study should be asked to complete the instruments immediately prior to starting renal replacement therapy.

3. Development and testing of the Kidney Knowledge Test and the Kidney Failure Attitude Scale should be continued with attention to reliability and validity procedures for the sub-scales of each instrument, the administration of separate subscales of each instrument, as well as the administration and testing of the instruments’ reliability and validity with a wider variety of adult populations representing a diversity of ages, cultural and racial/ethnic backgrounds, and literacy skills.

4. This study should be replicated with the addition of additional measures to consider the level of cognitive functioning.

5. Longitudinal studies should be initiated to describe, explore, and delineate the nature of cognitive changes. These studies should include efforts to evaluate alternate educational interventions and techniques for effectiveness.
APPENDIX A

LETTERS TO NEPHROLOGISTS REGARDING INTENT OF STUDY
Riverside Nephrology Associates  
James W. Lewis, MD  
Michael H. Mishkind, MD  
Steven E. Gerald, MD  
Christopher Saunders, MD  
3545 Olentangy River Road  
Columbus, Ohio 43214

Dear Doctors Lewis, Mishkind, Gerald, and Saunders:

I am writing to request your assistance with research that I am conducting in partial fulfillment of the requirements for the completion of the doctor of philosophy degree at The Ohio State University. The tentative title of the research is "AN EXPLORATORY STUDY OF THE ATTITUDES, KNOWLEDGE, UNCERTAINTY AND INFORMATION-SEEKING BEHAVIORS IN PATIENTS WITH PRE-END STAGE RENAL FAILURE." My academic advisor is David Boggs, Ph.D., Professor and Chairman, Department of Adult Education.

This research will explore the relationship between decrease in kidney function and 1) knowledge of kidney function, kidney failure, and treatment options; 2) attitudes and information-seeking about kidney function, kidney failure, and treatment options; and 3) perceptions of uncertainty in pre-end stage renal failure. My interest in this project stems directly from my years of involvement in pre-dialysis education and counseling. I am particularly intrigued that no prior research exists (as I have currently been able to locate through extensive literature reviews) concerning the cognitive alterations, educational needs, and concerns of the pre-end stage renal failure patient.

The study will be conducted by administration of a mailed survey. Study participants must meet the following criteria: 1) ability to read and speak English; 2) absence of blindness or visual impairment that limits reading ability; 3) lack of diagnosed neurological impairment (e.g. cva, cortical disease, etc), and 4) absence of diagnosed psychiatric disorder (e.g. schizophrenia). In addition, the participant must be identified as having a serum creatinine of 2.5mg/dl or greater and evidence of chronic renal failure. Individuals with acute renal failure, without evidence of chronic or progressive deterioration, are to be excluded. I hope to obtain n=500 through a convenience sample from cooperating nephrologists.

Specifically, I am requesting your assistance with the following:

a) identification of patients appropriate for inclusion in the
study; (I understand that I may need to personally sort records to identify the subjects).

b) access to records to identify full name, mailing address, telephone number (for follow-up procedures of non-respondents);

c) access to medical records to obtain clinical and laboratory data necessary to assign subjects to appropriate levels of the independent variable (decrease in renal function) or other intervening variables to be controlled through statistical procedures (e.g. blood count, blood urea nitrogen, bicarbonate/serum CO2 combining power, etc).

d) use of Riverside Nephrology Associates stationary and envelopes for the introductory letter to enhance the rate of return (see below)

Mailed surveys require considerable attention to procedures identified as helpful in obtaining an acceptable rate of return. These procedures include personalization of the communication and recognition of the importance/credibility of the source of the research. Of course, I would assume all responsibility for preparation of the mailings, cost of postage, and would reimburse for expenses of the requested stationary. I will personally guarantee that the stationary would be used for no other purpose and that any unused stationary would be returned. A copy of the proposed introductory letter is also attached.

e) your review and comments of the proposed instruments (panel of experts) (see next paragraph)

My tentative plan is to begin data collection in January, 1991. Prior to data collection, I will be conducting reliability and validity studies of the instruments to be used. For these studies, I am requesting that each of you serve as a content expert for review of the instruments.

and

f) identification of patients to establish validity and reliability of the proposed instruments (see next paragraph)

To determine face validity and reliability (through pilot testing of the instruments), I need to identify 10-20 individuals who are likely to start dialysis prior to January, 1991 with characteristics similar to those proposed to be included in the sample for the study. These individuals would then be excluded from the actual research.
I would attempt to conduct this work causing a minimum of disruption to your office staff and procedures.

I look forward to your reply. My address and phone number(s) are as follows:

Home Address: 1581 Sandringham Drive, Columbus, Ohio 43220
Home Phone: 459-0831 (answering machine)
Work Address: Riverside Methodist Hospitals
             3535 Olentangy River Road, Columbus, Ohio 43214
Work Phone: 261-5000 (page); 261-5207 (leave message)

Please do not hesitate to contact me if additional information or clarification is needed.

Again, thank you in advance for your assistance.

Sincerely,

Jeanette K. Chambers, MS, RN.
Doctoral Candidate
The Ohio State University
William Bay, MD
Fernando Cosio, MD
Lee Hebert, MD
Donald Middendorf, MD
Stanley Nahman, MD
Department of Renal Medicine/Nephrology
The Ohio State University
N-210 Means Hall
1654 Upham Drive
Columbus, Ohio 43210

Dear Doctors Bay, Cosio, Hebert, Middendorf, and Nahman:

I am writing to request your participation in research that I am conducting in partial fulfillment of the requirements for the completion of the doctor of philosophy degree at The Ohio State University. The tentative title of the research is "AN EXPLORATORY STUDY OF THE ATTITUDES, KNOWLEDGE, UNCERTAINTY AND INFORMATION-SEEKING BEHAVIORS IN PATIENTS WITH PRE-END STAGE RENAL FAILURE." My academic advisor is David Boggs, Ph.D., Professor and Chairman, Department of Adult Education.

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The study will be conducted by administration of a mailed survey. Study participants must meet the following criteria: 1) ability to read and speak English; 2) absence of blindness or visual impairment that limits reading ability; 3) lack of diagnosed neurological impairment (e.g., cva, cortical disease, etc.), and 4) absence of diagnosed psychiatric disorder (e.g., schizophrenia). In addition, the participant must be identified as having a serum creatinine of 2.5mg/dl or greater and evidence of chronic renal failure. Individuals with acute renal failure, without evidence of chronic or progressive deterioration, are to be excluded. I hope to obtain n=500 through a convenience sample from cooperating nephrologists.
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b) access to records to identify full name, mailing address, telephone number (for follow-up procedures of non-respondents);

c) access to medical records to obtain clinical and laboratory data necessary to assign subjects to appropriate levels of the independent variable (decrease in renal function) and other intervening variables to be controlled through statistical procedures (e.g. blood count, blood urea nitrogen, bicarbonate/serum CO2 combining power, etc).

d) use of the The Ohio State University Department of Renal Medicine/Nephrology stationary and envelopes for the introductory letter to enhance the rate of return (see below)

Mailed surveys require considerable attention to procedures identified as helpful in obtaining an acceptable rate of return. These procedures include personalization of the communication and recognition of the importance/credibility of the source of the research. Of course, I would assume all responsibility for preparation of the mailings, cost of postage, and would reimburse for expenses of the requested stationary. I will personally guarantee that the stationary would be used for no other purpose and that any unused stationary would be returned. A copy of the proposed introductory letter is also attached.

e) your review and comments of the proposed instruments (panel of experts) (see next paragraph)

My tentative plan is to begin data collection in January, 1991. Prior to data collection, I will be conducting reliability and validity studies of the instruments to be used. For these studies, I am requesting that each of you serve as a content expert for review of the instruments.

and

f) identification of patients to establish validity and reliability of the proposed instruments (see next paragraph)

To determine face validity and reliability (through pilot testing of the instruments), I need to identify 5-10 individuals who are likely to start dialysis prior to January, 1991 with characteristics similar to those proposed to be included in the sample for the study. These individuals would then be excluded from the actual research.
I would attempt to conduct this work causing a minimum of disruption to your office staff and procedures.

I look forward to your reply to these requests. My address and phone number(s) are as follows:

Home Address: 1581 Sandringham Drive, Columbus, Ohio 43220
Home Phone: 459-0831 (answering machine)
Work Address: Riverside Methodist Hospitals
             3535 Olentangy River Road, Columbus, Ohio 43214
Work Phone: 261-5000 (page); 261-5207 (leave message)

Please do not hesitate to contact me if additional information or clarification is needed.

Again, thank you in advance for your assistance.

Sincerely,

Jeanette K. Chambers, MS, RN.
Doctoral Candidate
The Ohio State University
Wesley Forgue, MD
Daniel Cotton, MD
395 E. Town Street
Columbus, Ohio 43215

Dear Drs. Forgue and Cotton:

I am writing to request your assistance with research that I am conducting in partial fulfillment of the requirements for the completion of the doctor of philosophy degree at The Ohio State University. The tentative title of the research is "AN EXPLORATORY STUDY OF THE ATTITUDES, KNOWLEDGE, UNCERTAINTY AND INFORMATION-SEEKING BEHAVIORS IN PATIENTS WITH PRE-END STAGE RENAL FAILURE." My academic advisor is David Boggs, Ph.D., Professor and Chairman, Department of Adult Education.

This research will explore the relationship between decrease in kidney function and 1) knowledge of kidney function, kidney failure, and treatment options; 2) attitudes and information-seeking about kidney function, kidney failure, and treatment options; and 3) perceptions of uncertainty in pre-end stage renal failure. My interest in this project stems directly from my 10+ years of involvement in pre-dialysis education and counseling, as a renal clinical nurse specialist affiliated with Riverside Methodist Hospitals. I am particularly intrigued that no prior research exists (as I have currently been able to locate through extensive literature reviews) concerning the cognitive alterations, educational needs, and concerns of the pre-end stage renal failure patient.

The study will be conducted by administration of a mailed survey. Study participants must meet the following criteria: 1) ability to read and speak English; 2) absence of blindness or visual impairment that limits reading ability; 3) lack of diagnosed neurological impairment (e.g. cva, cortical disease, etc.), and 4) absence of diagnosed psychiatric disorder (e.g. schizophrenia). In addition, the participant must be identified as having a serum creatinine of 2.5mg/dl or greater and evidence of chronic renal failure. Individuals with acute renal failure, without evidence of chronic or progressive deterioration, are to be excluded. I hope to obtain n=500 through a convenience sample from cooperating nephrologists.

Specifically, I am requesting your assistance with the following:

a) identification of patients appropriate for inclusion in the study; (I understand that I may need to personally sort records
to identify the subjects).

b) access to records to identify full name, mailing address, telephone number (for follow-up procedures of non-respondents);

c) access to medical records to obtain clinical and laboratory data necessary to assign subjects to appropriate levels of the independent variable (decrease in renal function) or other intervening variables to be controlled through statistical procedures (e.g. blood count, blood urea nitrogen, bicarbonate/serum CO2 combining power, etc).

d) use your letterhead stationary and envelopes to enhance the rate of return (see below)

Mailed surveys require considerable attention to procedures identified as helpful in obtaining an acceptable rate of return. These procedures include personalization of the communication and recognition of the importance/credibility of the source of the research. Of course, I would assume all responsibility for preparation of the mailings, cost of postage, and would reimburse for expenses of the requested stationary. I will personally guarantee that the stationary would be used for no other purpose and that any unused stationary would be returned. A copy of the proposed introductory letter is also attached.

e) your review and comments of the proposed instruments (panel of experts) (see next paragraph)

My tentative plan is to begin data collection in January, 1991. Prior to data collection, I will be conducting reliability and validity studies of the instruments to be used. For these studies, I am requesting that each of you serve as a content expert for review of the instruments.

and

f) identification of patients to establish validity and reliability of the proposed instruments (see next paragraph)

To determine face validity and reliability (through pilot testing of the instruments), I need to identify 5-10 individuals who are likely to start dialysis prior to January, 1991 with characteristics similar to those proposed to be included in the sample for the study. These individuals would then be excluded from the actual research.

I would attempt to conduct this work causing a minimum of disruption to your office staff and procedures.

I look forward to your reply to these requests. My address and phone number(s) are as follows:
Home Address: 1581 Sandringham Drive, Columbus, Ohio 43220
Home Phone: 459-0331 (answering machine)
Work Address: Riverside Methodist Hospitals
            3535 Olentangy River Road, Columbus, Ohio 43214
Work Phone: 261-5000 (page); 261-5207 (leave message)

Please do not hesitate to contact me if additional information or clarification is needed.

Again, thank you in advance for your assistance.

Sincerely,

Jeanette K. Chambers, MS, RN.
Doctoral Candidate
The Ohio State University
APPENDIX B

LETTERS OF SUPPORT FROM NEPHROLOGIST TO COOPERATE WITH STUDY
September 24, 1990

To whom it may concern:

The physicians in our Division will be cooperating with Jeanette K. Chambers, MS, RN, CS, by referral of appropriate subjects for the study entitled "An ex post facto study of the knowledge, attitudes, information-seeking characteristics and uncertainty in patients with pre-end stage renal failure".

Sincerely,

Lee A. Hert, MD
Professor of Medicine
Director, Division of Renal Diseases

LAH: cp
September 24, 1990

To Whom It May Concern:

Our practice will be participating in the research being conducted by Jeanette K. Chambers, MS, RN, CS, entitled, "An Ex Post Facto Study of the Knowledge, Attitudes, Information-Seeking Characteristics and Uncertainty in Patients with Pre-End Stage Renal Failure".

We will be referring appropriate subjects to be included in this study.

Sincerely,

James W. Lewis, M.D.

[Signature]
26 September 1990

Ms. Jeannette K. Chambers,
M.S., R.N., C.S.
1581 Sandringham Drive
Columbus, Ohio 43220

RE: Doctor of Philosophy
Degree program at
The Ohio State
University

Dear Ms. Chambers,

We would like to take this opportunity to accept your request for assistance with your research while completing your work toward your graduate degree at The Ohio State University. We will be most happy to assist you in whatever means we can so that you may complete your credit work.

Thank you for allowing us to participate in the fulfillment of this college requirement for you.

Sincerely,

Wesley V. Forgue, M.D.
Daniel S. Cotton, M.D.

WVF/DSC/1-rF
cc: file
APPENDIX C

APPROVAL FROM THE OHIO STATE UNIVERSITY
BEHAVIORAL AND SOCIAL SCIENCES
HUMAN SUBJECTS COMMITTEE
BEHAVIORAL AND SOCIAL SCIENCES
HUMAN SUBJECTS REVIEW COMMITTEE (HSRC)
THE OHIO STATE UNIVERSITY

Date November 16, 1990

RESEARCH PROTOCOL:

5080163 AN EX POST FACTO STUDY OF THE KNOWLEDGE, ATTITUDES, AND
UNCERTAINTY OF PATIENTS WITH PRE-END STAGE RENAL FAILURE,
David L. Boggs, Jeanette K. Chambers, Educational Policy and
Leadership

presented for review by the Behavioral and Social Sciences Review Committee
to ensure proper protection of the rights and welfare of the individuals
involved with consideration of the methods used to obtain informed consent
and the justification of risks in terms of potential benefits to be gained,
the Committee action was:

____ APPROVED                    ____ DEFERRED*

X____ APPROVED WITH CONDITIONS*    ____ DISAPPROVED

____ NO REVIEW NECESSARY

*CONDITIONS/COMMENTS:

Subjects were deemed NOT AT RISK and the protocol was
unanimously APPROVED WITH THE FOLLOWING CONDITIONS:

1. Subjects interested in participating in this study should
   return the postal card to the principal investigator
   rather than the physician.

2. Revise Attachment A, the third sentence of the third
   paragraph to read as follows and return copy to the
   Committee:

      "If you are interested in participating, please
      sign and return the enclosed postcard so that you
      may be contacted by Ms. Chambers."

3. Obtain the signature of Dr. David L. Boggs on the consent
   form and forward a copy to the Committee.
If you agree to the above conditions, PLEASE SIGN THIS FORM IN THE SPACE PROVIDED BELOW AND RETURN WITH ANY ADDITIONAL INFORMATION REQUESTED TO ROOM 205, THE OHIO STATE UNIVERSITY RESEARCH CENTER, 1314 KINNEAR ROAD, COLUMBUS, OHIO 43212, within one week. Upon such compliance, the approval form will be mailed to you. (In case of a deferred protocol, please submit the requested information at your earliest convenience. The next meeting of the Committee will be two weeks from the meeting date indicated above.)

DATE November 16, 1990

Signature(s) [Signatures]

RS-025A (Rev. 3/85)
(CONDITIONS/COMMENTS)

(Principal Investigators)
APPENDIX D

APPROVAL FROM THE RIVERSIDE METHODIST HOSPITALS
RESEARCH COMMITTEE AND
INSTITUTIONAL REVIEW BOARD
November 8, 1990

Jeanette Chambers, RN, MS, CS
3535 Olentangy River Road
Columbus, Ohio 43214

RE: AN EX-POST FACTO STUDY OF THE KNOWLEDGE, ATTITUDES, AND UNCERTAINTY OF PATIENTS WITH PRE-END STAGE RENAL FAILURE.

Dear Ms. Chambers:

Your protocol was reviewed and approved by the Research Committee on November 7, 1990, and will be forwarded to the Institutional Review Board (IRB) on November 15. Please do not begin your study until final IRB approval has been obtained.

Thank you for submitting your study to the Research Committee for review. If you have any further questions, please contact the Research Department at 261-5319.

Sincerely,

Ian M. Baird, MD
Chairman, Research Committee

cc: Mary Anne Zanetos, MS, Director, Research

/skw

/CHAMBERS
November 16, 1990

Jeanette Chambers, MS, RN, CS
3535 Olentangy River Road
Columbus, Ohio 43214

RE: AN EX POST FACTO STUDY OF THE KNOWLEDGE, ATTITUDES, AND UNCERTAINTY OF PATIENTS WITH PRE-END STAGE RENAL FAILURE. PROJECT #572.

Dear Ms. Chambers:

Your protocol was reviewed and approved by the Institutional Review Board (IRB) under the provisions for expedited review.

An expenditure allowance (no cash) in the amount of $2,790.50 has been awarded to cover the costs of data entry, statistical analysis, supplies, and miscellaneous expenses.

Any changes to your protocol must be reviewed and approved by the IRB prior to their implementation. In addition, the IRB must be notified immediately of any adverse experiences that are reported.

All correspondence regarding this study must be identified by protocol title and the assigned project number 572. Upon completion of this study, you will be required to submit a final written to the IRB.

Your protocol is due for rereview in six months. If you have any further questions, please contact the Research Department at 261-5319.

Sincerely,

[Signature]

Bruce A. Wall, MD
Chairman, Institutional Review Board

cc: Mary Anne Zanetos, MS, Director, Research

/skw

\572-JC
APPENDIX E

CONSENT TO PARTICIPATE
AND EXPLANATORY LETTER
Dear

Thank you for your interest in participating in a study of the "Knowledge, Attitudes, and Uncertainty of Kidney Patients in Order to Improve Patient Education."

In order to proceed, we need your consent. Please sign the enclosed consent form and ask someone to also sign as a witness to your signature. Please return the consent form in the enclosed, stamped envelope.

Your decision about participation in the study will not affect your care in any way. Participation in the study is completely voluntary. You may withdraw from the study at any time and your medical care will not be affected. None of the information received from the study will be placed in your medical record. The information obtained and your responses will be remain confidential.

We appreciate your interest in the study and encourage your participation.

Thank you.

Sincerely,

[Signature]
Principal Investigator

[Signature]
Doctoral Candidate
Co-investigator
The Ohio State University  
Columbus, Ohio  

CONSENT FOR PARTICIPATION IN  
SOCIAL AND BEHAVIORAL RESEARCH

I consent to participate in research entitled:

A STUDY OF THE KNOWLEDGE, ATTITUDES, AND UNCERTAINTY IN KIDNEY PATIENTS IN ORDER TO IMPROVE PATIENT EDUCATION

I understand that participation is voluntary. I understand that I can withdraw from the study at any time without any affect to my medical care.

I understand that my medical chart will be reviewed.

I understand that my responses to the questionnaire will remain confidential. I understand that this information will not become a part of my medical record.

Date: ____________________ Signed: ____________________

(participant)

Witness: ____________________

Signed: ____________________  
(Principal Investigator)  

______________________  
(Co-investigator)
APPENDIX F

FOLLOW-UP LETTER FOR CONSENT TO PARTICIPATE
Dear

Recently, I sent you a consent form to participate in a survey of kidney patients.

Perhaps it was never received, or has been misplaced. I have enclosed copies for you to review.

Would you please return the enclosed consent form today? Your participation is very important.

Thank you.

Sincerely,

Jeanette K. Chambers, MS, RN.
Ph.D. Candidate
APPENDIX G

QUESTIONNAIRE BOOKLET COVER AND
INTRODUCTORY LETTER
A Study of the Knowledge, Attitudes, and Uncertainty in Kidney Patients in order to Improve Patient Education
Dear Study Participant:

Thank you for agreeing to participate in the study.

Please complete each of the four sections. Please answer each question; please do not skip any questions. Please circle only one response to each question.

Please return the questionnaire in the self-addressed, stamped envelope.

The Code Number allows me to follow-up with participants who may have lost, misplaced, or never received the questionnaire.

Your responses will be confidential.

If you would like a summary of the study, please sign and date the enclosed postcard. Please return the postcard separately from the questionnaire.

Thank you again for participating in this study.

Sincerely,

Jeanette K. Chambers, MS, RN
Doctoral Candidate
APPENDIX H

KIDNEY KNOWLEDGE TEST
KNOWLEDGE QUESTIONNAIRE

Knowledge about Kidney Function, Disease, and Treatment Options

Directions: Circle the response that you believe is most correct. Please answer all questions.

1. Do the kidneys control heart rate?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

2. Do the kidneys control urine output?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

3. Do the kidneys control body temperature?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

4. Do the kidneys control minerals (salts) in the blood?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
5. Do the kidneys control the rate of breathing?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

6. Do the kidneys control the body's blood sugar?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

7. Do you think high blood pressure (high blood) might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

8. Do you think that poor eating habits might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

9. Do you think that asthma might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
10. Do you think infection(s) might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

11. Do you think that IV (intravenous) drug abuse might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

12. Do you think that some "drug store" medicines that you can get without a doctor's prescription might cause kidney disease?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

13. Is BUN a blood test to measure kidney function?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

14. Is albumin a blood test to measure kidney function?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
15. Is creatinine a blood test to measure kidney function?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

16. Is fatigue a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

17. Is having trouble sleeping at night a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

18. Is having an increased appetite a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

19. Is feeling sick to the stomach (nausea) or dry heaves a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
20. Is vomiting a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

21. Is hiccups a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

22. Is difficulty in concentrating a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

23. Is having trouble remembering a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW

24. Is itching a problem that occurs when kidney failure is present?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
25. The doctor would request a blood sample of creatinine to measure which of the following?
   a. HEART DISEASE
   b. LIVER DISEASE
   c. CANCER
   d. KIDNEY DISEASE

26. The doctor would request a blood sample of cholesterol to measure the chances of which of the following?
   a. HEART DISEASE
   b. LIVER DISEASE
   c. CANCER
   d. KIDNEY DISEASE

27. Which of the following types of dialysis is usually done at home by the patient or family member?
   a. HEMODIALYSIS
   b. PERITONEAL DIALYSIS
   c. UNSURE
   d. I DON'T KNOW

28. Which of the following types of dialysis is usually done at a hospital or outpatient center/clinic by trained staff?
   a. HEMODIALYSIS
   b. PERITONEAL DIALYSIS
   c. UNSURE
   d. I DON'T KNOW

29. Which type of dialysis uses needles for the treatment?
   a. HEMODIALYSIS
   b. PERITONEAL DIALYSIS
   c. UNSURE
   d. I DON'T KNOW
30. Which type of dialysis puts a bag of special fluid into the abdomen for the treatment?
   a. HEMODIALYSIS
   b. PERITONEAL DIALYSIS
   c. UNSURE
   d. I DON'T KNOW

31. Does the patient usually have a choice about the type of dialysis?
   a. YES
   b. NO
   c. UNSURE
   d. I DON'T KNOW
APPENDIX I

KIDNEY FAILURE ATTITUDE SCALE
ATTITUDE SURVEY

ATTITUDES ABOUT KIDNEY FAILURE, TREATMENT OPTIONS AND INFORMATION-SEEKING

Directions: For each item, circle the letter(s) that describes your level of agreement or disagreement. The scale is as follows:

SD = STRONGLY DISAGREE
D = DISAGREE
U = UNDECIDED
A = AGREE
SA = STRONGLY AGREE

SAMPLE QUESTION

Please read the following statement and the statements that follow that explain how you might respond to the question.

I like the idea of being informed about my health.           SD  D  U  A  SA

SAMPLE RESPONSES

You would circle SD (Strongly Disagree), if you are not interested at all in knowing about your health.

You would circle D (Disagree), if you are generally not interested in knowing about your health.

You would circle U (Undecided), if you are unsure about whether you are interested in knowing about your health.

You would circle A (Agree), if you are generally interested in knowing about your health.

You would circle SA (Strongly Agree), if you are very interested in knowing about your health.
Please answer each question. Circle only one response for each question.

SD = STRONGLY DISAGREE
D = DISAGREE
U = UNDECIDED
A = AGREE
SA = STRONGLY AGREE

Directions: For each statement, circle the letter(s) that describe(s) your level of agreement or disagreement.

1. I like the idea of learning all that I can about how kidney failure will make me feel. SD D U A SA

2. I like the idea of learning all that I can about the functions of the kidneys. SD D U A SA

3. I like the idea of learning all that I can about the treatments for kidney failure. SD D U A SA

4. I plan to do whatever is needed to treat my kidney problem. SD D U A SA
5. If needed, I would not hesitate to start dialysis treatments.

6. If needed, I think that I could learn to do my own dialysis treatments.

7. I think that the idea of needing dialysis treatments would scare most people.

8. I think that the idea of needing dialysis treatments would make most people sad.

9. I think that the idea of needing dialysis treatments would make most people angry.

10. If I needed dialysis or a kidney transplant, I would prefer that as few people as possible knew about it.

11. If needed, I would like to talk with someone who is having dialysis treatment for kidney failure.
12. If needed, I would like to talk with someone who has had a kidney transplant. SD D U A SA

13. I think that the idea of needing a transplant would make most people fearful. SD D U A SA

14. I think that the idea of needing a transplant would make most people sad. SD D U A SA

15. I think that the idea of needing a transplant would make most people angry. SD D U A SA

16. I think that the costs of dialysis or a transplant would be a concern. SD D U A SA

17. If I needed a kidney transplant, I would prefer that as few people as possible knew about it. SD D U A SA

18. If needed, I would like to tour a dialysis unit. SD D U A SA
19. I would be likely to read a brochure about kidney failure.

20. I might go to a library to get information about kidney failure.

APPENDIX J

PERMISSION TO REPRODUCE MUIS-C
Request Form
MUIS-C

I request permission to copy the Mishel Uncertainty in Illness Scale, Community Form for use in my research entitled, AN EX POST FACTO STUDY OF THE KNOWLEDGE, ATTITUDES, AND UNCERTAINTY OF PATIENTS WITH PRE-END STAGE RENAL FAILURE.

In exchange for this permission, I agree to submit to Dr. Mishel a printout of the uncertainty data or a 5½ inch disk containing the data with a data dictionary. The data must contain information in each subject's age, sex, education, and diagnosis, along with the raw data on the uncertainty scale. This data will be used to establish a normative data base for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses. I also agree to send Dr. Mishel a copy of my findings. I understand that my report will be used to compile information on the theory of uncertainty in illness. Credit will be given to me in any reports referring to my findings.

Jeanette K. Chambers
(Signature)
10-8-90
(Date)

Position and Full Address of Investigator.
Jeanette K. Chambers, MS, RN, CS.
1581 Sandringham Drive
Columbus, Ohio 43220
Doctoral Candidate-The Ohio State University
Clinical Nurse Specialist
Riverside Methodist Hospitals

Permission is hereby granted to copy the MUIS for use in the research described above.

Merle H. Mishel
(Signature)
10-26-90
(Date)

Please send two signed copies of this form to Merle H. Mishel, Ph.D., College of Nursing, University of Arizona, Tucson, Arizona 85721.

REV:pw
revised 1/89
Merle Mishel, Ph.D
Associate Professor
College of Nursing
The University of Arizona
Tucson, AZ

August 21, 1990

1581 Sandringham Drive
Columbus, Ohio 43220

Dear Dr. Mishel:

I am a doctoral candidate at The Ohio State University majoring in Adult Education. My background (bachelor's and master's) is nursing. I am a Renal/Medical Clinical Nurse Specialist at Riverside Methodist Hospitals in Columbus, Ohio.

During the past 13 years, I have worked with many patients and family members during the "pre-dialysis" period to provide educational counseling concerning treatment options. The concept of uncertainty is one which I have "observed" frequently in these discussions.

I am preparing my dissertation proposal and would like to review a copy of your "Uncertainty in Illness Scale." My research interest is in the information-seeking and information processing characteristics of adults who have developed chronic renal failure but who are not yet at end-stage requiring dialysis or transplantation. Specifically, I want to look at individuals attitudes and knowledge about kidney function, kidney failure, and treatment options.

I would be glad to provide any additional information that you may require. My phone number is (614) 261-5000 (work: ask operator to page me) or (614) 459-0831 (home: answering machine after four rings). If it is convenient, you can send me electronic mail at: Chambersj@osu-20.ircc.ohio-state.edu.

I look forward to hearing from you.

Sincerely,

Jeanette K. Chambers, MS, RN, CS.
APPENDIX K

PANEL OF EXPERTS COVER LETTER
AND QUESTIONNAIRE
Dear

As we have discussed, I am preparing to conduct research for my doctoral dissertation entitled "An Ex Post Facto Study of the Knowledge, Attitudes, and Uncertainty of Patients with Pre-end Stage Renal Failure."

I am writing to ask your assistance in reviewing the instruments to be used in the study. These instruments will be printed in a booklet format and mailed to study participants. To be eligible to receive the questionnaire, study participants must 1) have a serum creatinine of 2.5mg/dl or greater, 2) not be on dialysis or a transplant recipient, 3) be 18 years or older, 4) speak English, 5) have vision sufficient to read the instrument, 6) have no cerebral cortical dysfunction (e.g. CVA), and 7) have no major psychiatric disorder (e.g. schizophrenia). In addition, patients with acute renal failure who do not have underlying renal disease will be excluded.

As a health care professional working with renal patients, you have knowledge and experience that will assist in assuring that the content of the instruments is appropriate for the proposed target population (pre-end stage renal failure patients).

Please review the enclosed instruments. Write notes or comments directly upon the instruments, as needed. Then, please complete the enclosed brief questionnaire concerning each of the instruments.

A self-addressed, stamped envelope is enclosed for return of the materials. Please return the instruments, the rating forms, and any additional comments you would like to make. Thank you in advance for your assistance. I would appreciate the return of these materials by October 22, 1990.
If you have any questions, please do not hesitate to contact me at home (614) 458-0831 after 4pm, or (614) 261-5000 (page). I am not available on Tuesday and Thursday mornings from 8am to 11:30am.

Sincerely,

Jeanette K. Chambers, MS, RN, CS.
Doctoral Candidate
The Ohio State University
CONTENTS VALIDITY ASSESSMENT BY PANEL OF EXPERTS

Knowledge Instrument - Developed by Jeanette K. Chambers

The knowledge instrument seeks to determine the extent of the patient's familiarity with 1) the functions of the kidney; 2) the potential causes of kidney disease; 3) the symptoms of kidney failure; and 4) potential treatment options.

1. Please indicate by circling the appropriate response the extent to which you believe the instrument would measure knowledge about each of the following:

   SD = Strongly Disagree
   D = Disagree
   U = Undecided
   A = Agree
   SA = Strongly Agree

   a. functions of the kidney
   b. potential causes of kidney failure
   c. symptoms of kidney failure
   d. potential treatment options

   SD  D  U  A  SA

2. Are there other areas of content that you would identify as appropriate to include in a basic test of knowledge about kidney function, kidney disease, or treatment options?

   Yes_________ No_____________________

   Comments:

3. Would you recommend deletion of any of the items or areas of content on the knowledge instrument?

   Yes_________ No_____________________

Comments:

4. Do the questions seem clear?
   Yes__________  No__________
   Comments:

5. Does the wording of the questions seem appropriate?
   Yes__________  No__________
   Comments:
Attitude Instrument - Developed by Jeante K. Chambers

The attitude instrument seeks to assess the patient's feelings and beliefs about the nature of kidney disease, treatment options, and information-seeking.

1. Please indicate by circling the appropriate response the extent to which you believe the instrument would measure the patient's attitudes about each of the following:

   SD = Strongly Disagree
   D = Disagree
   U = Undecided
   A = Agree
   SA = Strongly Agree

   a. feelings about kidney failure        SD D U A SA
   b. feelings about treatment options     SD D U A SA
   c. feelings about information-seeking   SD D U A SA

2. Are there other areas of patient concern that you would identify as appropriate to include in a basic assessment of feelings and beliefs about kidney failure and treatment options?

   Yes_____________  No_____________

   Comments:

3. Would you recommend deletion of any of the items or areas of content on the attitude scale?

   Yes_____________  No_____________

   Comments:
4. Do the questions seem clear?
   Yes_________ No_________

   Comments:

5. Does the wording of the questions seem appropriate?
   Yes_________ No_________

   Comments:
Mishel Uncertainty in Illness Scale - Developed by Merle H. Mishel, Ph.D.

The Mishel Uncertainty in Illness Scale seeks to assess a patient's feelings of uncertainty that are associated with the presence of a chronic illness or health problem.

1. Do you think that uncertainty is experienced by persons with decreased kidney function that is not at end-stage?
   
   Yes_______ No_________

   Comments:

2. Do you think that the questions asked on the Mishel Uncertainty in Illness Scale are generally appropriate for persons who have decreased kidney function that is not yet at end-stage?

   Yes____________ No_________

   Comments:

3. Do you think it would be appropriate to administer the Mishel Uncertainty in Illness Scale to pre-end stage renal failure patients?

   Yes____________ No_________

   Comments:
4. Do the questions seem clear?
   Yes_________ No__________
   Comments:

5. Does the wording of the questions seem appropriate?
   Yes_________ No__________
   Comments:
APPENDIX L

PANEL OF EXPERTS PARTICIPATING IN INSTRUMENT REVIEWS
PANEL OF EXPERTS

IDENTIFIED RESPONDENTS TO THE QUESTIONNAIRE REGARDING THE CONTENT VALIDITY OF THE PROPOSED INSTRUMENTS

Nephrology Content Experts

Medicine

Riverside Nephrology Associates
Steven E. Gerald, MD
James W. Lewis, MD
Christopher Saunders, MD

The Ohio State University, Department of Internal Medicine, Renal Division
Jim Ogrowdowski, MD

Nephrology Practice (Attending Staff: Grant Hospital, St. Anthony Hospital and Riverside Methodist Hospitals
Wesley Forgue, MD

Nursing

Riverside Methodist Hospitals, Columbus, Ohio
Linda Wollenberg, RN, CNN
Nurse Manager, Dialysis Unit
Diane Hohwald, RN, CNN
Education Coordinator, Dialysis Unit

Mount Carmel Medical Center
Sherrie Hawley, MS, RN
Nurse Manager, Dialysis Unit

Social Work

Riverside Methodist Hospitals, Columbus, Ohio
Sandy LaRue, MSW, LISW
Ron White, MSW (formerly at RMH)
Nephrology Content Experts (continued):

**Nutrition**

Riverside Methodist Hospitals, Columbus, Ohio
Roselle Marino, RD

The Ohio State University, Department of Internal Medicine, Renal Division
Judy Hartman, RD

**Measurement/Design Experts**

David L. Boggs, Ph.D.
Professor, Adult Education
The Ohio State University
College of Education
Department of Educational Studies
Chair, Adult Education

Sandra J. Cornett, RN, Ph.D
Adjunct Assistant Professor,
The Ohio State University
College of Nursing and
Coordinator, Patient Education
University Hospitals

Anthony J. Frisby, MA, Ph.D. Candidate
Graduate Research Associate
The Ohio State University
College of Medicine

Emmalou Van Tilburg Norland, Ph.D
Associate Professor, Agricultural Education
APPENDIX M

FIELD TEST COVER LETTER
AND QUESTIONNAIRE
1581 Sandringham Drive
Columbus, Ohio 43220
November 9, 1980

Dear

I am writing you to ask your assistance with a survey that I am planning to do in the near future. This survey is research that is part of the requirement for my doctoral degree in Adult Education at The Ohio State University. My academic advisor is Dr. David L. Boggs.

As you may recall, I am a registered nurse who has been involved in many patient education projects, especially for people with kidney failure. My concern about improving patient education has lead to my interest in this study.

For this study, I am interested in surveying people with kidney failure who have not yet needed to start dialysis. I would like to know what they know about kidney failure and treatment options, what their concerns and feelings are about kidney failure and treatment options, and whether there are feelings of uncertainty. I believe that this information will help to improve future patient education efforts.

The survey will not be sent to current dialysis or transplant patients. But, as a dialysis or transplant patient, you probably remember how you felt and what questions you had before you started dialysis. Your ideas about these questionnaires will be very helpful and will help me know what changes to make.

I need your help in preparing to conduct this research survey. It is very important that the questionnaires ask the "right questions" and that the questions are "clear" and "make sense." Would you please read the questions and then answer a few questions to help me evaluate them?
Please complete the evaluation about the questionnaires. Circle words that you do not know. Write comments on the questionnaires about things that are confusing, unclear, etc.

Please return the questionnaires and the evaluation form in the stamped return envelope. I would appreciate receiving your response by Monday, November 19, 1990.

Thank you in advance for your assistance with this project.

Sincerely,

Jeanette K. Chambers
Doctoral Candidate
The Ohio State University
Field Test of Questionnaires

Knowledge Instrument - Developed by Jeanette K. Chambers

The following questions are a test of the knowledge that the pre-dialysis patient has about the functions of the kidney; 2) the potential causes of kidney disease; 3) the symptoms of kidney failure; and 4) potential treatment options.

1. Do these questions look like they would determine the patient's knowledge about kidney function?
   YES ________ NO ________
   COMMENTS:

2. Do these questions look like they would determine the patient's knowledge about the potential causes of kidney disease?
   YES ________ NO ________
   COMMENTS:

3. Do these questions look like they would determine the patient's knowledge about the symptoms of kidney failure?
   YES ________ NO ________
   COMMENTS:

4. Do these questions look like they would determine the patient's knowledge about treatment options?
   YES ________ NO ________
   COMMENTS:
5. Would you suggest that I delete any of the questions?
   YES_________  NO___________
   IF YES, WHICH ONES?

6. Do the questions seem clear?
   YES_________  NO___________
   IF NO, WHICH QUESTIONS NEED CHANGED?

7. Does the wording of the questions seem appropriate?
   YES_________  NO___________
   IF NO, WHICH QUESTIONS OR WORDS NEED CHANGED?

8. Please make any other comments or suggestions:
Attitude Instrument - Developed by Jeanette K. Chambers

The questions on this survey are meant to assess the patient's feelings and beliefs about the nature of kidney disease, treatment options, and information-seeking.

1. Do you think that the questions would find out about the patient's feelings about kidney failure?
   
   YES__________  NO__________
   
   COMMENTS:

2. Do you think that the questions would find out about the patient's feelings about treatment options?
   
   YES__________  NO__________
   
   COMMENTS:

3. Do you think that the questions would find out about the patient's feelings about information-seeking?
   
   YES__________  NO__________
   
   COMMENTS:

4. Are there other areas of patient concern that you think should be added?
   
   YES__________  NO__________
   
   IF YES, WHAT?
5. Are there any questions that you think should not be included?
   YES____________  NO____________
   IF YES, WHICH QUESTIONS AND WHY SHOULD THEY NOT BE USED?

6. Do the questions seem clear?
   Yes___________  No____________
   IF NO, WHICH QUESTIONS NEED TO BE CHANGED?

7. Does the wording of the questions seem appropriate?
   YES____________  NO____________
   IF NO, WHICH WORDS NEED TO BE CHANGED?

8. Please make any other comments or suggestions:
Mishel Uncertainty in Illness Scale - Developed by Merle H. Mishel, Ph.D.

The Mishel Uncertainty in Illness Scale asks questions to assess a patient's feelings of uncertainty that are associated with the presence of a chronic illness or health problem.

1. Do you think that uncertainty is experienced by persons with decreased kidney function, but who have not started dialysis?
   YES_______ NO__________
   COMMENTS:

2. Do you think that the questions asked on the Mishel Uncertainty in Illness Scale are generally appropriate for persons who have decreased kidney function but have not started dialysis?
   YES___________ NO__________
   COMMENTS:

3. Do you think it would be appropriate to ask patients who have not started dialysis to answer the questions on the Mishel Uncertainty in Illness Scale?
   YES___________ NO__________
   COMMENTS:

4. Do the questions seem clear?
   YES___________ NO__________
   IF NO, WHICH QUESTIONS NEED TO BE CHANGED?
5. Does the wording of the questions seem appropriate?
   YES_________ NO_________

   IF NO, WHICH WORDS OR QUESTIONS NEED TO BE CHANGED?

6. Please make any comments or suggestions:
APPENDIX N

DEMOGRAPHIC DATA
DEMOGRAPHIC DATA

Please CIRCLE the response that most closely describes you.

1. I am:
   A. MALE
   B. FEMALE

2. I am:
   A. 18-29 YEARS OF AGE
   B. 30-49 YEARS OF AGE
   C. 50-65 YEARS OF AGE
   D. 66-79 YEARS OF AGE
   E. 80 YEARS OF AGE OR MORE

3. I am:
   A. AFRO-AMERICAN
   B. ASIAN (CONTINENTAL)
   C. CAUCASIAN (WHITE)
   D. HISPANIC
   E. OTHER

4. I am:
   A. SINGLE, NEVER MARRIED
   B. MARRIED
   C. SEPARATED/DIVORCED/WIDOWED
5. Circle the years of formal schooling completed:

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6. My religious affiliation is:
   A. NONE
   B. PROTESTANT
   C. CATHOLIC
   D. JEWISH
   E. OTHER

7. To what extent are you concerned about being able to pay your medical bills?
   A. NOT AT ALL
   B. SOMEWHAT
   C. VERY
   D. EXTREMELY

8. I have:
   A. KNOWN NO ONE WHO HAS HAD KIDNEY FAILURE
   B. KNOWN OF A PERSON WITH KIDNEY FAILURE
   C. KNOWN A CLOSE FAMILY MEMBER OF FRIEND WITH KIDNEY FAILURE

Thank you for completing this questionnaire.
APPENDIX O

PILOT PARTICIPATION LETTERS
Dear Patient:

Jeanette Chambers, MS, RN, CS, a PhD candidate at The Ohio State University, is studying knowledge and attitudes of patients with kidney problems. She is hoping to learn more about this important subject. We think her project is a worthwhile one. For this reason, we have given her permission to contact all of our patients.

Please know that the questions being asked in this survey may not apply to you personally. For example, questions are asked about your knowledge of dialysis and transplantation, even though you may never need these treatments.

Your participation in the study is voluntary and, whether or not you participate in this study, it will not affect the care that you receive from us. Please also know that all of the responses are confidential, and that there are no "right" or "wrong" answers.

If you have any questions or comments regarding the study, please do not hesitate to contact us.

Sincerely,

William H. Bay, MD
Fernando Cosio, MD
John Dillon, MD
Lee A. Hebert, MD
N. Stanley Nahman, Jr., MD
Don F. Middendorff, MD
Brad H. Rovin, MD
Dear

You are being asked to consider participating in a pilot study being conducted by Jeanette K. Chambers. Jeanette is a registered nurse who has worked with kidney patients for over ten years and has a strong interest and commitment to patient education. Jeanette is conducting this study in partial fulfillment of the requirements for a doctoral degree at The Ohio State University. The principal investigator for the study is David L. Boggs, Ph.D.

The purpose of the pilot study is to test the questionnaires that will be used in the research to find out areas in which kidney patients might need or want more information, such as about kidney function, kidney disease, and treatment options. The study also seeks to understand more about any areas of concern or uncertainty that patients with kidney problems may have. Your viewpoint is extremely important to the study. It is important that we test the questionnaires before conducting the actual study.

This study will involve completing a questionnaire booklet in your home and returning it to Ms. Chambers in a stamped envelope. In addition to this, selected clinical and laboratory history will be obtained from your file. If you agree to participate, it is necessary for you to sign and return the enclosed postcard so that you may be contacted by Ms. Chambers.

Your decision about participation in the study will not affect your care in any way. Participation in the study is completely voluntary. You may withdraw from the study at any time and your medical care will not be affected. None of the information received from the study will be placed in your medical record. The information obtained and your responses will remain confidential.

Shortly after we hear from you, a questionnaire booklet will be sent to your home.

This study has been reviewed and approved by the Human Subjects Review Board of The Ohio State University and the Institutional Review Board of Riverside Methodist Hospitals.

Thank you.
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Sincerely,

James W. Lewis, M.D.    Christopher S. Saunders, M.D.
Michael H. Mishkind, M.D.    Steven E. Gerald, M.D.

Enclosure
Dear  

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Shortly after we hear from you, a questionnaire booklet will be sent to your home.  

This study has been reviewed and approved by the Human Subjects Review Board of The Ohio State University and the Institutional Review Board of Riverside Methodist Hospitals.  

Thank you.  

Sincerely,  

[Signature]

Wesley V. Forgue, M.D.

Daniel S. Cotton, M.D.
APPENDIX P

STUDY PARTICIPATION LETTERS
Dear Patient:

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Please know that the questions being asked in this survey may not apply to you personally. For example, questions are asked about your knowledge of dialysis and transplantation, even though you may never need these treatments.

Your participation in the study is voluntary and, whether or not you participate in this study, it will not affect the care that you receive from us. Please also know that all of the responses are confidential, and that there are no "right" or "wrong" answers.

If you have any questions or comments regarding the study, please do not hesitate to contact us.

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John Dillon, MD  
Lee A. Hebert, MD  
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A few weeks after we hear from you, a questionnaire booklet will be sent to your home.

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Thank you.
Dear

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Enclosure.
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Thank you.

Sincerely,

[Wesley V. Forgue, M.D.]

[Daniel S. Cotton, M.D.]
APPENDIX Q

BUDGET
1. Consultants

Goodwill Data Entry Services, Inc.
Data entry and tapes for
statistical analysis ($400)

2. Supplies

Booklet (500 copies)
(design, typesetting, printing) $750.00

First class mail (1 oz)
  1. 200 intro letter (request for consent) ($50)
  2. 200 return postage (consent) ($50)
  3. 150 follow-up request for consent ($37.50)
  4. 150 return postage (consent) ($37.50)
  5. 150 follow-up letter (booklet #1) ($37.50)
  6. 150 follow-up letter (booklet #2) ($37.50)
  7. 100 follow-up letter (booklet #3) ($25)

First class mail (4 oz)
  1. 200 Booklet #1 with 200 return @ $1/ ($400)
  2. 150 Booklet #2 with 150 return @ $1/ ($300)
  3. 100 Booklet #3 with 100 return @ $1/ ($200)

Postcards (request for study summary)
  1. Booklet #1 (200 @ $0.15) ($30)
  2. Booklet #2 (150 @ $ 0.15) ($22.50)
  3. Booklet #3 (100 @ $ 0.15) ($15)

Letterhead Stationary @ $50/box
(3 practice groups) $150

Business-size Envelopes $60
Letterhead @ $20/practice group
  intro w/consent 400
  follow-up for consent 200
Plain @ $3/100 $9
  f-up #1 150
  f-up #2 100
3. Supplies (continued):
   Manila Envelopes ($6/100) $54
   booklet #1 200
   return #1 200
   booklet #2 150
   return #2 150
   booklet #3 100
   return #3 100

4. Other

   Telephone (Non-respondent Interviews) (25) @ $5/call
   (possible long distance charges)
   $125.00

TOTAL EXPECTED EXPENSES: $2790.50

JUSTIFICATION/CLARIFICATION:

This study has the potential to benefit patients who receive inpatient and outpatient dialysis treatments at Riverside Methodist Hospitals. This study will help to identify the needs and concerns of patients in the earlier stages of chronic kidney failure progression; consequently, educational and counseling interventions may be initiated to better serve the patient.

The cost of mailing each booklet is based upon 4 ounces/booklet or $1.00 each. The inclusion of postage for return of 1) the consent form and 2) the questionnaire booklet are important to enhance the rate of return and minimize costs to the participant.

Potential long distance telephone costs are associated with 1) inquiries about the study made as a result of the consent form and letter and 2) follow-up telephone interviews of non-respondents. Study participants may be from all over central and southern Ohio.

The costs of layout, printing, and design of the booklet are necessary to produce a document that appears professional and important to the study participant. The appearance of the questionnaire is known to positively influence the rate of return.

Additional applications for competitive funding have been submitted. This request is for the balance not covered by other applications, if funding is awarded.
LIST OF REFERENCES


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