

FAMILY STRESS AND HEMODIALYSIS: AN  
ANALYSIS OF FAMILY STRESS VARIABLES

by

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Dissertation submitted to the Graduate Faculty of the  
Virginia Polytechnic Institute and State University  
in partial fulfillment of the requirements  
for the degree of  
DOCTOR OF PHILOSOPHY  
in  
Management, Housing, and Family Development

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May, 1981

Blacksburg, Virginia

## ACKNOWLEDGEMENTS

There are many people without whose inspiration, guidance and support this project could not have been completed.

I am particularly indebted to my Chairman, Michael Sporakowski for his continual support throughout this project. His coordinating efforts and willingness to spend many hours on the phone were particularly valuable. Thanks also to my committee members for their interest and editorial assistance.

Special thanks go to my colleagues in the nephrology community for their assistance in introducing me to the patients and the special professionals who work with them:

and

To my colleague , I offer my enduring thanks for the many hours spent typing, editing and retyping the manuscript. The dedication, perseverance, cheerfulness and moral support she provided was invaluable.

Finally special appreciation goes to my husband, , for encouraging my work, learning about stress along with me and keeping his sense of humor throughout.

## TABLE OF CONTENTS

	<u>Page</u>
Acknowledgements . . . . .	ii
List of Tables . . . . .	v
List of Figures . . . . .	vii
Chapter	
I. Introduction	
Introduction . . . . .	1
Summary of Burr's Synthesis . . . . .	6
Purpose of the Investigation. . . . .	9
Significance of the Investigation . . . . .	10
Organization of the Dissertation. . . . .	11
Summary . . . . .	12
II. Review of the Literature	
Introduction. . . . .	13
Renal Disease and Dialysis. . . . .	13
Development and Process of Chronic Hemodialysis. . . . .	17
Stress Variables in Dialysis Literature. . . . .	19
Measuring Stress Variables. . . . .	46
Theoretical Bridges . . . . .	46
Theoretical Hypotheses. . . . .	52
Summary . . . . .	54
III. Methodology	
Introduction. . . . .	55
Instrument. . . . .	56
Validity and Reliability. . . . .	59
Sampling. . . . .	61
Data Collection . . . . .	66
Data Processing . . . . .	68
IV. Results	
Descriptive Analysis. . . . .	69

	<u>Page</u>
Summary of Patient Ratings on Individual Stress Variables . . . . .	77
Results Pertaining to Hypotheses. . . . .	82
Results Indirectly Pertaining to Hypotheses . . . . .	114
V. Summary and Conclusions	
Summary . . . . .	117
Conclusions Regarding Research	
Methodology . . . . .	125
Stress Theory Conclusions . . . . .	127
Practice Conclusions. . . . .	130
Future Research . . . . .	132
Summary . . . . .	134
References . . . . .	136
Appendix A . . . . .	147
Appendix B . . . . .	150
Appendix C . . . . .	152
Vita . . . . .	153
Abstract . . . . .	155

## LIST OF TABLES

<u>Table</u>		<u>Page</u>
1	Scale Items Corresponding to Major Variables	58
2	Demographic Characteristics of Dialysis Patients	70
3	Responses, Means and Standard Deviations for Scale Items Grouped by Variables	78
4	Pearson Correlations Between Vulnerability and Amount of Crisis	83
5	Pearson Correlations Between Positional Influence and Vulnerability	85
6	Pearson Correlations Between Positional Influence and Regenerative Power	88
7	Pearson Correlations Between Personal Influence and Vulnerability	92
8	Pearson Correlations Between Personal Influence and Regenerative Power	95
9	Pearson Correlations Between Externalization of Blame and Vulnerability	97
10	Pearson Correlations Between Anticipation Socialization and Vulnerability	99
11	Pearson Correlations Between Anticipation Socialization and Regenerative Power	101
12	Pearson Correlations Between Extended Familism and Regenerative Power Over Time	104
13	Pearson Correlations Between Marital Adjustment and Regenerative Power	106

<u>Table</u>		<u>Page</u>
14	Pearson Correlations Between Spouse Social Activity and Regenerative Power	109
15	Pearson Correlations Between Regenerative Power and Level of Reorganization	110
16	Degree of Support for Hypotheses	112
17	Pearson Product Moment Correlations Between Selected Variables	115

## LIST OF FIGURES

<u>Figure</u>		<u>Page</u>
I	Propositions About Families Under Stress as Identified by Burr	8
II	Diagram of the Kidney	15

## Chapter I

### INTRODUCTION

The maintenance of life through hemodialysis is a complex process characterized by a delicate balance between skills in advanced medical technology and understanding of the relationship between stress and illness. Hemodialysis treatment for chronic renal failure became possible on a large scale in 1960.

Scribner (1964:210) described the life of the dialysis patient in the early 1960's as a continual battle for survival with neither patient nor doctor knowing from day to day what lay ahead. Patients concentrated primarily on staying alive and personal and family stresses were secondary. In the early days of dialysis treatment, the clinical significance of stress as a major cause of disability among patients who depend on the artificial kidney for their survival was noted, however (Shea, Bogdan, Freeman and Schreiner, 1965). Feelings of discouragement, loneliness, estrangement and fright are common experiences for the chronic dialysis patient (DeNour, 1970).

Over the past 20 years, technological advances have resulted in dramatic improvements in treatment for persons with severe renal failure. As technical and medical improvements in hemodialysis technique have resulted in medically healthier patients, renal staff have been able



to devote more time to the intrapersonal and intra-familial stresses experienced by dialysis patients (Abram, 1974).

Latos (1980:435) specifies that at present, more than 62,000 persons in the United States are undergoing maintenance dialysis compared with about 16,000 five years ago. The number rose by about 7,000 people last year despite the fact that 2,000 had transplants. Renal failure is the leading cause of death in juvenile onset diabetes; most patients who have diabetes mellitus for more than 10 years will develop renal signs (Rayl, 1980). According to Gutman, Stead and Robinson (1981:309), 12% of dialysis patients are diabetics and 53% are fifty years of age or older.

Whatever the stresses are for the dialysis patient himself, they do not exist in isolation from family members or members of the treatment team. Hampers and Schupak (1973) describe the impact of family adjustment on dialysis treatment outcome:

Often the patient is an emotionally strong person who adjusts reasonably well to his illness only to have his problems compounded by the general collapse of his spouse or immediate family. (p. 218)

Abrams (1980) summarizes the problem:

The stress of chronic serious illness reaches every facet of a person's being, as well as his family's. The patient may be angry at himself for becoming ill and upsetting his life

plan and his social, economic and family homeostasis. He must spend a considerable part of his time in treatment, dependent upon the machine and upon unknown personnel for intimate needs. (p. 521)

Research on how families react to and are influenced by stress remains an important area in family studies. Families under stress have been investigated by an array of sociologists, psychologists, physicians, social workers, and nursing professionals. Numerous theories and hypotheses have been generated and tested on a variety of stress related populations. Interwoven in these theories are a number of assumptions about how families operate in the stressed as opposed to the unstressed condition. If these theoretical and behavioral assumptions are valid, ideas about families under stress may be further stated and tested as parts of deductive theory.

Dialysis patients and their families experience an unique set of stressors. The need for dialysis is seldom anticipated by the patient and family, and almost universally requires major changes in the vocational, dietary, financial, marital and recreational patterns of the family. Unlike acute illness, once a person begins dialysis, it becomes an unending part of the patient's life, requiring treatments three times weekly for up to six hours per treatment. The dialysis patient rarely feels good and is usually too exhausted following

treatments to care for himself (DeNour, 1970; Levy, 1974; Abrams, 1980).

Dialysis related stress is fairly circumscribed, and the study of it as a family stressor avoids some of the tautological problems addressed by Hansen and Johnson (1979). Specifically, simultaneous events which cause stress in and of themselves and are also a possible response (such as the birth of a child as an attempt to alleviate marital problems) create problems in defining the primary stressor. Physical illness has also been cited as a response to stress (Eyer, 1975) but dialysis is often an outgrowth of other illnesses such as high blood pressure or diabetes and presents a stressor in itself.

Dialysis meets Hill's (1964) definition of a crisis as a sharp or decisive change for which old roles are inadequate. By Hill's criteria this stressor yields a high potential for family vulnerability: (1) most families define dialysis as a stressful event, (2) it is difficult to externalize the blame for dialysis, (3) the family usually has not had time to anticipate the changes, (4) there are few norms allowing for anticipatory socialization, (5) the crisis producing event is permanent, and (6) there are generally no collective support groups for family members (DeNour, 1978).

Dialysis also fits Hill's (1958) concept of the class of crises which produce low regenerative power: (1) the family experiences dismemberment or the "death" of a member as he once was, (2) accession or the addition of a disabled member, (3) demoralization due to the cultures strong negative view of the chronically ill, and (4) no normative guidelines because dialysis is needed so rarely that families feel they have to face the stress alone.

These two variables, 1) family vulnerability to stress and 2) family regenerative power are the two dependent variables in this investigation of the relationships among family stress variables.

While many of the situations upon which family stress theory is predicated had to do with the stresses of war, disaster, and economic depression, (Angell, 1936; Hill and Hansen, 1962) and while to date no consensual definition of stressor events has emerged, Burr's (1973: 200) definition of stress will be used in the investigation:

Stress is a continuous variable denoting variation in the amount of disruptiveness, incapacitatedness, or disorganization of the family.

The current study will test hypothesized relationships among family stress variables through a survey of patients on chronic maintenance hemodialysis. The results of the

study will have implications for the dialysis patient, his family and for professional caregivers in the dialysis field.

This chapter has a twofold purpose: (1) to describe the dependent variables of interest in the investigation of dialysis-related stress; and, (2) to indicate how this study relates to these issues.

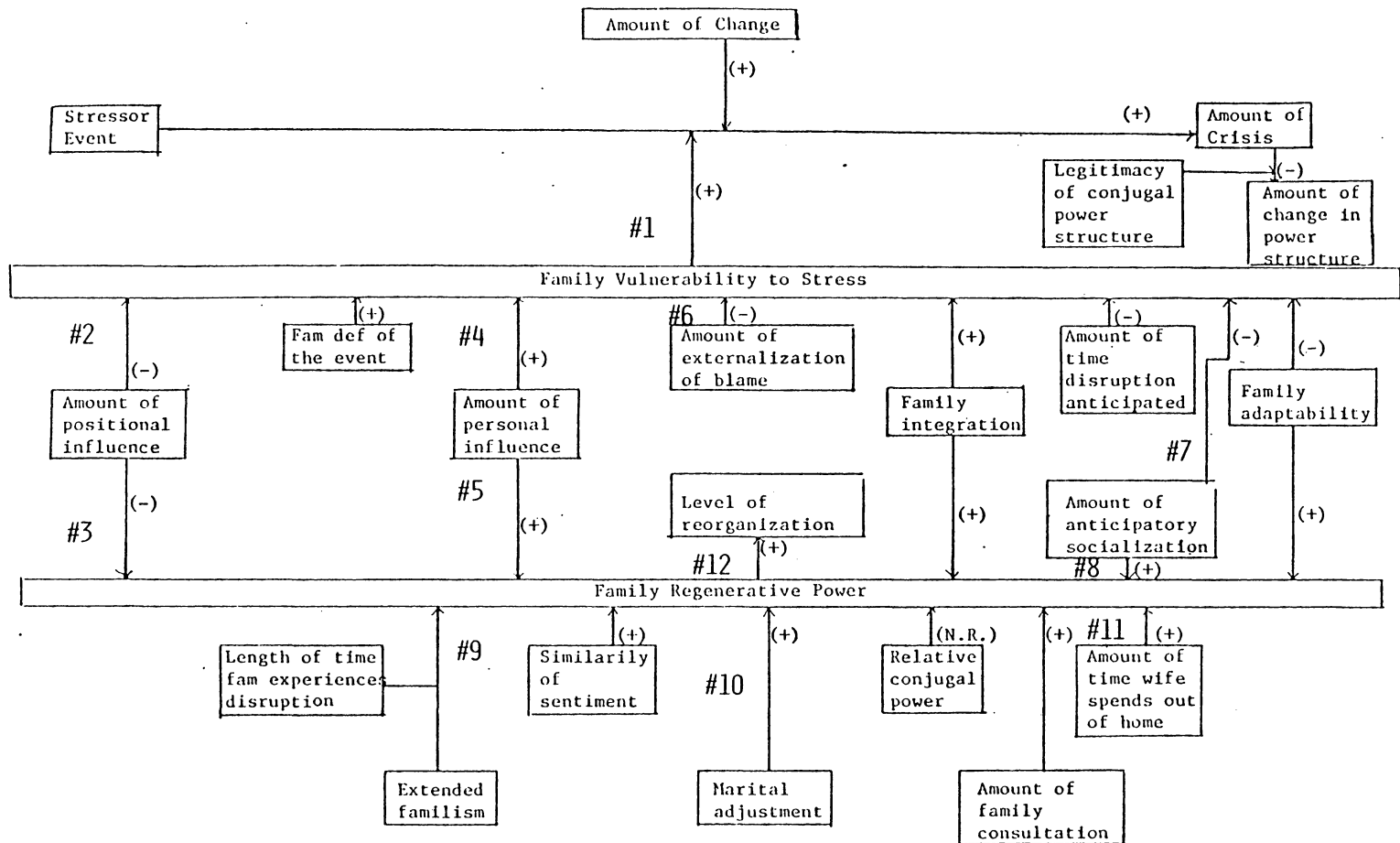
Pioneering works will be briefly outlined with the emphasis being placed on the variables which represent the way families react to and manage stress. Next, the interface between stress and renal disease will be addressed. A description of the study's purpose will then be presented and proposals regarding the significance of the study will be offered. The chapter closes with a summary of the organization of the study and a description of the remaining chapters.

#### Summary of Burr's Synthesis

Burr's (1973) inventory of propositions about families under stress synthesizes the major theories in stress research in the past fifty years and will serve as the theoretical framework for this study. (See Figure 1.) Burr's synthesis was drawn from theoretical formulations in earlier family research such as (1) Hill's (1949:11) "ABCX Model": A (stressor event) interacting with B (the family's crisis meeting resources) interacting with

C (the definition the family makes of the event) produces X (the crisis); (2) Angell's (1936) analysis of factors related to the ability of families to recover from the disruption introduced by the economic depression of the 1930's which identified family integration and family adaptability as two important variables; and, (3) Hansen and Hill's (1964:794-795) identification of the influence of "the amount of time changes are anticipated" varying between no period of anticipation to long periods of anticipation.

Burr's synthesis has two dependent variables: "family vulnerability to stress" and "family regenerative power" derived from Hill's (1949) "crisis meeting resources" and Hansen's (1965) "vulnerability" formulations. These two variables were never operationalized by their authors; however, Burr (1971:350-355) speculates on their derivation: (1) "Hill's 'crisis meeting resources' and Hansen's (1965) 'vulnerability' seem to be the same conceptual phenomenon. It apparently denotes variation in a family's ability to prevent a stressor event in a family social system from creating some crisis or disruptiveness in the system"; (2) Hansen (1965) introduced another variable that he referred to as the 'regenerative power' of families which denotes variation in the ability of the family to recover from a crisis. It is apparently a continuous variable



\* NUMBERS DENOTE HYPOTHESIZED RELATIONSHIPS TO BE EXAMINED IN CURRENT STUDY.

\* FIGURE 1

ranging between low and high power.

Burr's (1973) synthesis depicts a number of independent variables having positive or negative linear relationships with the two dependent variables. The propositions delineated by Burr comprise the theoretical framework for the hypotheses in this study. Burr's model is based on deductive theory which he describes as "a group of propositions that identify relationships between variables. It has multiple levels of generality that permit deductive explanation and deduction, and the testing of the theory through deduction and empirical testing". (Burr, 1973:29).

The hypotheses in this research will make predictions about the relationships between many of the variables in Burr's synthesis. The set of relationships to be tested will be selected on the following bases: (1) their relevance to the dialysis population under study; (2) the degree of correspondence with the variables in the general dialysis literature; and (3) the ease with which they can be operationalized in the short survey needed in this research.

#### Purpose of the Investigation

The ongoing need to improve the physical and emotional well-being of dialysis patients and their families provides the basis for this study. The general purpose is to design



a reliable instrument, gather data from dialysis patients and to utilize the data obtained to derive implications for the reduction of stress for individuals living with chronic disease.

No current research has been reported in which Burr's propositions have been empirically tested. Burr suggested such research be carried out to add to the family stress literature in two ways: (1) to determine if additional contingent variables can be identified, and (2) to assess the validity of the propositions in a variety of crisis situations. End stage renal disease patients requiring regular dialysis treatment constitute a highly stressed and unique population on which to test Burr's propositions.

The purpose of the present study is fourfold:

1. To attempt to operationalize selected propositions from Burr to render them empirically testable;
2. To attempt to construct and test an instrument designed to test some of Burr's propositions;
3. To make inferences about the validity of Burr's synthesis for renal patients; and
4. To attempt to give researchers and health care providers an instrument for future research.

#### Significance of the Investigation

This study will attempt to make contributions in four areas:

1. Generation of interest in Burr's model;
2. Examination of a few of Burr's propositions to determine their conceptual relevance for future researchers;
3. Addition to the current body of knowledge about stress and renal disease; and
4. Suggestion of factors related to the prevention or reduction of stress for renal patients, their families, and health care providers.

#### Organization of the Dissertation

The dissertation is divided into five chapters. The first chapter has provided an introduction to the theoretical basis of the study and to a few of the factors in stress and renal disease. Due to the need for systematic theory building in family research and the need for increased understanding of dialysis related stress, the general purpose of this study was identified as testing hypothesized relationships among family stress variables through a survey of patients on chronic maintenance hemodialysis.

Chapter II presents an indepth review of the literature on stress and renal disease. The variables in Burr's (1973) synthesis corresponding to the variables in the dialysis literature will be identified. Finally, the research hypotheses for this study will be identified.

Chapter III outlines the research methodology to be employed in the study. Questionnaire development, pre-testing, and administration procedures are discussed. Sampling procedures, data collection, data processing, statistical tests, and decision rules are described. The results of the data collection efforts will be extensively described in Chapter IV. The results will be presented in written, graphic, and tabular form.

Conclusions drawn from the data will be presented in Chapter V. Implications will be formulated for family researchers and health care professionals. The limitations of the study will be discussed and recommendations for future research will be made.

#### Summary

Chapter I introduced the need for continued research in the area of stress and hemodialysis and provided a theoretical framework from which to generate hypothesized relationships between family stress variables.

The dependent variables were identified as family vulnerability to stress and family regenerative power. Four purposes of the study were identified and the study's potential contributions were discussed.

## Chapter II

### A REVIEW OF SELECTED LITERATURE

#### Introduction

The purpose of this chapter is to review the body of existing literature with respect to family stress theory and the stresses associated with dialysis treatment for end stage renal disease.

The following discussion is divided into four major sections. The first section presents an overview of kidney function, the conditions leading to dialysis and the dialysis process itself. An extensive review of Burr's (1973) stress variables as documented in the dialysis literature will be presented in the second section. In the third section, the rationale for the exclusion of propositions to be tested will be outlined. The fourth section of this chapter identifies the hypotheses the present study is designed to address. A brief conclusion is then presented to integrate the literature search with the purpose of the study. A summary ends the chapter.

#### Renal Disease and Dialysis

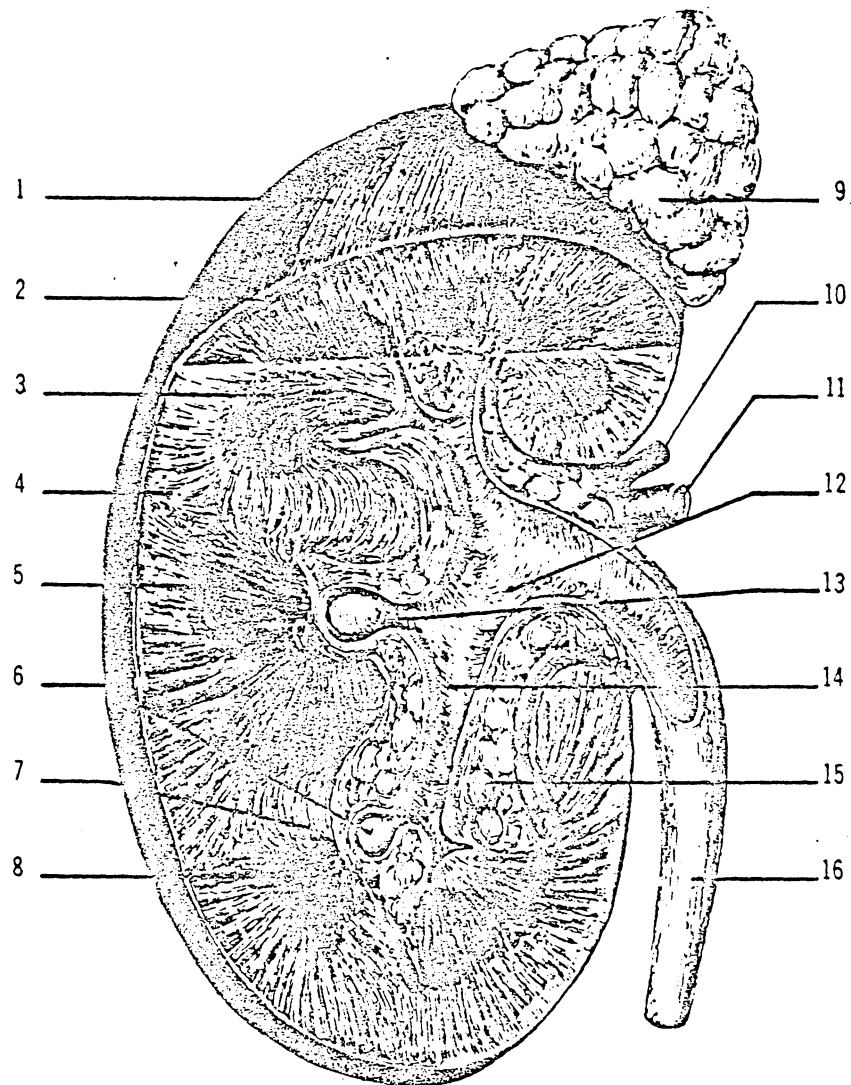
According to Rapaport (1973), the kidneys, which weigh less than a pound, are charged with the continuous elimination of the toxic end products of metabolism. For this purpose, the entire human blood volume circulates through each kidney at the rate of 120 millileters per minute. The kidneys consist of an elaborate network of blood capillaries

and renal tubules which continuously operates as a blood filter. Because the kidney is an enormously complex organ which must function without pause, it is highly susceptible to a variety of diseases. (Figure II). Briefly, the main conditions leading to kidney malfunction and the initiation of dialysis treatment are:

(1) Polycystic kidney disease: DeWardener (1967:377-382) describes this as a hereditary condition which may occur in infancy (the neonatal form), or in middle age (the adult form). Both forms occur equally between the two sexes. In the neonatal form, the infant may live for a few months or one to two years, only to succumb to chronic renal failure. The age of onset in the adult form may range from 8 to 77 years. The rate of renal impairment and the pattern of events varies enormously from patient to patient, but certain families show a tendency towards a recurring pattern. The average duration of the disease once it has become manifest is five to ten years. If treatment is effective, some patients may live many years without appearing to deteriorate.

(2) Pyelonephritis: This condition, states DeWardner, (1967:276) results from various infections. The majority of infections are associated with obstruction or deformation of the urinary tract; these cause a rise in pressure and a slowing in the rate of urine flow in those parts

## Kidney



- |                      |                         |
|----------------------|-------------------------|
| 1. Kidney            | 9. Adrenal Gland        |
| 2. Renal Capsule     | 10. Renal Artery        |
| 3. Medullary Tissue  | 11. Renal Vein          |
| 4. Cortical Tissue   | 12. Renal Pelvis        |
| 5. Interlobar Artery | 13. Minor Calyx         |
| 6. Papilla           | 14. Major Calyx         |
| 7. Renal Column      | 15. Fatty Tissue        |
| 8. Pyramid           | 16. Ureter (To Bladder) |

FIGURE II

which lie next to the obstruction. One of the most common causes of such an infection is the introduction of a catheter, or examining instrument into a bladder containing infected urine. The infecting organism may then be transported to the kidney through the blood stream, the bladder and ureters, or the lymphatic system adjacent to the ureters.

(3) Hypertension: Chronic renal failure and hypertension are closely related and, though hypertension may cause renal failure, the reverse is more common. The blood pressure frequently rises in chronic renal failure, but its rise may produce few symptoms; when symptoms occur they are usually due to increased narrowing of the renal arteries which bring the blood to the kidney. (Rapaport, 1973:5; DeWardener, 1967:277).

(4) Glomerulonephritis: Rapaport (1973:1) describes this condition which results from a simple cold or sore throat which gets complicated by a bacterial infection. According to Rapaport, a regularly predictable percentage of patients with this complication will develop glomerulonephritis weeks to months later. The affected kidneys produce symptoms such as high blood pressure, headaches or the occurrence of albumin in the urine. There is a slow, progressive decrease in renal function and later a rapid sequence of events which, if unchecked, inevitably results

in blood poisoning, coma and death.

(5) Diabetes: According to Rayl (1980), renal failure is the leading cause of death in juvenile onset diabetes, with most patients who have diabetes mellitus for more than 10 years developing renal signs. Dialysis for this group is discouraging due to the high mortality rate, especially in the first year. Cardiovascular disease is the most common cause of death for the diabetic patient with renal dysfunction.

#### Development and Process of Chronic Hemodialysis

The first artificial kidney was developed by a Dutch physician and scientist, Willem Kolff, during the Nazi occupation of the Netherlands. The first working model, developed in 1943, was quite primitive, consisting of a rotating drum and fixed blood lines. The first machine was able to extract 40 grams of urea from the blood of a uremic patient in six hours time.

The basic function of an artificial kidney or dialyzer is to pump blood out of an artery of a uremic patient, circulate it through lines of tubing made of semi-permeable membranes, which are then immersed in fluids whose salt concentration allow the elimination of accumulated toxic waste products. The blood, cleansed of uremic waste, is returned to the patient through a tube connected to a vein.

One of the fundamental problems in the early days of



hemodialysis was how to repeatedly connect the patient's blood vessels to the machine, since at least two or three dialysis treatments are needed each week to sustain life. This led to the development of the Scribner Shunt (Scribner, Caner, Buri and Quinton, 1960). The shunt consists of plastic tubes called cannulas, which are inserted into an artery and a vein of the arm or leg of the patient. The cannulas, which are not rejected as foreign tissue by the patient, can then be repeatedly connected to the dialysis machinery. Between each treatment, the cannulas are joined by a connecting tube, which allows blood to flow from the artery to the vein, avoiding clotting of the shunt.

Because shunts can only function well for six months to a year in one part of the body, and, as there are a limited number of superficial veins and arteries to accommodate a shunt, this method of prolonging life for uremic patients has distinct limits. The limitations of this external shunt were investigated by Brescia, Cimino, Appell and Hurwich (1966), who developed an internal direct arteriovenous shunt. This internal shunt is created surgically in the tissues of the patient's lower arm by connecting a superficial artery to a nearby vein. A portion of the vein thus becomes enlarged and has a rate of blood flow close to the arterial rate. This internal fistula is now in frequent

use and has the advantages of allowing simple needle insertion techniques to be used to remove, cleanse, and return the blood to the patient without the hazards of clotting, infections and restriction of activities requiring the use of the lower arm. Advances have been made in the technology of dialyzers and the theory relating to length of hemodialysis and have been reported by such researchers as Lipps, Perkins, Holmes, McLain, Rolfs, and Oja (1967) and Babb, Popovich, Christopher, and Scribner (1971).

#### Stress Variables in Dialysis Literature

This section of the literature review presents Burr's twenty-three stress variables as they appear in dialysis research. Note will be made of those family stress variables not addressed in the research on dialysis-related stress.

#### Dialysis as a Stressor Event

The fact that the initiation and continuation of life on dialysis is a cause of stress has been well documented in the literature. The following paragraphs outline the stresses unique to dialysis patients.

Once a person has begun dialysis, it becomes essential to health for the duration of the patient's life span unless they are fortunate enough to receive a successful transplant. Thus, chronicity has been cited as a stress

(Abram, 1965; Finkelstein, 1975). Before dialysis has even begun, however, the issue of patient selection may have been a stressor. Researchers such as Meldrum, Wolfram and Rubin (1968), Norris (1968), Abram (1969), Sand, Livingston and Wright (1966), and Scribner (1974) have discussed this issue. In the early years of dialysis, patients who did not meet criteria relating to ego strength, family stability, conformist tendency, intelligence, education, ability to handle stress and cooperate with medical recommendations, were not selected for dialysis and subsequently died. These criteria were questioned by Levy (1974) who suggested that they might reflect arbitrary values which may even correlate negatively with patient survival. The increase in Medicare funds has led to an increase in the number of dialysis facilities, broadening of the selection criteria and the virtual elimination of this factor as a stressor for new dialysands (Latos, 1980).

A major area of stress results from the frustrations of instinctual drives due to the myriad restrictions placed on the diet and mobility of dialysis patients (Wright, Sand, and Livingston, 1966; Crammond, Knight and Lawrence, 1967; DeNour, Shaltiel and Czaczkes, 1968; Goldstein and Reznikoff, 1971; and Levy, 1976). Restrictions in diet and fluid intake are never-ending, closely monitored and frustrating

to patients who are continually thirsty and hungry for forbidden foods. Retaining a sense of control over daily and weekly routines is extremely difficult due to the many hours patients are on the machine and the often great distance they must travel to receive treatment.

Physical discomfort of the dialysis treatment itself and the ever-present threat of sudden death are also cited frequently as stressors. Levy (1979) states that patients are never returned to the state of health they had prior to falling ill because there is a continual accumulation of waste products and fluid between treatments which leave patients chemically anemic and susceptible to medical complications. Abram (1980:441) describes the physical stress: "Sometimes patients are acutely ill during the course of treatment; their blood pressure drops, they vomit, itch, cramp. They may feel hot or cold. Their temperatures may rise and they may have convulsions. They are often exhausted following treatment". Stress associated with the possibility of untimely death has been addressed by Sand, et al. (1966), Beard (1969), and Wijssenbeek and Munitz (1970), who suggest that the mortality of dialysis patients is high, and they are usually treated in groups where witnessing a fellow patient's death is possible. That patients adapt constructively to this stress by quickly finding differences between

themselves and those who have died, and by concentrating on the medical advances in the field and the increasing possibility of a transplant, was discussed by Czaczkes and DeNour (1978). In several studies of dialysis and stress, threat of death ranked much lower as a stressor than dependence on the machine. The question is further complicated by the high suicide rate among dialysis patients (Levy, 1974) suggesting that fear of life may outweigh fear of death as a stressor.

Dependency, on the machine and on others, then seems to be a major stress unique to dialysis patients (Glassman, 1970; Reichsman and Levy, 1974; Abram, 1974; Foster, 1976). Conflicts about dependency are exacerbated by medical injunctions which often put patients in double binds (Alexander, 1976:1354): the directive to be independent with regard to fluid intake, diet, etc., is operationally denied by the situation which calls for the patient to be dependent on complex machinery and medical computations for support.

Dependency as a response to stress was discussed by Abram (1974) and Foster (1976); patients who regress and enjoy being taken care of often have a difficult time getting back to normal routines. On the other extreme, patients who are too independent may rebel against all treatment.

Finally, loss of earned income, inability to work and the role changes brought about by these events, has been noted as a source of stress (Czaczkes and DeNour, 1978). Only about 30% of men receiving hemodialysis return to full work productivity and most dialysis patients have moderate limitations upon work, school or household activity (Levy, 1979).

#### Amount of Change in Families Stressed by Dialysis

The dialysis literature includes few references pertaining to the amount of change both patients and their families experience as a result of the initiation of dialysis. Several authors have, however, described a number of conditions which indicate variations in the amount of disruption experienced by the patient and his family. Alexander (1976) outlines the following changes as responses to the stresses described in the previous section of this chapter: lassitude; organicity; psychoses or acute delirium or both; apathy; euphoria; acute and chronic anxiety; headaches; vomiting; depression and fatigue; insomnia; restlessness; irritability toward staff, family and employers; impatience; uncooperativeness; and suicide or attempted suicide.

The negative changes resulting from stress are also addressed by Rapaport (1973); long-term and exclusive use of the artificial kidney causes severe psychological

changes, with some patients never being able to adjust to the thought of their absolute dependence upon a machine three times per week, six to eight hours per session for the rest of their lives. Rapaport also maintains that most patients on chronic hemodialysis are weak, listless, and anemic and are actually not able to lead the same type of life that they had lived prior to the onset of their disease.

The repeated, severe crises which dialysis patients often encounter such as sudden drop in blood pressure, sudden need for hospitalization, operations for fistulae and shunts also produce severe changes for the dialysand and his family, according to DePalma (1978). When faced with the very real possibility of death, patients will put aside some of the denial that helps them focus on the more constructive parts of living; and when hospitalization is required, patients are faced with separation from family and trusted professionals.

#### Family Definitions of the Seriousness of the Changes

##### Required by Dialysis

The literature relating to perceptions of the seriousness of life changes as a result of dialysis is divided into three main areas: patient perceptions, staff perceptions, and family perceptions of the situation. Patients' perception of their situation cannot be

objectively measured, but it has been an area of inquiry for several researchers. Wright, et al. (1966) asked a small group of patients to rate their happiness in comparison to normal populations and to other kidney patients. They described themselves as happy as the healthy and as happier than other kidney patients; reflecting that on a conscious level (as a result of denial) they feel happy, but the comparison to other patients indicates their projected unhappiness.

In a questionnaire given to over 400 patients, Levy (1976) asked patients to compare the general quality of their life on hemodialysis to their previous life. Fifteen percent of the patients thought that it had deteriorated to some extent and only 14% reported that the quality had deteriorated a great deal. The finding that nearly 44% were satisfied with life on dialysis may reflect these patients' realization that without dialysis they might have no life at all, yet it does not explain the findings of DeNour and Czaczkes (1971) that kidney patients on the whole are poorly adjusted. In this study, the treatment team of one dialysis unit was asked to rate the "amount of suffering" of each patient along a 20-item questionnaire that described five aspects of life on dialysis (diet, restrictions and dependency, emotional well-being, condition during dialysis, and physical condition). The



Patients answered the same questionnaire. In each of the five areas, there was a high intrateam agreement about which patients suffer more or less. In all areas except the assessment of physical condition, patients' opinions differed greatly from those of the team.

The Kidney Foundation of Canada sponsored a major study of the perceptions of stresses experienced by 347 patients (Matthews, 1980). Eight stressors were ranked in order of severity by the patients, the treatment team and the family: weakness, work reduction, fluctuating health, dependence on others, inability to travel, dependence on the machine, threat of death and marital strain. The patients ranked the stresses in that order. Treatment team members and families ranked fluctuating health, weakness and threat of death as the greatest stressors. Family members perceived 'dependence on others' as the least stressful of the eight factors listed whereas the patients rated it in the top four stressors, suggesting that patients and their families do have differing definitions of the severity of the stress associated with dialysis.

#### Family Vulnerability to Stress

The dialysis literature includes many studies which examine small samples of patients for factors which appear to increase vulnerability to stress. The reasons proposed for why some patients and their families do not have a

high ability to prevent dialysis from seriously disrupting their lives are not consistent across the literature. Several variables associated with high risk emerge, however.

Very young patients appear to be more vulnerable: children do not grow adequately in weight and height (Scribner, 1974). Children physiologically remain children throughout the adolescent years, and neither dialysis nor transplantation is a satisfactory treatment (Morse, 1974). Like adults, children withdraw, become negative, rebel, are anxious, fear death and have conflicts about their dependency on others (Levy, 1974).

Personality type also appears to be related to vulnerability. Males who are conformist, and adaptive appear to have fewer difficulties with dialysis (Norris, 1968). Patients who cannot or are not permitted to express grief and anger are more susceptible to complications on dialysis (Ellis, 1974). Those who respond to stress with demoralization, depression and helplessness are at high risk (Sadler, 1976); as are those whose normal period of depression is unusually severe or prolonged, expressed in an abnormal manner, or occurs at an inappropriate time (Rosser, 1976). Lee, Patel, Bluestone and Kaufman (1978) describe as highly vulnerable the individuals who have chronic characteriological problems

of dependence, anger, excitability and impulsiveness in addition to chronic anxiety and depression. Psychotherapy and medication have been found to decrease the vulnerability and increase the quality of life in high risk patients (Streltzer, Markoff and Yano, 1977).

Missing in the research are reports of interpersonal relationships and their effect on vulnerability of in-center dialysis patients. Family members have been viewed as medical assistants who bring the patients to treatment, promote their rehabilitation, and help the patient comply to the diet (Czaczkes and DeNour, 1978). How family members feel about these tasks and how their perceptions affect the progress of the family as a whole has not been investigated.

#### Regenerative Power

Whereas the research on vulnerability to stress focused on factors associated with failure to adapt to the stress of dialysis, the research reported in this section will address those factors which are associated with or predictive of successful adaptation.

Patients who react to knowledge of their disease with a willingness to accept emotionally the full significance of the disease and who display an ability to cooperate and discuss their anxieties, appear to have a favorable prognosis (Menzies and Stewart, 1968). Personality factors

associated with adjustment include: success in life prior to dialysis, independence, assertiveness, and restraint (Short and Alexander, 1969).

Sand, et al. (1969) and Meldrum, et al. (1968) each found the following factors to correlate with positive adjustment: above average intelligence, ability to cooperate, and family acceptance and stability. Foster, Cohn, and McKegney (1974) investigated factors associated with survival and found that survivors were characterized by 1) having at least one living parent, 2) having survived at least 18 months, 3) showing fewer signs of psychopathology, fewer suicide attempts and fewer systemic manifestations of renal disease; and 4) showing marked indifference to fellow dialysis patients.

DeNour and Czaczkes (1975) found an association between amount of social activity and vocational rehabilitation. Patients who maintained their predialysis level of social functioning evidenced good vocational rehabilitation (working more than half-time) while patients who decreased their social activities manifested a lower rate of vocational adjustment.

Matthews (1980) found that regenerative power increases with the length of time on dialysis. The longer patients had been on dialysis, the greater the 1) amount and types of dialy activities, 2) employment or prospect

of employment, 3) social life, and 4) reduction in stress. And Cummings (1980) reported that regenerative power is enhanced by good support services from renal staff, particularly social workers as well as high motivation and compliance from patients.

#### Family Integration, and Family Adaptability

Family integration and adaptability were two variables identified by Angell (1936) that were later refined by Hill (1965:144). Family integration denotes variations in the degree to which a family is harmoniously well organized; and family adaptability denotes variation in the ability of a family to change its structure with little organizational discomfort. The way these two factors covary with the regenerative power and vulnerability of families of dialysis patients has been occasionally addressed in the literature and is discussed below.

There are few studies on children's reactions to dialysis-related stress in the family. Friedman, Goodwin and Chaudhry (1970) investigated parents' perception of the children's reactions and found that most of the families reported children's attitudes as positive and most allowed the children to observe the dialysis process.

Among home dialysis patients, Shulman, Pacey, and Diewold (1974) found few adverse reactions among offspring and few referrals for behavior problems. Mass and DeNour

(1975) on the other hand, found that children of center dialysis patients were restricted in bringing home friends and were often ashamed of the parents' illness. In a study of children of home dialysis patients, Tsaltas (1976) found that among a self-selected group, a large proportion of the children evidenced moderate to severe disturbance as assessed by MMPI patterns and family interviews.

Reports of patient adjustment within the family are contradictory. Holcomb and Macdonald (1973) report that 96% of the patients said they enjoy family life, 90% discussed problems with partner, 80% were interested in partners' activities, and more than 75% felt understood by partner. They also report that the spouse felt significantly more insecure than the patient, but did not specify the source of this insecurity. Czaczkes and DeNour find it difficult to accept claims that family integration is high and perhaps improved by dialysis. "Remembering the poor rehabilitation of the patients, the adverse reactions of spouses, and the often poor psychological condition of the patients, it is difficult to believe that they are so happy and involved in their family." (1978:93). Rather, they suggest that all families are overprotective at first and over time develop certain patterns:

In the non-dependent patients, this overprotection gradually disappears, with minor flare-ups whenever medical complications occur. In some of the dependent patients, the overprotection continues steadily for years. The third observed pattern is the one in which the overprotection grows thin over the years. In this pattern, overprotection sometimes breaks down and the attitude is temporarily that of overt rejection alternating with periods of overprotection. Only a few families reach a steady rejecting attitude. (1978:94)

Evidence that there is only limited communication in the family was found by Maurin and Schenkel (1976) who state according to Czaczkes and DeNour:

This finding of lack of communication within the family raises grave doubts whether the patient can or actually does fulfill his previous role within the family. It leads one to suspect that the patients' role is being dependent, often overprotected and isolated from the rest of the family...There appears to be only minimal overt communication between various family members, with the conspicuous omission of the children. (1978:95)

A recent study on adjustment of 40 patients on home dialysis found that patients with high scores on intra-family identity had higher survival, had fewer problems with compliance, achieved better vocational rehabilitation and were in better emotional condition than the group with low intrafamily identity scores (Pentecost, Zwerens, and Manuel, 1976). And Mallard (1977) studied psychological stability and family stability and their influence on adjustment and found a significant correlation between them.

These two factors were also associated with adjustment to dialysis.

Thus, the literature appears to support Hill's speculation that family attitude is related to the vulnerability and regenerative powers of the patient, if not the family.

Amount of Anticipation Socialization and Amount of Time Changes are Anticipated

Many factors associated with dialysis stress such as personality type, family influence, early and long term adjustment are mentioned in the literature and cited in various portions of this review. No studies have been found, however, on the effect of the patient or families previous experience with crisis on family vulnerability or regenerative power. This appears to be a rich area for research. Knowledge about crisis-proneness and the number, type, and severity of previous crises of dialysis patients and their families would increase dialysis staff's potential for understanding patient and family reactions under current stress.

The initiation of dialysis occurs after the condition of uremia appears; once a patient is diagnosed as having end-stage renal disease, the dialysis procedure is required to sustain life unless the patient has a successful transplant (Levy, 1974). Thus, there are variations in patients'



and family's level and length of adjustment to dialysis and the potential for successful transplant. No specific research has been reported in which this variable and its relationship to family vulnerability to stress has been reported.

Extended Familism and Length of Time a Family Experiences Disruption

Extended familism was viewed by Winch and Blumberg (1968) as a composite variable denoting variation in the interaction, intensity, extensity, and functionality of the kinship system. Hill and Hansen (1962) proposed that when the stress is experienced by the family for a short period of time, there is a negative relationship between extended familism and regenerative power, and when there is a long period of disruption there is a positive relationship.

Czaczkes and DeNour (1978:124) find it difficult to explain the higher survival rates for home dialysis patients than hospital patients. "The most accepted explanation is that home dialysis patients are a selected group and, therefore, generally 'better' patients than hospital patients". An earlier study (Shambaugh, Hampers, Bailey, Snyder, and Merrill, 1967) indicated that the frequency of psychopathological reactions in the spouses of home dialysis patients is surprisingly lower than in spouses of hospital dialysis patients.

The amount of stress patients experience while on dialysis appears to vary depending upon what stage of adaptation the patient is in: the 'Honeymoon', 'Disenchantment and Discouragement', or 'Long Term Adaptation'. The stages of adaptation appear to be tied to the increased feeling of physical health and to the recognition of long term dependency on treatment. According to Hall (1979), there are two methodological problems in studying the effects of the length of time a family system experiences disruption: 1) the fact that dialysis patients are interviewed at varying points in their dialysis and 2) the tendency for researchers to disregard the importance of 'time on dialysis' in their research designs. Hall's view is that "the specific point in a dialysand's career on chronic hemodialysis is an important determinant of the influence that generalized attitudinal factors will have on the psychological state of the individual." (p. 138)

#### Legitimacy of and Change in Power Structure

There has been no empirical research with dialysis patients investigating the interaction of legitimacy of family power structure with the amount of change in the power structure, yet several components of the proposition have been mentioned. The proposition suggests that most change in the power structure occurs when the power structure is instrumental (based on fear or coercion); and less

change occurs when the power structure is legitimate (in terms of personal and positional factors).

Instrumental or coercive power is implied in the work of Alexander (1976). The 'double bind' imposed by staff demanding patients to be dependent and independent at the same time may be viewed as a power applied in a fearful or coercive manner.

DeNour (1977) examined dominance and dependence patterns in marriages in which one spouse is a dialysis patient and found that (1) for the basically dominant spouse of a patient, dialysis is not stressful and might at times even reduce stress, and (2) for the basically dependent spouse, dialysis will be stressful because of increased demands to be strong and resourceful. DeNour speculates that the spouse will have dual stresses: the frustration of their needs and their own increased aggression. A study supportive of this hypothesis was conducted with home dialysis patients, (Streltzer, Finkelstein, Fiegenbaum, Kitsen, and Cohn, 1976) and found that independent spouses succeeded in home dialysis while all failures occurred in those who had a clearly dependent relationship with the patient. Family power structure remains an interesting avenue of research in dialysis.

Relative Conjugal Power and Amount of Consultation in Decision Making

Burr (1973) suggests that the data supporting Hills' (1949) stress research "seem to indicate that the relative amount of power of individuals is not related to regenerative power, but that the amount of consultation in decision making is." (p. 213) Much of the dialysis literature previously cited addressed the amount of relative power of spouses, particularly in the area of dependence and independence.

#### Positional and Personal Influence

Hansen (1965) suggested that difference in "influence" has an effect on both vulnerability to stress and regenerative power (Burr, 1973):

There are two kinds of cohesiveness in a group: The first involves the influence members have on each other because of their personal relationship; the second involves the influence they have on each other because of their position in the group structure. (p. 204)

Most of the dialysis literature relating to these variables addresses the relative position and subsequent level of reorganization dialysis patients achieve. Alexander (1976:1354) indicated that it is necessary to look at the one attribute common to all hemodialysis contexts, "the attribute of the patterned, on-going complementary relationship between patients and medical professionals". One factor affecting patients' position in the group is staff attitude toward the patient. Abram

(1974) addressed this issue in-depth noting that when the patient's attitude toward his treatment goals differ from those of the staff, the patient is likely to be labeled "uncooperative". Thus, patients become labeled as good patients or bad patients, distinctions which do not go unnoticed by fellow dialysis patients. Sadler (1976) suggests that the goal of therapy should be to increase the patients' dignity, sovereignty and ability to actively contribute to his partnership with the clinical team. Not all dialysis staffs share this democratic attitude, however. Czaczkes and DeNour (1978) reported that staff nurses strongly rejected maladjusted and ungrateful patients, however no evidence was available of what is cause and what is effect in that situation. Alexander's (1976) application of the double-bind theory illustrated how staff attitudes created a negative cycle resulting in poor progress of the patient. Thus, the available data seem to indicate that personal influence is related to both vulnerability and regenerative power of the patient in the medical system.

The positional influence of the patient and his family is also affected by hemodialysis. Factors such as education and socioeconomic status have been investigated in relation to regenerative power. Fishman and Schneider (1972) found that education did not influence adjustment. Foster, Cohn,

and McKegney (1973) found that it did not influence survival. Meldrum, et al. (1968) and DeNour and Czaczkes (1974) found that there was an increase in adjustment and compliance associated with higher levels of education. Chyatte (1979) found a relationship between income and success on dialysis: the higher the income, the greater the success in adapting to treatment. Socioeconomic status is affected in all dialysis patients and their families according to Silver and Silverman (1980:653): "the dialysis patient is legally defined as a handicapped person. The handicap, however, is often as great psychologically as it is physically." Silver maintains that the most difficult problem associated with regenerative power is helping patients get back into the job stream without loss of their government benefits. The current system thwarts the drive to succeed in the work world by punishing wage earning rather than encouraging it. Thus, patients' status and positional influence is affected by the initiation of hemodialysis.

#### Externalization of Blame

"Externalization of blame is apparently a dichotomous variable denoting variation in whether the blame or responsibility for a stressor event is placed on a family member or on an external source" (Burr, 1973:205). The assumption that externalization of blame is inversely

related to family vulnerability appears to be supported in the dialysis literature.

Spouses' hostility and aggression to the patients was described by Shambaugh, et al. (1967), Short and Wilson (1969), DeNour and Czaczkes (1970), and Mass and DeNour (1975) who each found evidence of displacement of aggression from the patients to various scapegoats. Patients themselves attempt to externalize blame through the defense of anger toward staff (Reichsman and Levy, 1974): During the periods of disenchantment, discouragement, and long-term adaptation, anger and aggression was directed openly toward dialysis personnel.

Much attention has been paid to the patients' use of denial as a defense mechanism. Short (1969) described patients' excessive attempts to resume former lives by taking a "flight into health" and denying that the changes are irreversible when these attempts fail. Wright, et al. (1966) found that failure of denial as a defense frequently led to depression. Abram (1974) found that denial protects and guards the patient from multiple dangers which could confront him but denial can be dangerous if the patient reaches the point of believing that he is not ill and in need of treatment.

Goldstein and Reznikoff (1971) investigated suicide in chronic hemodialysis patients from an external locus of

control framework, using Rotter's (1966) paradigm which proposes that externally oriented patients believe that reinforcements occur on a random basis and therefore his behavior has no effect upon what happens to his life. Goldstein and Reznikoff (1971:126) conclude that in a chronically ill patient, external locus of control can produce disastrous consequences whenever his cooperation in his treatment is essential for him to remain alive: "If the chronically ill patient perceives his behavior as being unrelated to his condition, the likelihood of his rejecting his role in the treatment program increases." (p. 126) They further suggested that renal staff work toward helping patients gain or regain a more internal locus of control, thereby putting patients more in control of their health status.

Contradictory findings were presented by Wilson, Muzekari, Schneps and Wilson, (1974): high external locus of control scores were found in patients after a mean of 15 months on dialysis, and at 27 months, the scores were even higher. Associated with the shift to external control was an increase in well being as measured by the California Personality Inventory. Thus, although a shift toward external control may be regarded as regressive, for dialysis patients it appears to be adaptive. In light of the conflicting results, this remains an important area



of study with interesting implications for patients, families and staff.

### Marital Adjustment

Burr (1973:212) proposed that the amount of marital adjustment influences the regenerative power of families and this is a positive relationship. Marital adjustment is a multidimensional, continuous variable which includes specific dimensions such as consensus, satisfaction, happiness and stability. The research on marital adjustment is divided into two major areas; patient and spouse overall ratings of marital satisfaction and sexual adjustment.

Steele, Finkelstein and Finkelstein (1976) described a substantial discrepancy between couple's overall rating of marital problems and their assessments of specific aspects of the marriage; global ratings revealed little discord while more thorough analysis of specific areas showed substantial difficulties. Brackney (1979) investigated reciprocal interactions of home dialysis patients and spouses and suggested that non-conflicted marital relationships are associated with positive medical adaptation. Matthews (1980) reported that among 243 married patients, 42% indicated that their marital relationship had become closer since onset of the renal failure and another 40% thought that the illness had not lessened their relationship.

Only six percent clearly expressed negative results. Spouses, however, voiced much more concern than patients and team members about marital stress and the need for more practical and emotional help in the form of dialysis relief and continued support from hospital staff. These studies indicate that the depth of the questions about the marital relationship may account for some of the discrepancies in results among studies and that dialysis patients as well as renal staff use the defense mechanism of denial in this area.

Several basic surveys (Levy, 1973; Abram, Hester, Sheridan, and Epstein, 1975; Milne, Golden, and Fibus, 1978) established that many patients with chronic renal disease will experience some impairment of their sexual capacities: fear of death, feelings of malaise, weakness, nausea, dizziness and other symptoms of severe illness and renal failure, body image distortion resulting from fluid gain, steroid medications, jaundice, acne as well as the presence of shunts or fistulae are all factors associated with lack of sexual desire on the part of renal patients and their partners.

Levy (1973) in a nationwide survey of 429 male and female dialysis patients, found deteriorated sexual functioning among women as measured by decreased frequency of intercourse and of orgasm during coitus. The extent of

change was greater for men: of the 287 male patients, 50% reported being totally or partially impotent. Analysis of "no problem" and "not sure" responses showed that 32 more males stated that they had not had intercourse at all since the initiation of dialysis, thereby raising the prevalence of impotence to 70%. These findings are consistent with those of others (Larsen, 1972; Abram, et al. 1975).

#### Similarity of Sentiment

Several studies previously referenced (Shambaugh, et al. 1967; Short and Wilson, 1969; Mass and DeNour, 1975) have indicated discrepancies between patients' and spouses' reactions to the stress of dialysis. Discrepancies in the willingness of patients and family members to participate in dialysis research (Czaczkes and DeNour, 1978) suggest differences in the similarity of sentiment about dialysis. Whether this discrepancy concerns differences in the way spouses feel about life with a dialysis patient or about researchers in general is not clear. Further research in this area is needed to determine the degree to which family members differ in their perceptions of the stress of dialysis and the way in which these differences affect regenerative power.

#### Amount of Wife's Social Activity

The literature on home dialysis research on family

adjustment to dialysis (Holcomb and Macdonald, 1973; Shulman, et al. 1974; and Steele, 1976) cited previously, is somewhat indicative of the level of involvement wives have in the treatment process of their spouses. No references have been found however which examine the amount of the wife's social activity outside the home and its relationship to regenerative power. An examination of husband's social activity outside the home would be an interesting addition to the family stress literature as well as the dialysis literature.

#### Level of Reorganization

After the disease process is brought under control, dialysis patients begin the rehabilitation period, with restoration as completely as possible to a purposeful and satisfying life (Cumming, 1980). The level of reorganization reached by dialysis patients and their families has been frequently investigated using the degree of vocational rehabilitation as a measure of a higher level of reorganization (Strauch, Huber, Rahauser, Werner, Walzer and Hafner, 1971; Reichsman and Levy, 1972; Freyberger, 1973; Foster, Cohn and McKegney, 1973; DeNour and Czaczkes, 1976). In general, the level of full vocational rehabilitation among center patients is low, varying between 28 and 36% in these studies. Variations in patient schedules, unreliability of nurses as observers and physician denial

have been noted as possible explanations for the low level of reorganization as measured by return to full or partial employability.

#### Measuring Stress Variables

Obtaining empirical data upon which to test the hypothesized relationship in Burr's syntheses is hampered by the difficulty in soliciting responses from spouses and family members. Variables presenting particular difficulty include: family definition of the seriousness of the event, family integration, family adaptability, similarity of sentiment, relative conjugal power, legitimacy of conjugal power structure, and amount of change in power structure. The hypotheses, therefore, will center around the remaining variables in Burr's theoretical model.

#### Theoretical Bridges

The literature thus includes many references to the proposed relationships in Burr's synthesis. The following issues drawn from the family stress and the dialysis literature are reflected in the operationalization of Burr's propositions:

1. How much experience has the family had in the past year with crisis; how much change has the family experienced in the past year (Amount of Stress) and how much do these contribute to the overall level of stress reported by the family

(Amount of Crisis)? The literature suggests that families who have experienced a great deal of stress over the years are better prepared to handle additional problems. This may be the case in families which are flexible and able to assume productive roles in facing crisis. On the other hand, families that have much more stress than they can actually handle may perceive dialysis as an extremely severe crisis.

2. What are family members' incomes, educational attainment, work status, and occupation (Positional Influence) and how are these related to the degree of family disorganization, ability to handle additional stress, and regularity of schedules (Vulnerability)? Factors in the literature which appear to have a positive mediating effect on vulnerability are greater income, education and capacity for employment. Families experiencing higher levels of these factors are assumed to be more organized, more able to handle additional stress.
3. What is the relationship between family income, educational status, work status and occupational level (Positional Influence) and level of the

family interest in dialysis, speed of adjustment and ability to handle stress (Regenerative Power)? The literature suggests that the higher the income, educational level and occupational status, the better the family can understand and appreciate the stress the patient is under and the easier the period of adjustment becomes.

4. How well does the dialysis patient get along with the medical staff and with the family (Personal Influence) and how is the factor related to the family's level of disorganization ability to handle more stress and regularity of schedules (Vulnerability)? Previous research indicates that patients who are compliant, uncomplaining and generally well-liked by staff have an easier time on dialysis. Staff appear to respond well to these patients, and their families. This positive interaction may support family organization and enhance the ability to handle additional stress.
5. What is the relationship between the patient's ability to get along with family and medical staff (Personal Influence) and the families' interest in the patients' dialysis, speed of

adjustment to new problems and general ability to handle stress (Regenerative Power)? The research on patient personality and ability to relate well with family and staff indicated that once dialysis was initiated, these relationships often become strained. To the degree that positive relationships are created or maintained, family interest, speed of adjustment and family ability to handle additional stress may be greater.

6. How are the degree to which the patient accepts blame for problems with dialysis (Externalization of Blame) and family organization, ability to handle more stress and regularity of schedules (Vulnerability) related? The literature generally supports the assumption that externalization of blame is associated with lower vulnerability. The exception may be those patients who blame others or use denial to such a degree that they cease all attempts of self-care.
7. If a dialysis family has generally had more stress than the average family, had little advance notice that dialysis would be needed, and had little past experience with chronic illness (Anticipation Socialization) are they disorganized,



poorly equipped to handle more stress and irregular in their schedules (Vulnerability)? The issue of anticipation socialization was not addressed in the dialysis literature. It may be assumed, however, that the more patients and families understand about dialysis through past exposure to medical and other problems, and the more warning they have about the need for dialysis, the less vulnerable they would be to its effects.

8. What is the relationship between general level of stress over the years, amount of advance notice for dialysis and past experience with chronic illness (Anticipation Socialization) and family interest in dialysis, speed of family adjustment and ability to handle stress (Regenerative Power)? The literature does not specifically address the variable anticipation socialization. Thus, the relationship between it and regenerative power can only be surmised. The assumption is that the longer the family has to prepare for dialysis, and the better their previous experience with chronic illness, the greater will be their ability to recover.
9. What is the relationship between the degree to

which relatives have been a source of emotional support for a dialysis patient and his family, the wish for more contact with relatives (Extended Familism) and the family interest in dialysis, speed of adjustment and ability to handle stress (Regenerative Power)? Relationships with relatives was only mentioned in the context of home dialysis and referred primarily to nuclear family members. It can be speculated however that because dialysis is a long-term stressor, the greater the extended family support and contact, the greater the regenerative power.

10. What is the relationship between dialysis patients' desire to marry a different person, given a chance, and reporting being happily married (Marital Adjustment) and the family interest in dialysis, speed of adjustment and ability to handle stress (Regenerative Power)? Marital adjustment was frequently addressed in the dialysis literature. Positive marital adjustment was associated with positive medical adaptation and the stress of dialysis itself was cited as a factor in bringing some couples closer together. It can be assumed that greater

marital adjustment may be associated with greater regenerative power.

11. What is the relationship between the spouse's friendship pattern (Spouse's Time Out of the Home) and the family interest in dialysis, speed of adjustment and ability to handle stress (Regenerative Power)? No references were found in the literature to indicate what influence the amount of spousal social activity might have on the ability of a family to adjust to the stress of dialysis. The stress literature indicates that spouse social activity level is positively associated with regenerative power.
12. What is the relationship between the family interest in dialysis, speed of adjustment and ability to handle stress (Regenerative Power), and the degree to which things are going well for the family (Level of Reorganization)? Family acceptance, stability and ability to cooperate was found to be associated with positive adjustment to dialysis. The family stress literature predicts the same relationship.

#### Theoretical Hypotheses

The twelve hypotheses were developed in response to Burr's propositions which were stated in directional form.

The alternate form of the hypotheses thus appear below. The hypotheses were tested in the null form, and the results are presented in Chapter IV.

1. The greater the amount of crisis, the greater the vulnerability.
2. The greater the positional influence, the less family vulnerability to stress.
3. The greater the positional influence, the less family regenerative power.
4. The greater the personal influence, the greater the family vulnerability to stress.
5. The greater the personal influence, the greater the family regenerative power.
6. The greater the amount of externalization of blame for the stressor event, the less family vulnerability to stress.
7. The greater the amount of anticipation socialization, the less family vulnerability to stress.
8. The greater the amount of anticipation socialization, the greater the family regenerative power.
9. The greater the amount of extended familism, the greater the family regenerative power for long periods of disruption.
10. The greater the marital adjustment, the greater the family regenerative power.

11. The greater the amount of social activity of the spouse, the greater the family regenerative power.
12. The greater the amount of regenerative power, the higher the level of reorganization.

#### Summary

This chapter has presented findings from a body of selected literature dealing with the effects of dialysis on patients and families. Research findings were selected for their bearing on the variables in Burr's (1973) synthesis of family stress theory. The need for further research on some of the variables was noted as were limitations in the potential for generation of empirical data with which to investigate the hypotheses. The theoretical hypotheses for this proposal were outlined.

## Chapter III

### METHODOLOGY

The previous chapters have discussed the need to further the development of theory in the area of family stress, the impact of hemodialysis as a stressor for families having a member in treatment, and hypotheses about the relationships among several family stress variables. The review of the existing research on dialysis as a stressor for patients and their families revealed several methodological shortcomings: nonsystematic sampling techniques, small samples, selected samples, insufficient development of hypotheses, inadequate reliability and validity measures, and overreliance on secondary sources and mailed questionnaires for data.

Investigations in the area of dialysis are difficult. Access to patients is restricted, patients may find research an unwelcome and unnecessary intrusion, and patients' difficult emotional and physical conditions make such research problematic. The present study was designed to address some of the difficulties inherent in dialysis research. Patients were interviewed by one investigator and at a time most convenient to them. In addition, hypotheses were grounded in existing theory, the sample was as large as needed for the analyses planned, and efforts were made to maximize validity and reliability.

Initially, this chapter discusses the development, validity and reliability of the research instrument. A second section describes the selection and description of the dialysis units and outlines factors which aided the data collection efforts. The subjects and the interviewing procedure are described in a third section. A fourth section describes the data collection effort, and a description of the tools used in the analysis of the data ends the chapter.

#### Instrument

A closed-ended interview schedule was developed which provided for the collection of demographic data and data related to the variables identified in research hypotheses. A structured interview format was chosen to ensure a large percentage of completed surveys, to require a relatively short administration time and to provide information which would be easily codified. (See Appendix A)

Most of the schedule items were original attempts at operationalizing the variables. Exceptions were the items relating to marital adjustment and general life satisfaction. The marital adjustment items (23 and 30) had been developed by Locke and Wallace (1959) and used individually and collectively to measure marital adjustment. Although measurement data is lacking, predictive validity has been indicated (Rollins and Feldman, 1970; Rollins and Cannon,

1974; Orthner, 1975). The item relating to life satisfaction (26) was drawn from a National Opinion Research Center survey (1977).

Other measures which might have been drawn from the literature were not used for one or both of the following reasons: words or phrases would be needed to make them relevant to dialysis patients, or the measures may have been too lengthy or complex to use given the particular constraints involved in surveying dialysis patients. An example is the Multi-dimensional Health Locus of Control Scale developed by Wallston, Wallston and DeVellis (1978). The scale has only eleven items which measure whether people presume that the factors which determine their health are external such as luck, fate, or chance or whether they presume that the locus of control for health is internal and that one stays healthy or becomes sick as a result of his or her behavior. Using eleven items to measure one variable in the present study would have resulted in a lengthy interview which would have been difficult for dialysis patients to complete. Measures for the remaining variables were developed by the investigator to represent the contextual issues outlined in the family stress and dialysis literature and presented in the hypotheses. Table 1 presents the variables identified in the hypotheses and the items corresponding to each.



TABLE 1

Scale Items Corresponding to Major Variables

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Variable	Items
Positional Influence	9, 12, 15
Length of Time of Disruption	16
Anticipation Socialization	18, 21, 25
Vulnerability	20, 22, 27
Regenerative Power	19, 31, 36
Marital Adjustment	23, 30
Personal Influence	24, 28
Extended Familism	29, 34
Amount of Spouse Social Activity	33
Amount of Crisis	35, 38
Externalization of Blame	37

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### Validity and Reliability

The first draft of the schedule was shown to a panel of judges familiar with the variables in the study. The panel included renal social workers, physicians and academicians in the fields of psychology and family studies. The panel examined the items for content validity and offered suggestions for revision or possible addition of items. Advice was also solicited about the format of the schedule. As a result, the body of the instrument was revised to ensure uniformity in the response mode (strongly agree to strongly disagree). Several items were stated in a negative format to prevent the formation of a response set. The schedule was then presented to the nursing and social work staff of one of the Roanoke centers to be included in the investigation in order to determine which questions they might believe to be objectionable or difficult to answer. Finally, a convenience sample of five patients was interviewed using the schedule and later questioned by the interviewer to discuss information about items which were considered ambiguous, offensive, or otherwise undesirable. This process resulted in some minor changes in item wording and in some cautions about the sensitivity of some items (income, staff-patient relationships) for some patients.

Reliability of the research instrument was investigated

through analysis of its construction and administration. According to Kerlinger (1964), there are three advantages in using the fixed alternative interview format which was used in this study:

(1) With most or all of the items of the closed type, greater uniformity of stimulus and thus greater reliability can be achieved;

(2) The interviewer can know whether the respondent does not understand a question and, within limits repeat or rephrase the question; and

(3) The interviewer can gather more accurate information and can probe into the context of and reasons for answers to questions.

An indicator of internal consistency used was Cronbach's coefficient alpha. Alpha provides a lower bound estimate of the amount of variance that the first factor in a factor analysis would account for. As alpha increases in value, it means that a major factor running through the test items is emerging (Cronbach, 1961).

Coefficient alpha represents the expected correlation of one scale with a second, alternative scale with the same number of items. The square root of alpha represents the estimated correlation of a construct score with the true (errorless) score (Nunnally, 1967:196). Thus, the higher the alpha value the greater the reliability of measures.

The determination of the alpha coefficient for the instrument (.59) suggested that there is more than one major factor present in the interview schedule.

### Sampling

#### Selection and Description of Dialysis Units

The subjects for this study included patients diagnosed with end-stage renal disease, and who were being dialyzed three times weekly in renal units designed to care for stable and potentially long-term patients. The sample was drawn from each center in Western Virginia meeting the above criteria. These centers constituted a convenience sample and were located in Roanoke, Danville, Lynchburg, Charlottesville, and Marion, Virginia. These five centers incorporated all of the "in-center" patients in Western Virginia. Excluded from the sample were patients who 1) dialyzed at home, and 2) were dialyzing by CAPD (Continuous Ambulatory Peritoneal Dialysis). According to George Roman, M.D., a nephrologist in the Roanoke Center, exclusion of these groups would result in the most homogeneous sample possible. The home dialysis and CAPD patients, according to Roman, are characterized by being the most successful, employed, intelligent and happily married group, and the acutely ill patients are generally the most volatile, depressed and poorly motivated patients.

Chapter II reviewed mainly those studies which dealt

with in-center patients. Thus, while these other groups of patients were potentially accessible to the investigator, it was determined that the final sample would be drawn from center patients exclusively.

Newell Falkinburg, M.D., Dr. Roman's colleague in Roanoke, approved the study design and wrote a letter of endorsement which was sent to the physician/owners of the four centers located outside of the Roanoke area. The letter may be found in Appendix B. A second letter was mailed to each center director by the investigator further explaining the study procedure. This sampling design was selected to yield a final sample of approximately 200 patients, a number approaching five times the number of variables in the study as recommended by Kerlinger (1964). Plans were made to contact centers in the northern and eastern parts of Virginia should this design fail to yield sufficient numbers from Western Virginia.

Positive responses were obtained from each of the centers contacted. The center directors encouraged the investigator to work with either the head nurse or the social worker in each center and within two weeks an itinerary was determined and the interviewing was initiated.

Prior to the arrival of the investigator at each location, the social worker or head nurse discussed the nature of the project with all patients and assured them

that their participation was purely voluntary. It was felt that this was an extremely important step because of the dilemma described by Alexander (1976) in which patients are frequently afraid to object to various tasks and procedures for fear of alienating caretakers. Skipper (1965) also addressed the bind patients are in as they try to follow the rules, respond in socially approved ways and remain "good patients" while also attempting to retain some sense of autonomy. Prior contact was made by phone with the nurse or social worker acting as liaison to the research project in each center. This was done to establish a positive working relationship and to mollify any negative reactions of the staff resulting from being appointed to the task. While the conditions alluded to by Bates (1970) in her article about the difficulties in physician-nurse role relationships were potentially present, in actuality, staff and patients were extremely cooperative.

A number of factors may have accounted for the positive reception on the part of the center staff and patients:

- 1) The good will generated by the Roanoke area physicians, nurses and social workers who were associated with other center staffs in informal networks;
- 2) The high caliber of dialysis professionals present in each center, many of whom had received training in the behavioral sciences and who were interested in increasing

their knowledge;

3) The fact that these particular centers had not been included in previous research and were uncontaminated by negative experiences;

4) The often stated desire by patients to have their family stress understood and to decrease the level of stress for fellow patients; and,

5) The opportunity for staff and patients to speak confidentially to a consultant familiar with their problems yet "outside the system".

Out of the 215 potential interviewees, 207 participated in the study. Of the eight who were not included, one patient in Roanoke refused to be interviewed, two Danville patients were not included because the investigator ran out of time to interview them before they went home. One patient in Marion was excluded because he was currently a mental patient at Southwestern State Hospital and was not verbally responsive. An elderly female in Lynchburg was excluded because she suffered a heart attack half-way through the interview. Two patients in Charlottesville were excluded because they had total hearing loss and communicated freely only with each other; and one patient in the Roanoke hospital sample was left out because a formaldehyde spill in the unit made breathing and talking too difficult. The 207 patients who agreed to be inter-

viewed exhibited a wide range in willingness and talkativeness. The vast majority participated freely and contributed many spontaneous thoughts and bits of advice for the investigator.

Discussions with patients and staff prior to and during the data collection revealed several situations which may be of importance in interpreting the results:

1) All but one of the centers had experienced the death of at least three patients within one month prior to the survey;

2) One of the centers was experiencing severe intrastaff conflict which was readily apparent and of considerable personal concern to the patients;

3) One center was completely restricting the ingestion of food and drink while patients dialyzed as a result of an outbreak of hepatitis. In addition, patient morale was probably affected due to the presence of a peritoneal dialysis patient in the unit who was near death and who was moaning and shrieking intermittently throughout two shifts;

4) Two of the centers used beds rather than the chairs for the patients (restricting their movement) and used a single needle access which lengthens the dialysis time from 4 to 6 hours; and,

5) One center was significantly larger than the others, dialyzing 15 rather than the usual 7 to 10 patients



per shift.

#### Data Collection

Data collection took place between January 21 and February 21, 1981. Two to four days were spent in each center to ensure contact with all possible patients on each shift.

At the beginning of each shift, while the patients were being put on the dialysis machines, the investigator met with the center social worker and head nurse to schedule the day and to discuss individual patient situations which should be taken into consideration during the interview. It was necessary for the investigator to reiterate at these times that the discussions with each patient had to remain confidential but that the summarized data and analyses would be shared with the staff. This became a difficult issue in several centers as patients would confide specific thoughts and concerns with the investigator which they had not previously shared with the center staff and staff members expressed concern about what patients may have said about themselves as well as the staff.

Within the first hour, while each patient was on dialysis, the nurse or social worker introduced the investigator who again informed the patient about purpose of study. Each patient was then extended a personal invitation to participate.

Each participant was interviewed individually for about one-half hour. The background information was gathered first; the patient was then asked to respond to the items specifically relating to his or her family. Patients were permitted to elaborate on any item and much anecdotal data was collected in this manner. When spouses or other family members were present, they were asked to go to a waiting area until the patient was through and then they were also invited to talk with the interviewer, if they wished. No patients were interviewed while they were being put on the machine but several were still being interviewed after they had been taken off and were waiting for their puncture sites to clot.

The vast majority of interviewees were cooperative and cheerful. Some patients were depressed and difficult to interview and a few were intermittently nauseated, sick, cramping, or in shock which necessitated a multi-staged interviewing process.

It was not at all unusual for the interviewing to be interrupted by a loud buzzer which signalled problems requiring medical intervention, such as 1) problems in blood flow which resulted from patients moving their arms as they spoke causing the needle to brush the wall of an artery and slow the flow of blood; or 2) a sudden drop in blood pressure which would require the immediate administration of salt

either in the form of a venous infusion or the ingestion of a dill pickle to keep the patient from losing consciousness and dying. With the exception of the one interview which terminated midway when the patient went into cardiac arrest, there were no incomplete questionnaires.

#### Data Processing

The data were coded and key punched on an 80 column IBM card (one card per case). An SPSS (Statistical Package for the Social Sciences) computer program was utilized in processing data for this investigation. The groups of background and demographic variables were tabulated, and means, ranges, and standard deviations were calculated. Pearson's product-moment correlation coefficient was then computed to test each of the hypothesized relationships in this study. The nonstatistical aspects of the study included a discussion of the anecdotal data arising from the structured interview.

## Chapter IV

### RESULTS

Of 215 in-center dialysis patients available for inclusion in this study, 207 comprised the final sample. Only one patient was unwilling to be interviewed. Eight patients were omitted because temporal, mental or physical conditions prevented their participation. Patients were interviewed in six dialysis centers in Western Virginia: Lynchburg (N=36), Danville (N=45), Charlottesville (N=33), Marion (N=14) and two locations in Roanoke (N=56), (N=18). Differences in characteristics among patients in these locations were not considered in this study. Face-to-face interviews were conducted with patients while they were being dialyzed. The data from the 207 completed interviews were used to test proposed relationships among the variables in the family stress model.

#### Descriptive Analysis

##### Demographic Variables

There was a slightly greater number of males (N=107, 51.7%) than females (N=100, 48.3%) in the sample. This distribution matches those found in other large-scale studies (Burton and Hirshman, 1979; and Gutman, Stead, and Robinson, 1981). (Table 2)

More patients were black (N=113, 54.9%) than white (N=94, 45.1%). This is a much larger proportion of black

TABLE 2  
Demographic Characteristics of Dialysis Patients

VARIABLE	N	%	
<u>Gender</u>			
Male	107	51.7	
Female	100	48.3	
<u>Race</u>			
White	93	45.1	
Black	113	54.9	
<u>Age</u>			
12-20	9	4.3	
21-30	14	6.6	
31-40	35	16.9	
41-50	47	22.7	$\bar{X}=49.8$
51-60	48	23.1	SD=15.1
61-70	38	18.4	
71-80	14	6.8	
81-86	2	1.0	
<u>Marital Status</u>			
Never Married	42	20.3	
Married	95	45.9	
Separated	13	6.3	
Divorced	14	6.8	
Remarried	14	6.8	
Widowed	29	14.0	
<u>Years Wed</u>			
1-10	28	18.0	
11-20	27	17.3	
21-30	44	28.2	$\bar{X}=26.3$
31-40	32	20.5	SD=14.0
41-60	23	14.7	
51-60	3	1.9	

TABLE 2 continued  
Demographic Characteristics of Dialysis Patients

VARIABLE	N	%	
<u>Residence</u>			
Family of Origin	30	14.5	
Spouse Only	48	23.2	
Spouse and Children	52	25.1	
Children Only	24	11.6	
Sibling	7	3.4	
Self/Nonfamily	41	19.8	
Extended Family	5	2.4	
<u>Children</u>			
None	50	24.2	
1-3	96	46.4	$\bar{X}=2.6$
4-6	44	21.3	SD=2.4
7-9	15	7.2	
<u>Education</u>			
0-3	20	9.7	
4-8	79	38.2	
9-12	84	40.6	$\bar{X}=8.9$
13-16	21	10.1	SD=3.8
17-18	3	1.4	
<u>Patient Work Status</u>			
Not Working	192	92.3	
Part Time	10	4.8	
Full Time	4	2.0	
<u>Patient Occupational Level - Now or Past</u>			
One	4	1.9	
Two	12	5.8	
Three	16	7.7	
Four	25	12.1	$\bar{X}=5.0$
Five	49	23.7	SD=1.6
Six	45	21.7	
Seven	36	17.4	
None	20	9.6	

TABLE 2 continued  
Demographic Characteristics of Dialysis Patients

VARIABLE	N	%	
<u>Income</u>			
\$1,000-\$2,000	9	4.3	
\$3,000-\$7,000	117	56.5	
\$8,000-\$12,000	40	19.3	$\bar{x}=\$9,570$
\$13,000-\$20,000	25	12.1	SD=10.47
\$21,000-\$30,000	11	5.3	
\$31,000+	5	2.4	
<u>Months on Dialysis</u>			
1-12	65	31.4	
13-24	36	17.4	
25-36	36	17.4	
37-48	26	12.6	$\bar{x}=3.26$
49-60	15	7.2	SD=28.7
61-78	13	6.3	
79-84	2	1.0	
85-96	5	2.4	
97-168	8	3.9	
<u>Underlying Disease</u>			
High Blood Pressure	100	48.3	
Glomerulonephritis	29	14.0	
Diabetes	25	12.1	
Polycystic Disease	15	7.2	
Lupus	2	1.0	
Congenital	7	3.4	
Other	10	4.8	
Unknown	19	9.1	

patients compared with their estimated prevalence (24%) among the entire dialysis population in the United States (Burton and Hirshman, 1979).

The age distribution was great (12 to 85 years). The mean age, (49.8), was similar to the mean age found in the Gutman, Stead, and Robinson (1979) study (53%, 50 years of age or older, N=2,481). Ten percent of the respondents were under 30 and 10% were over 65 years of age.

The distribution of patients according to marital status was divided among six classifications. Of those who had never married (N=42, 20.3%), eleven were under 25 years of age. Of these, six patients considered themselves too young to marry, three had experienced renal problems prior to puberty resulting in incomplete sexual maturation, and two patients stated homosexual orientations as reasons for never marrying. Of the currently married group (N=109, 52.7%) relatively few had been previously married (N=14, 6.8%). Thirteen patients (6.3%) were separated at the time of the interview and 14 (6.8%) were currently divorced. A large proportion of the sample (N=29, 14%) were widowed, reflecting the increased incidence of widows and widowers in an older population.

Of those who had been or currently were married (N=165), the mean number of years wed was 26.3 years. These figures reflect the age and values held by this



population of predominantly religious and rural people who reside in communities where the divorce rate is generally low. The fact that these same patients are often maintaining unhappy relationships is suggested in responses to items relating to marital adjustment described below.

All patients were asked who they were currently living with. A full 80% (N=166) of the respondents lived with a family member or members. Those living on their own (N=22) or in boarding homes (N=19) comprised 20% of the sample. Twenty-nine patients (14%) lived with their family of origin, 60% (N=124) lived with spouse and/or children and about six percent (N=12) lived with a sibling or an extended family member.

Fifty patients (24%) had no children (41 patients had never been married) and 76% had one or more children. The mean number of children was 2.6 per patient.

The level of education ranged from no years of formal schooling (N=4) to those who had completed graduate education (N=3). The average number of years of education was 8.9 years.

The data on the patients' work status differed markedly from data in other studies which have indicated a greater percentage of patients working or able to work (Gross, Keane, and McDonald, 1973; Gutman, et al. 1981). Of the

patients surveyed, only fifteen (two percent) were working either part-time or full-time. Of the 207, about 25% (N=65) were either over 60 years of age or were too young to work. Even allowing for the number of homemakers in the group, the percentage of patients who were working at all was quite low. A much higher percentage of the spouses worked either part-time or full-time (34%, N=122) and contributed income to the patients' households.

Patients' and spouses' occupational levels were rated on a scale of one to seven with one representing the highest level (lawyers, physicians) and seven representing mill hands, heavy labor or unskilled works (McGuire and White, 1955). The mean level of patients' occupation currently or in the past was 5.0 representing clerks, repairmen, apprentices to skilled trades, practical nurses, police, and tenant farmers or farm foremen. The mean level of spouses' occupations currently or in the past was slightly higher (4.7) indicating small business owners, bookkeepers and small land owners in greater proportion than the patient group.

The mean annual family income in thousands was 9.6 (N=207). This figure included the supplementary social security income (SSI), Medicare benefits, privately financed disability incomes and retirement income, as well as earned income in each household.

Only three patients refused to state their exact income. The rest were very familiar with the exact dollar amounts and volunteered the information freely. Patients often talked at length about the pressures of inflation, poor vocational rehabilitation, wasteful governmental practices and the low morale induced by their financial dependence in general. Several patients reported high incomes generated through extra-legal means such as card playing, prostitution, transporting cocaine and maintaining family moonshine operations. In each center, there was evidence that some patients knew which of their fellow patients were in need of money or services and it was apparent that the patients quietly took care of each other during extremely difficult times.

Time on dialysis, calculated in months, ranged from less than one month to 14 years. The mean was 32.6 months (N=207) and the median was 25.3 months. About 20% (N=53) had been on dialysis four years or longer, 15% (N=37) had been on five years, and seven percent (N=20) had been on over six years. These figures are quite similar to the data on the dialysis population as a whole in the United States (Burton and Hirshman, 1979).

Patients were asked to state the medical condition which they felt was the reason they needed dialysis. There are no data on the reliability of patients' reports of this

information. Forty-eight percent (N=100) cited high blood pressure, 12% (N=25) cited diabetes, 14% (N=29) indicated glomerulonephritis, 7.2 % (N=15) cited polycystic disease, one percent (N=2) cited lupus erythmatosis as the precipitating factor and 3.4% (N=7) felt that congenital problems were the cause. About five percent cited other reasons such as accidents, or poisoning. Nine percent (N=19) reported that they did not know the medical reason they were on dialysis.

#### Summary of Patient Ratings on Individual Stress Variables

Results on individual interview items are reported to provide a more comprehensive understanding of characteristics of the respondents in this sample. The data appear in Table 3.

Patients in this sample appear to view their situations optimally indicating the presence of denial as a defense so frequently cited in the literature (Glassman, 1970; DeNour and Czaczkes, 1972; Foster, Cohn and McKegney, 1973). About 60% disagreed that their family had generally had more stress than the average family. About 65% said that their family does not tend to become disorganized as a result of their dialysis. This finding may be in part due to the fact that the committment to a dialysis regimen requires extreme organization in meal planning, travel and treatments themselves. The family may become organized around these

TABLE 3

Responses, Means and Standard Deviations for Scale Items Grouped by Variables

	Disagree	Strongly Disagree	Disagree	Agree	Strongly Agree	Under- cided	N	X	SD
<u>ANTICIPATION SOCIALIZATION</u>									
18. My family has generally had more stress than the average family (ANTISOC1)	5	117	51	27	7		207	2.59	.87
21. We had little advance notice that I would need dialysis (ANTISOC2)	18	68	55	71	0		207	2.87	.99
25. This is the first long term illness my family has dealt with (ANTISOC3)	34	46	54	73	0		207	2.80	1.10
<u>REGENERATIVE POWER</u>									
19. My family tried to learn about my dialysis soon after I began it (REGPOW1)	39	49	95	20	4		207	2.48	.82
31. My family usually adjusts quickly to new problems (REGPOW2)	5	32	150	11	9		207	2.94	.69
36. My family usually handles stress well (REGPOW3)	1	11	174	15	6		207	3.1	.51
<u>VULNERABILITY</u>									
30. My family tends to get disorganized because of my dialysis (VULN1)	7	126	47	22	5		207	2.48	.82
22. My family could not handle much additional stress just now (VULN2)	8	57	81	56	5		207	2.97	.89
27. We keep regular schedules for things like meals and bedtimes (VULN3)	59	38	79	29	2		207	2.41	.91
<u>MARITAL ADJUSTMENT</u>									
23. If I had it to do over again, I might marry a different person (HAPMAR1)	41	57	25	36	0		163	2.42	1.16
30. Everything considered, my marriage has been relatively happy (HAPMAR2)	26	23	91	24	0		164	2.69	.91
<u>PERSONAL INFLUENCE</u>									
24. Our relationships with the medical staff are sometimes hard (PERSINF1)	10	106	74	17	0		207	2.47	.72
28. My family sometimes resents me for having to be on dialysis (PERSINF2)	15	121	48	11	12		207	2.44	.92
32. My family usually goes along with what I ask (PERSINF3)	15	86	87	17	2		207	2.5	.79
<u>LEVEL OF REORGANIZATION</u>									
26. In general, things are going well for our family these days (LEVORG)	10	31	161	3	2		207	2.79	.59
<u>EXTENDED FAMILISM</u>									
29. Relatives have been a source of emotional support for our family (EXFAM1)	25	149	106	24	3		207	2.69	.91
34. Our family should spend more time with relatives (EXFAM2)	44	104	43	8	8		207	2.19	.94
<u>SPOUSES SOCIAL ACTIVITY</u>									
33. My spouse has one or more close personal friends (SPOUSOUT)	9	14	67	24	6		120	3.03	.91
<u>AMOUNT OF CRISIS</u>									
35. In the past year our family has faced some big problems (AMICRIS1)	5	56	78	66	2		207	3.02	.85
38. Our family life has changed some for the worse since my dialysis began (AMICRIS2)	2	64	78	61	2		207	2.99	.83
<u>EXTERNALIZATION OF BLAME</u>									
37. When I have a bad time medically, it is usually my fault (EXBLAME)	52	66	59	10	20		207	2.42	1.20

requirements.

Denial may be a factor for almost 80% of the sample who agreed that, in general, things are going well for their family these days. The reasons why patients reported that their families did not resent them for being on dialysis (66%) may be complex. Discussions around this item indicated that patients concentrate on caring for themselves, managing diet, transportation and money with as little interference for family members as possible. The quick responses to this item and the discomfort which it obviously produced, suggested that this is a difficult area for patients to think about or discuss.

The item relating to families' compliance to patients' wishes produced some very interesting results. Although the responses were evenly divided on an agree-disagree dichotomy, 80% (N=165) of the respondents spontaneously added comments such as "But I don't ask", "I never ask them for anything", "They leave me alone and I leave them alone", "They do enough for me already", etc. Follow-up questions related to these responses revealed patients who had always perceived themselves as "independent", "the backbone of the family", or "the one everyone else comes to for help or advice" and were those who were struggling to maintain their accustomed independence and self-reliance. This finding is similar to ones reported by Frank (1975) in

his discussion of the psychological correlates of disease.

Frank as well as Theorell and Rahe (1972) have suggested that over-functioning, emotion-withholding, and chronically stressed individuals may be more prone to chronic degenerative diseases such as cancer and heart disease. The personality characteristics revealed by this item suggest the interesting possibility of a similar personality link with kidney failure. The impressions that these patients made after longer discussion correspond with those of Drees and Gallagher (1981) who suggest that the tense, holding-in patient may deny the existence of medical problems when they occur and are often overly demanding in what they expect of themselves.

The extended familism item which related to whether or not a patient and his family should spend more time with relatives, produced a strong negative response indicating that more contact with relatives was not desired. Upon further questioning, the patients responded in one of several ways: 1) patients reported feeling too physically exhausted and over-extended to be comfortable socializing with relatives; 2) patients' families were small, isolated and already too interdependent; or, 3) patients were afraid that increased contact with extended family members might lead to requests for money or favors from the patient and his family. For a variety of factors, then, dialysis

patients in this study described themselves as isolated and withdrawn from extended family members, a finding consistent with those of Maurin and Schenckel (1976) and Speidel, Koch, Balck and Kniess (1981).

Isolation was further emphasized in the follow-up questions to the question "If I had it to do over again, I might marry a different person". A frequent spontaneous response (N=52) was "If I had it to do over again, I would never marry at all." This comment was coded separately and was made by married and divorced patients as well as those who were widowed.

Responses to the question "Everything considered, my marriage has been relatively happy" were equally compelling. Thirty percent of the patients responded negatively to this item and many were straightforward in their reasons which were, for example: "I'm sure its been no fun to live with a sick wife/husband" or "I've had to do all the work in the marriage and I would have been better off without him/her anyway." All patients married over 20 years (N=106) were asked for the secret to living with one mate so long. Answers to this query were grouped in the following categories: 1) I don't know (20%); 2) belief in marriage (30%); 3) you just keep living day by day (20%); 4) pick a good man/woman (20%); and 5) other (10%).



### Results Pertaining to Hypotheses

Hypothesis one stated that the greater the amount of crisis, the greater the family vulnerability. The Pearson correlation coefficients were calculated between the three items measuring vulnerability and the two items measuring amount of crisis (Table 4). Patients who agreed that their family had experienced big problems in the past year also agreed that their families get disorganized because of their dialysis (N=207,  $\underline{r}=.23$ ,  $\underline{p}<.001$ ), and felt that their families could not handle much additional stress, (N=207,  $\underline{r}=.29$ ,  $\underline{p}<.001$ ). Amount of recent crisis did not correlate significantly with regularity of schedules, however (N=207,  $\underline{r}=0.04$ ,  $\underline{p}=.28$ ).

Patients who agreed that their family life had indeed been affected by the initiation of their dialysis treatments also agreed that their families became disorganized (N=207,  $\underline{r}=.27$ ,  $\underline{p}<.001$ ) and that their families could not handle much additional stress (N=207,  $\underline{r}=.12$ ,  $\underline{p}=.04$ ). Amount of crisis as measured by this item did not correlate significantly with regularity of schedules (N=207,  $\underline{r}=-.01$ ,  $\underline{p}=.45$ ). Since this study does not posit the ascendancy of one predictor variable over the other, evidence that the majority of the relationships tested in this and other hypotheses are significant at .05 or below will serve to support the hypothesis. Hypothesis one is thus supported.

TABLE 4  
 Pearson Product Moment Correlations Between  
 Vulnerability and Amount of Crisis

	VULN1	VULN2	VULN3
AMTCRIS1	0.2287 (207) $\underline{p} < .001$	.2872 (207) $\underline{p} < .001$	-.0404 (207) $\underline{p} = .282$
AMTCRIS2	.2668 (207) $\underline{p} < .001$	.1240 (207) $\underline{p} = .038$	-.0097 (207) $\underline{p} = .445$

The greater the crisis as perceived by the family, the more disorganized and strained the family is. The greater the family vulnerability, the more likely it is that the family is experiencing dialysis as a major stressor. Hill (1964) and Hansen (1965) referred to this depletion of crisis-meeting resources as a major factor in the family ability to cope with stress.

The present findings appear to support the earlier research reported in the literature review. Dialysis produces myriad stresses around dietary restrictions (Goldstein and Reznikoff, 1971), control over daily schedules (Levy, 1976), and management of physical complications (Sand, et al. 1966). The repeated severe crises which dialysis patients and their families encounter do appear to produce substantial stress as described by DePalma (1978).

Hypothesis two stated that the greater the positional influence the less the family vulnerability to stress. Positional influence was measured by income, patients' work status, patients' occupational level, and spouses' work status. Pearson correlations were calculated between these and the three items measuring vulnerability. Amount of income was inversely related to amount of family disorganization (N=207,  $r=-.11$ ,  $p=.05$ ), (Table 5), and positively related to the regularity of schedules in the home (N=207,

TABLE 5  
 Pearson Product Moment Correlations Between  
 Positional Influence and Vulnerability

	INCOME	PTWORK	PTOCC	SPWORK
VULN1	-.1117 (207) p=.055	-.1337 (207) p=.027	.0425 (187) p=.282	-.1974 (122) p=.015
VULN2	-.0808 (207) p=.123	-.1480 (207) p=.017	.1526 (187) p=.019	-.0791 (122) p=.193
VULN3	.1493 (207) p=.016	.0621 (207) p=.187	-.1967 (187) p=.003	.1172 (122) p=.099

$r=.15$ ,  $p=.02$ ). Patients who did not work had families who were significantly more likely to be disorganized ( $N=207$ ,  $r=-.13$ ,  $p=.03$ ) and unable to handle additional stress ( $N=207$ ,  $r=-.15$ ,  $p=.02$ ). The higher the patients' occupational status the more likely the patients' report that the family could handle additional stress ( $N=187$ ,  $r=-.15$ ,  $p=.02$ ) and the less likely the family had experienced major problems in the past year ( $N=187$ ,  $r=-.20$ ,  $p=.01$ ). Patient work status and spouses work status were weakly yet positively related to regularity of family schedules. And spouses' work status was not correlated very highly with the family ability to handle more stress and regularity of family schedules. Seven out of twelve possible correlations in this analysis were significant at the .05 level or beyond. Thus, the hypothesis two was supported.

These statistics suggest that patients and their families have more ability to withstand the stress associated with dialysis if they have the financial resources and meaningful employment. No amount of government benefits could adequately compensate for the lowering of positional influence. Although the patients in this sample did not on the whole, have high socioeconomic status before becoming ill, the family standard of living was definitely lowered as a result of the dialysis treatment. Most of the patients had been involved in occupations requiring great physical

effort. The drop in hemoglobin levels caused by dialysis prevented patients from engaging in their former occupations and their ages and educational levels left them ill-equipped to engage in more sedentary occupations. These findings support those by Czaczkes and DeNour (1978) who found that loss of earned income, inability to work and the role changes brought about by these events is a major factor in families' ability to handle additional stress.

The third hypothesis stated that the greater the positional influence the lower the family regenerative power. Income was positively correlated with speed of family adjustment ( $N=207$ ,  $r=.13$ ,  $p=.04$ ) but not with family interest in dialysis or family ability to handle stress (Table 6). Patients' work status was positively related to family interest ( $N=207$ ,  $r=.11$ ,  $p=.05$ ) but not with speed of adjustment or ability to handle stress. Patient occupational status was inversely related to family interest in dialysis ( $N=187$ ,  $r=-.19$ ,  $p<.01$ ) and to speed of adjustment ( $N=187$ ,  $r=-.11$ ,  $p=.07$ ). An inverse relationship was found with ability to handle stress but it was not significant. Spouses' work status was positively related to interest in dialysis ( $N=122$ ,  $r=.16$ ,  $p=.04$ ) and speed of adjustment ( $N=122$ ,  $r=.15$ ,  $p=.05$ ) but not to ability to handle stress. Only two of the five

TABLE 6

Pearson Product Moment Correlations Between  
Positional Influence and Regenerative Power

	INCOME	PTWORK	PTOCC	SPWORK
REGPOW1	.0815 (207) p=.122	.1136 (207) p=.052	-.1869 (187) p=.005	.1553 (122) p=.044
REGPOW2	.1251 (207) p=.036	.0064 (207) p=.463	-.1100 (187) p=.067	.1474 (122) p=.053
REGPOW3	.0320 (207) p=.324	.0482 (207) p=.245	-.0037 (187) p=.480	.0933 (122) p=.153

relationships were found to be significantly inversely related as hypothesized. Hansen and Johnson (1979) predicted difficulty with this hypothesis, citing the problems with operationalizing the variable regenerative power, and reasoning that it had more to do with the family resources than other factors. In this analysis, only the patients' occupation, a measure of present or past earning power, was inversely related to measures of regenerative power, affirming Hansen and Johnson's speculation. Only five of the twelve relationships were significant at the .05 level or beyond and all but two of these were positively related. Thus hypothesis three was only partially supported in the null and not supported in the alternative form.

Hansen (1965) suggested that regenerative power denoted variation in a family's ability to recover from a crisis. Hansen did not speculate on the nature of this proposition other than to specify its direction. A closer examination of the findings then, might begin to clarify some elements of this hypothesis as operationalized in this study.

It appeared that the greater the financial resources, the faster the family was able to stabilize after the dialysis began. This was consistent with the finding that in the families in which the patient was still



employed either part-time or full-time, greater interest and motivation on the part of the family to learn about the patients' condition was evidenced. Patient anecdotes supported this reasoning. Patients and family members who were employed, who had higher incomes, and who were more educated, were the ones who availed themselves of written information and asked social workers and physicians questions pertaining to the patients condition.

The dialysis literature does not specifically address the relationship between family socioeconomic status and family regenerative power as measured by family interest in dialysis. However it does discuss the greater amount of regenerative power as evidenced by home dialysis patients who generally have more financial resources than center patients (Shulman, Pacey and Diewold, 1974; Pentecost, et al. 1976). The literature also suggests strong positive relationships between education and adjustment (Meldrum, et al. 1968; DeNour and Czaczkes, 1974) and income and success on dialysis (Chyatte, 1979). The present study agrees with these as various measures of family regenerative power were found to covary significantly with income, patient work status, patient occupational level and spouses' work status.

Hypothesis four stated that the greater the personal influence in a social system, the greater the vulnerability

to stress. Family disorganization was positively related to reported difficulties with medical staff, (N=207,  $r=.10$ ,  $p=.08$ ), to family resentment toward the patient for having to be on dialysis (N=207,  $r=.41$ ,  $p<.01$ ) and to family reluctance to go along with patient requests (N=207,  $r=.16$ ,  $p<.01$ ) (Table 7). Family inability to handle additional stress was positively related to difficult family-staff relationships (N=207,  $r=.11$ ,  $p=.06$ ), family resentment of the patient (N=207,  $r=.20$ ,  $p<.01$ ), and family reluctance to go along with patient requests (N=207,  $r=.12$ ,  $p=.04$ ). And families who were erratic in their family schedules were also likely to have difficult relationships with the medical staff (N=207,  $r=.10$ ,  $p=.06$ ) and to be somewhat reluctant to accommodate patient requests (N=207,  $r=.07$ ,  $p=.15$ ).

Why these findings are in the opposite direction from those predicted is unclear. A reason might be found in the Hansen and Johnson (1979) discussion of the source of the variables positional and personal influence, suggesting that the formulations have remained undeveloped and problematic and that the utility of these concepts are thus compromised. The findings in this study are easily interpreted and correspond well with other studies using concepts similar to the ones operationalized in this hypothesis however (Short and Wilson, 1969; DeNour and Czaczkes,

TABLE 7  
 Pearson Product Moment Correlations Between  
 Personal Influence and Vulnerability

	VULN1	VULN2	VULN3
PERSINF1	.0999 (207) p=.076	.1085 (207) p=.076	-.1058 (207) p=.065
PERSINF2	.4125 (207) p<.001	.2007 (207) p=.002	-.1075 (207) p=.062
PERSINF3	.1631 (207) p=.009	.1210 (207) p=.041	-.0723 (207) p=.150

1970; Mass and DeNour, 1975). It was concluded in these studies that patients who were in precarious positions with family and staff were often becoming scapegoats and living in disruptive and increasingly disturbed family relationships. A second reason may be the way in which the investigator chose to interpret and operationalize the variable positional influence. In this investigation, the intent was to denote variation in the ability of dialysis patients to influence and to get along with family and dialysis center staff. The present findings suggest that dialysis staff members do not get along well with patients whose family lives are disorganized as a result of the dialysis. They also suggest that the more stressed and disorganized a family is, the more they openly resent the patient, avoid accommodating his/her requests, and have reported difficulties with the medical staff.

As in the findings by Alexander (1976) and Czaczkes and DeNour (1978), a difficulty in interpreting the present findings is ascertaining what is cause and what is effect. Are the family and staff responding to the patient in a negative fashion because the patient is agitated and disorganized or is the patient disorganized and upset at the responses of others? On the basis of present results, hypothesis four is supported because strong relationships

were found between personal influence and vulnerability measures. The alternate hypothesis is rejected, however, as the direction of the relationship was found to be inverse, rather than positive as predicted.

Hypothesis five which stated the greater the personal influence, the greater the family regenerative power was not supported. All correlations were extremely low and inverse ( $N=207$ ,  $r=-.05$  to  $-.07$ ,  $p=.16$  to  $.28$ ) (Table 8). Apparently the degree to which patients and families get along well with the medical staff, and with each other is not related to the families' interest in learning about the patients' dialysis, the speed with which families adjust, or the perceived family strength.

These findings may be explained by some of the previous research reporting levels of patient adjustment within the family (Holcomb and Macdonald, 1973; Czaczkes and DeNour, 1978). These studies present extremely contradictory results. The former found high levels of enjoyment with family life, discussions with partners and shared interests with partners. The latter suggested that such claims of family solidarity and support are hard to believe given the poor rehabilitation of patients, adverse reactions of spouses and often poor psychological condition of patients. Both these and the present findings suggest that denial of severe intrafamily stresses may be operating in some

TABLE 8  
 Pearson Product Moment Correlations Between  
 Personal Influence and Regenerative Power

	REGPOW1	REGPOW2	REGPOW3
PERSINF1	-.0499 (207) p=.238	-.0476 (207) p=.248	-.0485 (207) p=.244
PERSINF2	-.0515 (207) p=.231	-.0403 (207) p=.282	-.0535 (207) p=.222
PERSINF3	-.0686 (207) p=.163	-.0483 (207) p=.245	-.0498 (207) p=.238

patient reports and more honest reactions are being presented by others. The variations in the patients' openness in reporting may thus be responsible for the low correlations found here.

Hypothesis six states that the greater the amount of externalization of blame for the stressor event, the less vulnerability to stress. No significant relationships were found between these variables and the hypothesis was not supported (Table 9). The dialysis literature may provide an explanation for the present findings. While past research was generally in support of the hypothesis that an external blame orientation is associated with low vulnerability (Wilson, et al. 1974), another study (Goldstein and Reznikoff, 1971) found that an internal locus of control orientation was more conducive to health.

The present findings indicate a very slight positive association between internalization of blame and family disorganization (N=207,  $\underline{r}=.06$ ,  $\underline{p}=.21$ ) and internalization and family inability to handle additional stress (N=207,  $\underline{r}=.08$ ,  $\underline{p}=.14$ ). These findings suggest that there may be other factors influencing the results such as length of time on dialysis which are not reflected in this analysis but which has been found to influence the direction of findings in previous research.

Hypothesis seven states that the greater the amount

TABLE 9  
Pearson Product Moment Correlations Between  
Externalization of Blame and Vulnerability

---

EXBLAME	
VULN1	.0562 (207) p=.211
VULN2	.0769 (207) p=.135
VULN3	-.0011 (207) p=.493

---



of anticipation socialization, the less the family vulnerability to stress. Results indicate that patients whose families had reportedly experienced more stress than the average family were also more likely to be disorganized as a result of the dialysis ( $N=207$ ,  $r=.17$ ,  $p<.01$ ) and were less likely to be able to handle additional stress ( $N=207$ ,  $r=.13$ ,  $p=.03$ ) (Table 10). Patients who had little advance notice that they would need dialysis also were more likely to experience family disorganization as a result of their dialysis ( $N=207$ ,  $r=.13$ ,  $p=.03$ ). Patients whose families had had much prior experience with illness were also more disorganized as a result of the dialysis ( $N=207$ ,  $r=.13$ ,  $p=.03$ ). This relationship was not in the hypothesized direction. This may be explained by the fact that dialysis is a long-term stressor and that no amount of prior experience with illness could equip a family to deal with the unending rigors associated with dialysis. It may be that in responding to the question about past experience with stress, patients were referring to and including their dialysis as part of the stress overload experienced by their family, thus confounding this relationship by defining in terms of itself.

Three other relationships were in the predicted direction but were not significant at the .05 level or beyond. Regularity of family schedules was positively

TABLE 10  
 Pearson Product Moment Correlations Between  
 Anticipation Socialization and Vulnerability

	ANTSOC1	ANTSOC2	ANTSOC3
VULN1	.1701 (207) p=.007	.1273 (207) p=.034	.0194 (207) p=.391
VULN2	.1314 (207) p=.030	.0332 (207) p=.318	.0278 (207) p=.345
VULN3	.0876 (207) p=.105	.0883 (207) p=.103	-.0716 (207) p=.152

associated with prior experience with stress (N=207,  $\underline{r}=.09$ ,  $\underline{p}=.10$ ), with advance notice of the need for dialysis (N=207,  $\underline{r}=.09$ ,  $\underline{p}=.10$ ) and with prior experience with chronic illness (N=207,  $\underline{r}=.07$ ,  $\underline{p}=.15$ ). These figures suggest that people who understand or can anticipate the rigors of extended illness, prepare for and cope with it by establishing and maintaining organized routines. The trends in the data suggest support of hypothesis seven but too few of the correlations reached a level of significance great enough to formally support it.

There was a paucity of research in the area of anticipation socialization and vulnerability in the dialysis literature. The relationships found in the present investigation continue to suggest that this is a rich area for further research.

The eighth hypothesis stated that the greater the amount of anticipation socialization, the greater the regenerative power. All of the nine relationships in this analysis were in the predicted direction, yet only two achieved statistical significance at the .05 level or beyond (Table 11). Families who tried to learn quickly about the patients' dialysis were also those families who had much prior experience with stress (N=207,  $\underline{r}=.12$ ,  $\underline{p}=.04$ ), and families that adjusted quickly to the stress of dialysis were also those familiar with chronic illness

TABLE 11  
 Pearson Product Moment Correlations Between  
 Anticipation Socialization and Regenerative Power

	REGPOW1	REGPOW2	REGPOW3
ANTSOC1	-.0352 (207) p=.307	-.0840 (207) p=.115	-.0130 (207) p=.426
ANTSOC2	.1244 (207) p=.037	-.0338 (207) p=.315	.0955 (207) p=.085
ANTSOC3	.0247 (207) p=.362	-.1835 (207) p=.004	.0068 (207) p=.462

(N=207,  $\underline{r}=.18$ ,  $\underline{p}< .01$ ). A weaker relationship was found between families who usually handle stress well and greater amounts of time anticipating the initiation of dialysis (N=207,  $\underline{r}=.10$ ,  $\underline{p}=.09$ ). It does appear that families having recent and past experience with stress and chronic illness are able to reorganize more quickly and at higher levels than families who are less used to dealing with stress. However, these relationships were too few and too weak to formally support hypothesis eight.

As the dialysis literature does not address the variable anticipation socialization, and as the present findings suggest some interesting relationships between it and measures of regenerative power, future concentration on these relationships may provide additional insights into the timing and extent of information given to patients and families about to initiate dialysis treatment.

The ninth hypothesis stated that the greater the amount of extended familism, the greater the family regenerative power for long periods of disruption. Dialysis, by its nature, is invariably considered a long-term disruption and patients and their families are aware of this fact at the outset.

The more that relatives have been a support for the family, the higher the family interest in learning about dialysis (N=207,  $\underline{r}=.17$ ,  $\underline{p}< .01$ ), the greater facility

families display in being able to handle stress ( $N=207$ ,  $r=.07$ ,  $p=.15$ ) and the faster the family adjusts to the stress ( $N=207$ ,  $r=.06$ ,  $p=.19$ ) (Table 12). Although these latter two relationships were weak, these three relationships do suggest a positive link between extended family cohesion and regenerative power.

The lower the interest in spending more time with relatives the faster the family adjustment to dialysis stress ( $N=207$ ,  $r=.15$ ,  $p=.01$ ). This finding suggests that 1) nuclear families that close ranks and concentrate their energies on helping themselves recover more quickly, or 2) that families who do not wish for more contact with extended family already perceive their support and this contributes to overall speed of adjustment. It is difficult to tell from the data which of these interpretations is correct but anecdotal data appear to support the first alternative; many patients discussed the need to marshal their own family's resources in coping with the stress of dialysis and while extended family support was appreciated, silent moral support was more effective than face-to-face dealings with relatives.

This impression was further supported by the finding that the lower the interest in spending time with extended family, the greater the family interest in learning about the patients' dialysis soon after it began ( $N=207$ ,  $r=-.14$ ,

TABLE 12

Pearson Product Moment Correlations Between  
Extended Familism and Regenerative Power Over Time

	EXFAM1	EXFAM2	TIMEDIAL
REGPOW1	.1694 (207) p=.007	.1519 (207) p=.014	.0266 (207) p=.352
REGPOW2	.0608 (207) p=.192	-.1381 (207) p=.024	-.0198 (207) p=.388
REGPOW3	.0719 (207) p=.152	.0037 (207) p=.479	.1386 (207) p=.023

$p=.02$ ). This relationship supports hypothesis nine: the greater the amount of extended familism, the less the regenerative power in the early stages of the stressful situation. The relationship between the amount of time on dialysis and family ability to handle stress was positive ( $N=207$ ,  $r=.14$ ,  $p=.02$ ) indicating that the longer the family lives with the rigors of dialysis the stronger they become.

The dialysis literature does not address the relationship between extended familism and regenerative power. Most of the research in this area concentrates on the relationships within the nuclear family. Further investigations into the strength of extended family bonds and desire for increased interaction with relatives, may, on the basis of the present findings, provide some useful data about the inclusion of extended family in dialysis planning treatment, and maintenance.

Hypothesis ten stated that the greater the marital adjustment, the greater the regenerative power. The results of the analyses between measures of these two variables were all in the predicted direction. Two were significant at the .05 level or beyond and none was above .10 indicating moderate to strong relationships between these variables in general (Table 13).

Patients agreeing with the item asking if they would



TABLE 13  
Pearson Product Moment Correlations Between  
Marital Adjustment and Regenerative Power

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	HAPMAR1	HAPMAR2
REGPOW1	-.1296 (163) p=.050	.1326 (164) p=.045
REGPOW2	-.1072 (163) p=.087	.1075 (164) p=.085
REGPOW3	-.0992 (163) p=.104	.1016 (164) p=.098

---

marry a different person if they had it to do over again also tended to report low family interest in their treatment (N=163,  $r=-.13$ ,  $p=.05$ ), slow speed of adjustment to new problems (N=163,  $r=-.11$ ,  $p=.09$ ) and poor ability of the family to handle stress (N=163,  $r=-.10$ ,  $p=.10$ ).

Patients who considered their marriages to be relatively happy, said their families took an interest in their dialysis treatment (N=164,  $r=.13$ ,  $p=.05$ ), adjusted quickly to new problems (N=164,  $r=.11$ ,  $p=.09$ ) and usually handled stress well (N=164,  $r=.10$ ,  $p=.10$ ). Thus, hypothesis ten was supported.

These findings concur with those of Brackney (1979) suggesting that non-conflicted marital relationships are associated with positive medical adaptation. Other research (Matthews, 1980) indicated a strengthening of the marital bond resulting from the necessity of facing the illness together. Comments made by many of the respondents in the present study were evidence of a similar experience for these patients. Further research is thus indicated to investigate the possible reciprocal interactions of marital adjustment and regenerative power.

Hypothesis eleven stated that the greater the amount of social activity of the spouse, the greater the regenerative power. This relationship was measured by analyzing the responses to a question about the spouses' friendship

pattern. The correlations between this item and the items relating to regenerative power were all extremely low and inverse (Table 14). This may have been due to any number of factors: 1) the item was not a good measure of spousal social activity; 2) the predicted relationship does not apply to dialysis patients and their families because of their unique patterns of interaction around the dialysis stressor; or, 3) no causal relationship exists.

The dialysis literature contained no references on the amount of spouses' social activity or its relationship with regenerative power. The family stress literature suggested that participation in external roles and activities was positively related to regenerative power (Hill, 1949; Burr, 1973). This area of inquiry has only begun. Further investigations could be made to determine if indeed this possible relationship has a bearing on patients' ability to cope with the stress of dialysis.

Hypothesis twelve stated that the greater the regenerative power, the higher the level of reorganization. This hypothesis was significantly borne out by only one of the three analyses (Table 15). Agreement with the item relating to rapid adjustment to new problems was highly associated with agreement on the item stating that, in general, things are going well for the family ( $N=207$ ,  $r=.17$ ,  $p<.01$ ). There was also a weak positive association between family interest

TABLE 14  
Pearson Product Moment Correlations Between  
Spouse Social Activity and Regenerative Power

	REGPOW1	REGPOW2	REGPOW3
SPOUSOUT	-.0287 (12) p=.378	-.0742 (120) p=.210	-.0008 (120) p=.496

TABLE 15

Pearson Product Moment Correlations Between  
Regenerative Power and Level of Reorganization

---

	REGPOW1	REGPOW2	REGPOW3
LEVORG	.0755 (207) p=.140	.1686 (207) p=.008	-.0004 (207) p=.498

---

in dialysis and positive level of family reorganization (N=207,  $r=.08$ ,  $p=.14$ ). The relationship between perceived family strength and current family functioning was extremely weak ( $r= .0004$ ,  $p=.498$ ). This may be in part attributable to the nonspecific nature of these two items and to the largely positive response to each. The weak relationships may also be due to the warning given by Burr (1973): The term level of reorganization seems acceptable if it does not eliminate the connotation that when a family social system is highly organized, it is in many ways flexible, changing and inefficient. In summary, this was not strong enough evidence to support hypothesis twelve.

These findings are in general support of those of Short and Alexander (1969) and Sand, et al. (1969). Families reacting well to the stress of dialysis through acceptance, cooperation, organization and stability appear to make more favorable progress.

#### Summary

Table 16 provides a summary of the degree of support found for each of the hypotheses. The data were recorded according to the patients' response at the time each item was asked. Three questions were asked near the end of the interviews which served to shed additional light on the data. These questions related to:

TABLE 16

## Degree of Support for Hypotheses

HYPOTHESIS	NONE	LOW	MODERATE	HIGH
1				X
2				X
3			X	
4				X
5	X			
6	X			
7			X	
8		X		
9			X	
10				X
11	X			
12			X	

- 1) What advice the patient would give to physicians to better treat patients and their families;
- 2) Advice patients would give nurses in the interest of better treatment for themselves and their families; and
- 3) What advice the patient would give to a friend who had just learned that he/she needed dialysis treatment.

These questions were only asked of the energetic, verbal and apparently willing patients (N=132) but the responses served to indicate that patients responded in many socially acceptable ways in the structured interview and revealed more about their true thoughts in the last few moments of the interview, after more rapport had been established.

The results of these questions have not been tabulated and analyzed in the current investigation. They do appear however to more fully explain the ways in which:

- 1) Relationships with the staff are perceived and dealt with;
- 2) The family has responded to the demands of dialysis;
- 3) Medical problems are perceived as surmountable or intolerable; and,
- 4) Dialysis has affected the quality of life for themselves and their family.

The integration of this data into the structured



interview results might have served to increase the degree of support for hypotheses 4, 5, 6, and 12.

#### Results Indirectly Pertaining to Hypotheses

A number of significant correlations were found among variables not directly related to the hypotheses but which serve to shed additional light on the present findings. They will be briefly described here and may be found in Table 17.

The greater the amount of time on dialysis, the less likely the family is to be experiencing crisis ( $r=.33$ ,  $p<.001$ ). A family with a member who began dialysis within the past year would be expected to be more confused, disorganized and strained as they were being called upon to ascertain the nature of the disruption as well as to begin coping with it. The less time on dialysis, the more likely the patient report that their family life had changed for the worse since their dialysis began. Many patients commented during the interview that the crisis had brought their family closer together but the data indicate that this did not have a significant impact on either the amount of disorganization or the amount of additional stress the family could tolerate.

Black patients were particularly apt to suffer a decline in positional influence and were therefore more vulnerable. They worked significantly less, ( $r=.17$ ,

TABLE 17  
Pearson Product Moment Correlations  
Between Selected Variables

VARIABLES	CORRELATION	PROBABILITY
TIMEDIAL, AMTCRIS1	-.33	<.001
RACE, PTWORK	-.17	.03
RACE, EDUC	.27	<.01
RACE, CHILD	.22	<.01
EXBLAME, TIMEDIAL	-.07	<.01
HAPMAR2, LONGMAR	.34	<.001
HAPMAR2, RACE	.05	.07
HAPMAR2, TIMEDIAL	.03	.09
HAPMAR2, AGE	.24	.04

$p=.03$ ), had less education, ( $r=.24$ ,  $p<.01$ ), and had more children to care for ( $r=.22$ ,  $p<.01$ ). More black patients than white were employed in occupations requiring great physical exertion which they could not maintain following the initiation of dialysis.

Externalization of blame was significantly related to length of time on dialysis ( $r=.06$ ,  $p<.01$ ). The greater the time on dialysis, the more likely the patient would register on the extremes of the internalizing-externalizing continuum. Perhaps the long-term patients have stronger convictions about where the blame belongs. Patients on dialysis for a short length of time may be more confused and less sure of the source of the blame. This finding may help explain the conflicting results found in recent locus of control investigations (Calhoun, Cheney and Dawes, 1974; Rotter, 1966).

There were several interesting findings related to marital satisfaction. The longer patients were married, the greater the satisfaction ( $r=.34$ ,  $p<.001$ ), white patients were more happily married than blacks ( $r=.05$ ,  $p=.07$ ), the less time patients had been on dialysis the greater the marital satisfaction ( $r=.03$ ,  $p=.09$ ), and the older the patient the greater the reported marital satisfaction ( $r=.24$ ,  $p=.04$ ).

## Chapter V

### SUMMARY AND DISCUSSION

#### Summary

The primary purpose of this investigation was to develop and pre-test an instrument designed to examine relationships among family stress variables which were identified by Burr (1973) in his synthesis of over 50 years of family stress research. Twelve propositions from Burr's model were selected and tested in this study.

Of particular interest in this investigation was the degree to which Burr's model explained the stressful experiences of end-stage renal disease patients and their families. The two dependent variables in this model were family vulnerability and family regenerative power, denoting variations in the ability of a family to prevent stress from seriously disrupting the family and variation in the ability of a family to recover from a crisis. The independent variables in this investigation were selected on the basis of their relative absence in the dialysis literature and their ease of measurement through contact with dialysis patients themselves. These variables, selected from Burr's model were: amount of crisis, amount of time the crisis was anticipated, positional influence, personal influence, externalization of

blame, anticipation socialization, extended familism, duration of disruption, amount of spouse's social activity and level of reorganization.

Other variables such as gender, race and marital status were included to aid in the interpretation of the results. Little prior research had been conducted in the validation of Burr's heuristic model and none of the literature on stress and hemodialysis was found to be theoretically grounded. It was determined that dialysis related stress was an appropriate area in which to investigate the relationships outlined by Burr.

The first step in the investigation was the development of an instrument which would represent the constructs in Burr's model. This was done by reviewing the past interpretations provided by family theoreticians such as Hill and Hansen. Very little information about the meaning of the variables was available, however, and most of the items on the schedule were original attempts of operationalizing the variables. The instrument was then reviewed by a panel of experts and was revised in ways which served to maximize the construct and face validity for each item. The schedule was then administered to a group of dialysis patients who provided information needed to further refine the instrument. A 41-item closed-ended interview schedule was thus developed.

The interview format was chosen to enhance the reliability of the information obtained as well as to ensure the maximum participation of patients, some of whom were too physically or educationally handicapped to manage a lengthy written questionnaire. The schedule included items designed to elicit demographic statistics as well as questions pertaining to the variables in the investigation. The format for the latter items was a strongly agree to strongly disagree continuum.

A measure of internal consistency, the alpha coefficient, was performed on the instrument. The alpha coefficient indicated the presence of several subscales within the instrument. It could be argued that validity in this instance was equally if not more important than reliability since the purpose of this study was to demonstrate the existence and direction of relationships among stress variables rather than to produce a unidimensional scale.

Dialysis patients in six Western Virginia in-center facilities were asked to participate in the study. Of 215 potential respondents, 207 comprised the final group, representing virtually all of the dialysis patients dialyzing in-center in this portion of the state. Patients were informed of the purpose of the interview and later interviewed using the schedule and three open-ended

questions.

The mean age was 49.8 years with a range from 12 to 85. Ninety-three were white and 113 were black. Eighty percent had been or were currently married, and 80 percent were currently living with one or more family members. The average number of years of education was 8.9 and 6.8 percent of the patients were working either full or part-time. The average income was \$9,570 with 80 percent earning \$12,000 or less annually. Length of time on dialysis ranged from less than one month to 14 years with the average being 32.6 months. Underlying conditions were varied; high blood pressure (48%), glomerulonephritis (14%), diabetes (12%) and polycystic disease (7%) combined accounted 73% of the reasons patients were started on dialysis.

Patients, as a group, exhibited some interesting characteristics which confirmed and occasionally explained previous research on the personality characteristics of dialysis patients. Patients frequently used denial. They also seemed depressed and angry yet accommodating. Most patients portrayed themselves as independent, strong and self-reliant. They were divided on the dimension of marital happiness and the degree to which they externalized blame for their situations. Patients were, for the most part, very willing to be interviewed

and seemed to enjoy the opportunity to converse in detail and in confidence about their family problems and strengths.

Pearson correlations were calculated for each of the relationships within the hypotheses. The criterion for formal acceptance or rejection of the hypotheses was an alpha level of .05 or smaller for half or more of the relationships within each hypothesis. The twelve hypotheses received varying levels of support as illustrated in Table 16.

Four hypotheses received strong support (1, 2, 4, 10). The results of the testing of the first hypothesis indicated that the greater the amount of crisis, the greater the family vulnerability and, as Hill (1964) suggested, the more vulnerable the family is before the event, the more the dialysis is perceived as a crisis. Dialysis patients who had experienced a number of disruptions within the past year and who agreed that the dialysis was a stressor for their family were more disorganized and less capable of handling additional stress. The longer patients are on dialysis, the less dialysis is perceived as a stressor for the family.

The second hypothesis also received strong support. The greater the positional influence, the less vulnerable to stress the family appeared to be. Patients whose families had higher incomes, who were working and/or who



had working spouses were more likely to be both organized and capable of handling additional stress. Even if the patient was not working, his former occupational status correlated highly with ability to handle additional stress and regularity of home schedules.

Another hypothesis which received strong support was hypothesis four which was that the greater the personal influence in a social system, the greater the vulnerability to stress. Moderate to strong relationships were found between these variables yet the results were not always in the predicted direction. Disorganized patients reported difficult staff-patient relationships, family resentment toward them because of the dialysis, and families who were reluctant to go along with their wishes. Families that could handle no additional stress were also likely to have poor relationships with medical staff, to resent patients because of the treatments, and to avoid going along with patient requests. Disorganized families were more likely to have difficult relationships with both the medical staff and the patient-family member. It was suggested that a problem in interpreting the meaning of "personal influence", or an undeveloped formulation of the relationship between vulnerability and personal influence may have affected the direction of the findings which were inverse rather than positive as hypothesized.

The fourth hypothesis which received strong support stated that the greater the marital adjustment, the greater the regenerative power. Patients who reported their marriages were relatively happy, also reported that their families took an interest in their treatment, adjusted quickly to problems, and handled stress well. Marital happiness appeared to be more predictive of positive overall adjustment than any other variable in the schedule.

The four hypotheses which received moderate support were numbers 3, 7, 9 and 12. For hypothesis three generally, the greater the positional influence, the lower the family regenerative power. Higher income was associated with greater speed of adjustment. Patients and spouses who worked either part-time or full-time reported more family interest in the treatment. And the lower the patients' occupational status, the less interest the family took in the treatment and the slower they adjusted to new problems. For the most part the greater the amount of anticipation socialization, the less vulnerability to stress. The results of hypothesis seven indicated that there were indeed strong relationships yet not always in the predicted direction. The more the past stress in the family, the greater the current disorganization and current inability to handle additional stress. Yet the greater the past exposure to stress, the greater advance notice of the

need for dialysis and the more prior exposure to chronic illness, the greater the family organization in the face of the current dialysis-related stress.

The results of hypothesis nine suggested a positive relationship between extended familism and regenerative power but only for short periods of disruption, as predicted. The longer the family has lived with the rigors of dialysis, the stronger they appeared to be.

Finally, hypothesis twelve received moderate support: the greater the regenerative power, the greater the family level of reorganization. This finding was tempered by the notion that while a family may be strong, it may also look weak as a result of being in a state of flux.

Hypotheses 5, 6, 8 and 11 received little or no formal support. No significant relationships were found among the measures of personal influence and regenerative power (Hypothesis 5). Measures of vulnerability to stress did not correlate significantly with externalization of blame although a relationship was found between externalization of blame and time on dialysis (Hypothesis 6). Some measures of anticipation socialization and regenerative power achieved statistical significance. Families who had previous experience with stress and chronic illness showed higher levels of interest in learning about dialysis and were able to adjust rapidly. Trends in the data suggested

that the more prior notice the family had about the initiation of dialysis and the greater the amount of past experience with stress, the greater the speed of adjustment and eventual level of reorganization (Hypothesis 8). Hypothesis 11 had only one measure of the amount of spouse's social activity and no relationships were found near the alpha level specified for significance. These results illustrate the need to have larger and more representative sets of measurements for the variables.

#### Conclusions Regarding Research Methodology

The most immediate application of this study is in the measurement of patient responses regarding their dialysis related stress by means of a personal interview schedule using a closed-ended item format. Both the schedule itself, as well as the manner of administration proved successful - if success is indicated by the number of completed schedules and reliability of the responses obtained. This result implies that with some modifications, similar methodology may be used in other studies of stress and chronic illness.

Since there were some questions raised about the reliability of response solicitation using this instrument, the schedule should certainly be extended to include additional items for each variable. The schedule could be modified to reduce the number of variables to be investigated in any one administration. This would reduce the

number of analyses which could be performed at any one time, yet it would result in higher estimates of internal consistency in the schedule.

The manner in which the schedule was administered was the investigation's greatest safeguard of reliability. When the questions which were each carefully worded as unambiguously as possible, were not clearly understood by the respondent, the interviewer was able, within limits, to clarify the meaning of the item.

The methodology used in this investigation could also be deemed successful if the validity of the schedule and its responses are indicators. The panel of experts who assessed the validity of the items indicated modest support for the content validity. The representativeness of the items for each construct involved was somewhat limited by the need to keep the schedule as short as possible. The panel gave the schedule high marks for construct validity. Each item was judged to be a reasonable measure of the theoretical construct implied. Finally, the responses and analyses suggested the presence of concurrent validity, indicated by the high level of agreement with other measures cited in the dialysis literature.

Personal interviewing is necessary in this type of data collection. Patients may be too ill, or unable to see clearly or too poorly educated to read a self-administered

instrument. In addition, they may not be motivated to fill out an impersonal form or uncooperative due to multiple past intrusions on their personal lives.

In the interview, patients were able to become comfortable with the nature and the depth of the questions and, with few exceptions, were free and open in their responses to and elaboration of the content items. While there are obvious limitations in the amount of data that can be gathered in this fashion, the personal interviewing procedure utilizing an investigator who is not a member of the routine medical system, was a potent method of soliciting honest, unguarded and in-depth data.

The interview schedule detected differences in opinions expressed by the patients. For most items, there appeared to be wide ranges of opinion scores. In-depth structured interviews should thus be used in future research with this population.

#### Stress Theory Conclusions

This investigation has attempted to operationalize and demonstrate empirically some relationships among variables that have valuable meaning and ties to existing theory. It can be concluded that this was successfully done, depending upon the degree to which problems in working with the hypotheses as elements of deductive theory were overcome.

The first of these problems is the circularity that can result when descriptive concepts are related to each other as in the concepts of vulnerability and regenerative power. Another one of the difficulties lies in the fact that Burr's model focused more on the meaning of concepts than to ease of operationalizing them.

The validity checks on the instrument construction indicated one advantage in using operational definitions in that there could be high consensus about what the terms denote. This strategy of defining and refining the variables also evidenced a major disadvantage, however. That is, the meaning of each concept became very limited. Burr (1973) warned that this is a most serious limitation because if investigators are working with concepts which have very limited meaning to them, this might justify wondering about the clarity of the concepts in the investigators' minds.

The concepts in Burr's model had not been previously operationalized for use in empirical investigations. A decision was made to attempt to operationalize as many as possible for inclusion in this preliminary test of selected propositions in the model. Two separate indicators imply that the operationalizations and analyses in this investigation have contributed to the groundwork begun by Burr and others to heueristically further the development of family

stress theory. The first indicator is the consensus achieved by a panel of expert judges in the validation of the operationalized constructs used in this investigation. The second indicator is the unexpectedly high degree of statistically significant relationships found in the testing of the hypothesized relationships.

Inferences such as these must be made with caution, however. The fact that some relationships among the variables were found to exist in this investigation does not mean that they would be found to exist in other empirical investigations. Replications of this design on another patient population, or analysis of the population in this study using a different instrument might produce different results. In addition, the fact that little or no support was found for some of the hypothesized relationships is not conclusive evidence that such relationships do not exist.

In the present state of the art and science of family studies only some of the circumstances that influence family stress have been specified to the degree that a causal relationship is thought to exist. This research has hopefully furthered the clarity of the conceptual thinking about family stress variables and indicated processes by which propositions about family stress may be empirically examined.



### Practice Conclusions

The results and discussion of the empirical findings in this investigation have led to several implications and suggestions for health practitioners in the dialysis specialty area. A large proportion of these are aimed at the renal social worker who according to Tramo (1981) is one of the most significant members of the dialysis center staff.

While working with patients and their families to resolve problems conjointly may be beneficial, there are a number of factors which make this situation difficult:

- 1) Many patients, both male and female, relayed that keeping home and center separate was extremely important. These patients viewed their time at the center almost as if it were a full-time job, a place to go regularly and "earn" enough "health" to enjoy their "non-work" hours;
- 2) The fact that many patients had maintained a lifestyle of independence and self-reliance may preclude their wish to change that style and become the seeker rather than the usual provider of emotional support; and 3) The fact that patients for many reasons such as age, fatigue, or lack of previous exposure to counseling as an alternative, are poorly motivated to avail themselves of an outside helper. The implication from these facts is for social workers to present counseling alternatives slowly and

conservatively, two things which are difficult to do when being confronted daily with the patients' medical and personality problems resulting from poor marital and family relationships.

Another recommendation can be made on the basis of the finding that patients do care about and often help each other. Arranging the beds or chairs in the dialysis unit in a manner which would enable patients to talk to each other more directly than is possible when machinery is in the way would be helpful.

One of the most important implications arising from this investigation is the major impact of the amount of income on the vulnerability and regenerative power of the patient and the family. This factor, more than any other was discussed in great detail by the patients who indicated that if they could only feel that they were earning an income or receiving a higher income from government sources, the quality of their lives would be much improved. These findings suggest the need for increased services such as vocational rehabilitation and for increased financial aid from governmental or other sources.

The dialysis staff members themselves may be able to make their jobs somewhat less rigorous. The empirical findings imply several areas in which staff could be more central in raising the level of reorganization of patients

and their families: 1) Initiating more family contact in order to provide education and information might raise family interest level in the patients' care. This would, in turn, result in the patient feeling less isolated and resented by the family; 2) It may be that the more opinionated and headstrong patients live longer because these are personality factors but the possibility must not be overlooked that the patients who have more information about their situations have stronger convictions about where the blame lies when they have medical problems, feel more in control, and live longer as a result. Thus, spending more time with patients and giving them as much information as they request may have beneficial results; and 3) The family might be encouraged to modify its patterns in ways which have been shown to correlate highly with decreased vulnerability and increased regenerative power. These areas include keeping regular schedules for meals and bedtimes, enlisting the aid of extended family in the early period of adjustment to dialysis, maintaining good marital and family relationships by helping the patient maintain a sense of belonging and independence, and established position in the family.

#### Future Research

The present research has indicated the feasibility of testing Burr's model. Future investigations should focus

upon more indepth definitions of the variables and a more thorough understanding of the direction and degree of the relationships between them.

The model should be tested on other populations of chronically ill patients and their families to determine if the proposed relationships hold for a wider group of stressed individuals. In addition, attempts should be made to study the entire family to determine the degree to which the stress factors are perceived or experienced in a similar or dissimilar manner by individual members.

For the dialysis population, this investigation suggests many areas which need further clarification:

- 1) Data regarding family income, work status and vocational rehabilitation and the manner in which these variables are related to regenerative power of patients and families would provide additional information about the reduction of two major stressors - inadequate income and loss of occupational status;

- 2) More information is needed about the personal relationships between patient and the family. What role does the illness play in the family organization? Is the illness more of a stressor or more the result of stress in the family?

- 3) What other variables may be influencing the relationship between anticipation socialization and

vulnerability? Do patients who have time in which to anticipate the rigors of dialysis really adjust better as the present findings indicate?

4) More research needs to be done to assess the relationship between internal versus external locus of control and patient vulnerability to stress. In addition, the impact of a patient's locus of control on staff and family relationship would be a productive avenue of inquiry;

5) The relationship between marital adjustment and regenerative power needs further investigation. The impact of the degree of spouses' activity out of the home could also be further studied to determine if stress may be reduced when spouses spend some social time apart.

#### Summary

The purposes of this investigation were: 1) To operationalize selected propositions from Wesley Burr's synthesis of family stress theory; 2) To construct and test an instrument designed to test some of Burr's propositions; 3) To make inferences about the validity of Burr's synthesis for dialysis patients; and 4) To attempt to give researchers and health care providers an instrument for future research.

The significance of the investigation lies in the four areas outlined in Chapter I and confirmed by the data:

1) The study was able to generate interest in Burr's

heuristic model among members of the medical profession;

2) Several of Burr's propositions were examined and inferences about their conceptual relevance for future research were drawn;

3) New information was added to the current body of knowledge about stress and end-stage renal disease; and

4) Suggestions were made regarding the reduction of stress for dialysis patients, their families and health care providers.

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APPENDIX A

1. Interview number \_\_\_\_\_.
2. Male \_\_\_\_\_ Female \_\_\_\_\_
3. Age \_\_\_\_\_
4. Race: White \_\_\_\_\_ Black \_\_\_\_\_
5. Never Married \_\_\_\_\_ Married \_\_\_\_\_ Separated \_\_\_\_\_  
Divorced \_\_\_\_\_ Remarried \_\_\_\_\_ Widowed \_\_\_\_\_
6. Years Married \_\_\_\_\_
7. Who do you currently live with? \_\_\_\_\_
8. How many children do you have? \_\_\_\_\_
9. How far did you go in school? \_\_\_\_\_
10. Do you have advanced degree or training? \_\_\_\_\_
11. Your current employment status: Not Working \_\_\_\_\_  
Working Part-time \_\_\_\_\_ Full-time \_\_\_\_\_
12. Your occupation \_\_\_\_\_
13. Spouse's employment status: Not Working \_\_\_\_\_  
Working Part-time \_\_\_\_\_ Full-time \_\_\_\_\_
14. Spouse's Occupation \_\_\_\_\_
15. Annual family income in thousands \_\_\_\_\_
16. Number of months on dialysis \_\_\_\_\_
17. Underlying medical condition:  
High Blood Pressure \_\_\_\_\_  
Diabetes \_\_\_\_\_  
Glomerulonephritis \_\_\_\_\_  
Polycystic Disease \_\_\_\_\_  
Lupus Erythematosus \_\_\_\_\_  
Other \_\_\_\_\_

I will now ask you a number of questions about your family. Please indicate whether you strongly agree, agree, disagree, strongly disagree or are undecided about the question. You may elaborate if you wish.

	S	A	D	S	D	U
18. My family has generally had more stress than the average family.						
19. My family tried to learn about my dialysis soon after I began it.						
20. My family tends to get disorganized because of my dialysis.						
21. We had little advance notice that I would need dialysis.						
22. My family could not handle much additional stress just now.						
23. If I had it to do over again, I might marry a different person.						
24. My relationships with the medical staff are sometimes hard.						
25. This is the first long-term illness my family has dealt with.						
26. In general, things are going well for our family these days.						
27. We keep regular schedules for things like meals and bedtimes.						
28. My family sometimes resents me for having to be on dialysis.						
29. Relatives have been a source of emotional support for our family.						
30. Everything considered, my marriage has been relatively happy.						
31. My family usually adjusts quickly to new problems.						
32. My family usually goes along with what I ask.						

- 33. My spouse has one or more close personal friends.
- 34. Our family should spend more time with relatives.
- 35. In the past year our family has faced some big problems.
- 36. Others would say my family usually handles stress well.
- 37. When I have a bad time medically it is usually my fault.
- 38. Our family life has changed some for the worse since my dialysis began.
- 39. What advice would you like to give doctors about better ways to treat you and your family?

	S	A	A	D	S	U

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- 40. What advice would you like to give nurses?

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- 41. What advice would you give to a friend who just learned he or she was going to need dialysis?

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APPENDIX B

Roanoke Valley Artificial Kidney Center  
Bio-Medical Applications of Roanoke, Inc.

Roanoke, Virginia 24018

ADMINISTRATOR

CONSULTING NEPHROLOGISTS

Dear

Mrs. Susan Molumphy has been providing our center with monthly in-service training seminars and periodic consultations in the areas of family stress and intra-office relationships. The result has been increased rapport between our staff and patients and better working relationships in the center itself.

Mrs. Molumphy is conducting her doctoral research in family stress and hemodialysis, including many of our patients in her survey. As a result of her research, we anticipate continued in-service training seminars and an increase in our understanding of the ways stress may be reduced for our patients and their families.

Because her research requires the surveying of more patients than we have available at our center, I would encourage your center to participate in this project which will benefit us all. Mrs. Molumphy administers the short survey personally and only surveys those patients willing to participate.

If you have any questions, please do not hesitate to call.

Sincerely,

January 19, 1981  
Page 2

I will call you this week to hear your response to this request and to make arrangements to come to Danville if it is in the affirmative.

Thank you.

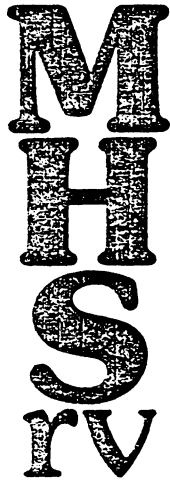
Sincerely,

Susan Molumphy  
Health Systems Consultant

SM/ta

Enclosure

APPENDIX C



January 19, 1981

Danville Urologic Clinic

Danville, Va. 24541

Dear Gentlemen:

I am currently in the process of collecting data for my doctoral research which is on the subject of family stress variables in hemodialysis.

My research has two major thrusts:

- Chairman
- Vice Chairman
- Secretary
- Treasurer
- Executive Director
- Director, CMHC
- Consultation & Education Director
- Community Relations
- Criminal Justice
- Special Projects
- Welfare
- Health Services PCE
- Education
- Clergy Churn
- Secretaries

1. To examine two dependent variables - family vulnerability to stress and family regenerative power - assessing how the following independent variables relate with them in positive or negative linear fashion: time spent with relatives, externalization of blame for the dialysis, marital adjustment, personal influence, amount of spouse's activity out of the home, previous experience with illness and the length of time dialysis was anticipated.

2. To provide data which will then be integrated into future in-service training programs for dialysis center staff in their work with patients and their families.

\_\_\_\_\_ will be writing to you to outline the way in which his center is participating in the research. I have been conducting in-service programs for his staff and have learned much from them also.

Would your social worker \_\_\_\_\_ be willing to work with me on this project by introducing me to the patients before I administer the enclosed survey?

CONSULTATION & EDUCATION - MENTAL HEALTH SERVICES OF THE ROANOKE VALLEY  
 — , Roanoke, Virginia 24016 — Phone

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FAMILY STRESS AND HEMODIALYSIS:  
AN ANALYSIS OF FAMILY STRESS VARIABLES

by

Susan D. Molumphy

(ABSTRACT)

Most prior research on stress and hemodialysis has focused on physical, psychological and staff-patient dimensions. Little research has been conducted on the correlates of stress experienced by dialysis patients in the context of the family. The purposes of this investigation were to operationalize 12 propositions from a model synthesizing 50 years of family stress research and to determine the applicability of the propositions for a population of in-center dialysis patients.

The two dependent variables were family vulnerability to stress and family regenerative power. The independent variables were selected on the basis of the relative absence in the dialysis literature, and the applicability to dialysis patients and their families.

A 41-item closed-ended interview schedule was designed by the investigator, analyzed for validity and reliability by a panel of experts, and pretested on a small group of dialysis patients. Six dialysis centers in Western Virginia participated in the investigation and 207 of a possible 215 patient interviews were completed.

Pearson product-moment correlation coefficients were

calculated for each of the relationships within the hypotheses. Four hypotheses received strong support: the greater the amount of crisis, the greater the vulnerability; the greater the family positional influence, the less the vulnerability; the greater the personal influence, the greater the vulnerability; and, the greater the marital adjustment, the greater the regenerative power. Four hypotheses received moderate support: the greater the positional influence, the lower the family regenerative power; the greater the anticipation socialization, the less the vulnerability; the greater the extended familism, the greater the regenerative power; and, the greater the regenerative power, the greater the family level of reorganization. Several additional correlations were reported which helped explain the findings related to the hypothesis testing. Methodological, theoretical and practical implications were discussed and recommendations for future research were made.