



A study of the initial problems encountered by home dialysis patients related to proximity to the home training center

by Teresa Elizabeth Kelly Snyder

A thesis submitted in partial fulfillment of the requirements for the degree of MASTER OF NURSING
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Abstract:

The purpose of this study was to answer these three questions: 1.) What are the most frequently encountered problems of home dialysis patients who reside at a distance of at least 50 miles from the home training center? 2.) What are some of the resolutions patients have used in coping with distance from the center? 3.) Are there differences in kinds of problems and resolutions between those patients who are proximate to the training center and those patients who reside at a distance from the training center? A conceptual framework based on the concepts of adaptation and coping was utilized. A descriptive/exploratory design was used in order to provide a comprehensive picture of the problems and resolutions faced by home dialysis patients. Relative ideas of distance perception by rural and urban samples was also investigated.

A sample of 15 home dialysis patients was selected from the Missoula area to represent the patient group "distant" (greater than 50 miles) from the home dialysis training center. This sample was directly interviewed by the researcher. Another sample of 18 home dialysis patients residing "proximate" (within 50 miles) to the training center was selected from the Spokane, Washington area. The research instrument was administered by mail to this sample.

The research instrument was a checklist of various problems which could occur while the patient is on home dialysis. Problems were scored on a one to five rating scale—five, being very serious, and one, not serious. A separate form requesting demographic data regarding variations in dialysis procedures was also utilized. Data was analyzed in terms of group and individual scoring of problems. Mean analysis of scores was also done. A profile of common problems was developed.

The study indicated that there were problems common to all home dialysis patients, but that differences did exist between the urban and rural populations in terms of distance perception and resolution of dialysis problems. The distant (rural) sample utilized more group support mechanisms than the proximate (urban) group, and displayed more independence in home care. Indications for improvement of care of the home dialysis patient were evident, particularly in terms of patient support systems.

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A STUDY OF THE INITIAL PROBLEMS ENCOUNTERED BY HOME
DIALYSIS PATIENTS RELATED TO PROXIMITY
TO THE HOME TRAINING CENTER

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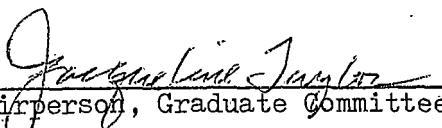
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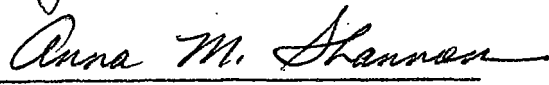
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Approved:


Chairperson, Graduate Committee


Head, Major Department


Graduate Dean

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iii
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TABLE OF CONTENTS

	Page
VITA	ii
ACKNOWLEDGEMENTS	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	viii
LIST OF FIGURES	ix
ABSTRACT	x
Chapter	
1. INTRODUCTION: A BACKGROUND AND CONCEPTUAL FRAMEWORK FOR STUDYING THE PROBLEMS OF HOME HEMODIALYSIS PATIENTS	1
INTRODUCTION	1
REVIEW OF LITERATURE	3
CURRENT MONTANA DIALYSIS INFORMATION	12
CONCEPTUAL FRAMEWORK AND RATIONALE FOR THE STUDY	16
2. METHODOLOGY	27
STATEMENT OF PURPOSE	27
RATIONALE FOR THE STUDY	27
RESEARCH DESIGN	28
DEFINITION OF TERMS	29
SAMPLE AND SETTING	30
DATA COLLECTION METHODS	31

Chapter	Page
DATA ANALYSIS	34
3. DISTANT HOME HEMODIALYSIS PATIENTS:	
DESCRIPTION AND FINDINGS	35
DISTANT HOME HEMODIALYSIS PATIENTS:	
DESCRIPTION	35
SUMMARY	47
FINDINGS: RESPONSES TO IDENTIFIED STRESSORS . . .	48
IDENTIFIED STRESSORS	49
MEDICAL PROBLEMS	50
Needle Insertion	53
Headaches, Cramping, Nausea and Vomiting	
During the Run	54
High Blood Pressure	56
Other Medical Problems	57
Air Emboli	59
Summary	60
MECHANICAL PROBLEMS	61
Machine Malfunctions	61
Artificial Kidney Malfunctions	64
Faulty Ancillary Equipment	66
Equipment Delivery Problems	67
Power Failure	68
Summary	70

Chapter	Page
PSYCHO-SOCIAL PROBLEMS (OTHER PROBLEMS)	71
Dependence on Partner	71
Financial Problems	75
Mobility, Vacation and Recreation	77
Fear/Anxiety	79
Depression	82
Disruption of the Family During Training	83
Sleep Disturbances	85
Sexual Difficulties	86
Diet	87
Family Problems	89
Restriction of Social Activities	90
Relationships with Friends	91
Additional Identified Stressors	92
Identified Resolutions	93
Summary	95
4. DESCRIPTION OF THE PROXIMATE SAMPLE AND FINDINGS . .	97
Introduction	97
Population Profile	97
Summary	101
FINDINGS RELATED TO STRESSORS	102
PSYCHO-SOCIAL PROBLEMS	106

Chapter	Page
MEDICAL PROBLEMS	108
MECHANICAL PROBLEMS	110
ADDITIONAL PROBLEMS	112
SUMMARY	112
5. LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS	114
INTRODUCTION	114
LIMITATIONS	114
Limitations	114
Sample Size	115
CONCLUSIONS AND RECOMMENDATIONS	116
Conclusions	116
Nursing Implications	121
Recommendations	122
LIST OF REFERENCES	126
APPENDICES	130

LIST OF TABLES

Table	Page
1. Stress of Home Dialysis (Wick and Rye, 1976)	8
2. End Stage Renal Disease Utilization Statistics for Montana Facilities, 1977 (HSA Bulletin, 1978) . .	14
3. Profile of Distant Patient Population	36
4. Comparison of Actual Distance to HDTC, and Perception of Distance by Respondent	40
5. Number of Responses Per Rating Designation - Medical Problems	52
6. Number of Responses Per Rating Designation - Mechanical Problems	62
7. Number of Responses Per Rating Designation - Psycho-Social Problems	72
8. Profile of Proximate Patient Population	98
9. Comparison of Composite Scores and Mean Scores Per Sample, Listed in Descending Order Per Category	105

LIST OF FIGURES

Figure	Page
1. Identified Stressor Profile in Descending Order of Composite Scores (Range = 0-75), Distant Sample	51
2. Identified Stressor Profile in Descending Order of Composite Scores (Range = 0-30), Proximate Sample	104

ABSTRACT

The purpose of this study was to answer these three questions: 1.) What are the most frequently encountered problems of home dialysis patients who reside at a distance of at least 50 miles from the home training center? 2.) What are some of the resolutions patients have used in coping with distance from the center? 3.) Are there differences in kinds of problems and resolutions between those patients who are proximate to the training center and those patients who reside at a distance from the training center?

A conceptual framework based on the concepts of adaptation and coping was utilized. A descriptive/exploratory design was used in order to provide a comprehensive picture of the problems and resolutions faced by home dialysis patients. Relative ideas of distance perception by rural and urban samples was also investigated.

A sample of 15 home dialysis patients was selected from the Missoula area to represent the patient group "distant" (greater than 50 miles) from the home dialysis training center. This sample was directly interviewed by the researcher. Another sample of 18 home dialysis patients residing "proximate" (within 50 miles) to the training center was selected from the Spokane, Washington area. The research instrument was administered by mail to this sample.

The research instrument was a checklist of various problems which could occur while the patient is on home dialysis. Problems were scored on a one to five rating scale--five being very serious, and one, not serious. A separate form requesting demographic data regarding variations in dialysis procedures was also utilized. Data was analyzed in terms of group and individual scoring of problems. Mean analysis of scores was also done. A profile of common problems was developed.

The study indicated that there were problems common to all home dialysis patients, but that differences did exist between the urban and rural populations in terms of distance perception and resolution of dialysis problems. The distant (rural) sample utilized more group support mechanisms than the proximate (urban) group, and displayed more independence in home care. Indications for improvement of care of the home dialysis patient were evident, particularly in terms of patient support systems.

CHAPTER 1

INTRODUCTION: A BACKGROUND AND CONCEPTUAL FRAMEWORK FOR STUDYING THE PROBLEMS OF HOME HEMODIALYSIS PATIENTS

INTRODUCTION

A major role of professional nurses consists of assisting persons who have become afflicted with a chronic illness to maximize healthy adaptation to their disability. In order to provide appropriate nursing interventions, it is imperative that nurses and other health care personnel understand both the physiological and social-psychological processes related to the adaptation that the patient experiences; the "verstehen" must occur not only in terms of theoretical knowledge, but also in terms of what the experience means to that individual who suddenly (or slowly) discovers that his life style has been altered. One group of patients who experience dramatically altered life styles are those persons who are stricken with end stage renal disease. Unless they are among the "fortunate" ones who may benefit from a kidney transplant, life becomes dependent on the use of an "artificial" kidney, i.e., a large machine external to the patient's body. How do individuals and families cope with such a major life stress, and how can nurses provide the most appropriate interventions?

The author first became interested in exploring the answers to the above questions while working as a member of an in-center dialysis team during duty as a U. S. Army nurse. It was evident that most of the dialysis patients were functioning in an extremely altered

environment, and manifesting many signs of anxiety and denial related to their illness. Many seemed to adapt by taking a totally passive role related to their disease, and seemed disinterested in active participation in their care.

When the author moved to Montana and sought information about in-center dialysis in the Missoula area, she was referred to the large population of home dialysis patients residing in the area. The in-center unit functions only as a back-up unit for emergency dialysis situations, and has no routine dialysis patients. This type of situation was quite unusual in terms of the author's previous experiences, and incited a great interest in the adaptation of home dialysis patients as contrasted with in-center patients. Questions related to their coping strategies, as compared to the coping strategies of persons who retained dependence on a center evolved. The focus of the present study subsequently became one of learning more about how patients who live long distances from a dialysis center preceive the stresses, and how their coping strategies differ from those who live in close proximity to a center. The purpose of the study was to learn more about the problems associated with coping with one form of chronic illness (namely renal disease) and to derive implications for improving the health care they are provided. Particular attention was given to the role of professional nurses in rural areas where in-center programs are not available for either training or back-up. Identification of possible methods of improving the support and care of the home patient who

resides great distances from his training center became a secondary purpose.

REVIEW OF THE LITERATURE

In recent years, the subject of hemodialysis has become a topic of significant and varied interest. Many studies have been done regarding hemodialysis, and a great deal of recent emphasis has been placed upon home dialysis and specific problems associated with this method of dialysis treatment. A review of the literature also reveals many studies conducted in the area of specific dialysis problems such as stress, finance, psycho-social impact, home dialysis versus center dialysis, and spouse/family interaction. A basic description of dialysis, however, precedes the review of the studies in this narrative.

Dialysis is a physico-chemical process in which a chemical in one solution may pass into another solution when a semi-permeable membrane is in existence between them. It is based upon the principles of simple diffusion and osmosis, that is, that a substance will pass from an area of greater concentration of that substance to an area of lesser concentration of the substance through a membrane permeable to the substance (Cameron et. al., 1976). The usual function of the normal kidney is the filtering of the waste products of cell metabolism from the blood, out of the body. However, when the kidney is unable to function in this normal capacity, these waste products will continue to accumulate until toxic levels are reached in the blood and the body,

and eventually death will ensue due to the inability of the body to rid itself of these poisonous products. Hemodialysis, through the processes of diffusion and osmosis across a semi-permeable membrane, is the continuous artificial process by which a small amount of blood (100 to 150 milliliters at a time) is pumped through an artificial dialyzer and returned to the patient free of harmful toxic waste products.

End stage renal disease is usually an irreversible condition. Unless successful kidney transplantation is effected, renal dialysis as a medical regimen must become a major part of living for the individual with this disease process. The renal dialysis unit, or "in-center", hospital dialysis unit, normally cares for the patient population with end stage renal disease who are being treated with maintenance hemodialysis (dialysis occurring two or three times a week for five to eight hours each treatment).

It has now been fifteen years since the first patients with end stage renal disease were selected for maintenance hemodialysis. In the United States alone, over 10,000 patients are currently being dialyzed, and with costs being somewhat less demanding due to state and federal assistance programs, hemodialysis is available to almost every person who requires it, providing he has access to a dialysis treatment facility. For those patients who lack proximity to dialysis centers, and for those patients who wish to be more directly responsible for their own care, home hemodialysis may be a viable alternative.

Home dialysis was initially developed in 1963-1964 by a number of physicians (Scribner in Seattle, Merrill in Boston, and Shaldon in London), who envisioned substantial savings in cost, personnel and equipment to both the patient and the operating unit, if patients could be trained to dialyze at home. The home setting was considered to be more desirable for several reasons. Kolodner, et.al., (1976) consider the home setting more acceptable due to: 1.) Extremely high cost of hospital-based dialysis born by the patient and institution; 2.) Limitation of appropriate space in hospital facilities; 3.) Limitation of treatment capacity in hospital units; 4.) Need for planning a specific dialysis schedule to meet the patient's requirements; 5.) Lack of opportunities for proper rehabilitation of the patient, and for the training of relatives in care and treatment techniques. Home hemodialysis, according to Chojnacki (1975), is then based on three general principles: 1.) Chronic illness is better treated at home than in the hospital; 2.) The more responsible the patient is for his own care, the better off he will be; 3.) The more informed the patient is about details and complications, the better he is able to take care of himself.

Home dialysis is thought to be superior to center dialysis for medical as well as psychological reasons. In reference to the medical aspect, the patient can receive a longer total time on dialysis, due to the increased flexibility of dialysis time at home. In reference to the psychological benefits, home dialysis, as opposed to center

dialysis, appears to induce independence and self-confidence in the patient who is expected to take responsibility for his own care (Malmquist and Hagberg, 1974).

Criteria for acceptance of patients into a home training program include availability of an assistant, suitable physical facilities in the home, few external medical problems other than renal failure, intellectual capacity and reasonable emotional stability existing within the patient and between the patient and his dialyzing partner (Chojnacki, 1975; Veverbrants, 1972). Successful home dialysis is most prominently contingent upon the continued and effective participation and involvement of the patient and the dialysis partner (Snow, 1976). According to Kolodner (1975), the home process can not only reduce the personal freedom of the partner, but can also precipitate the induction of an overwhelming apprehension in relation to the technical aspects of treatment, and the assumption of life-and-death control over the patient by the partner. Home care effectiveness will definitely indicate a deficit however, if either the patient or his family undertake these responsibilities of home care and treatment without the constant support of the inpatient setting.

For families who are successful in sustaining home dialysis, continues Kolodner (1976), the ability of the family to maintain ties as well as the medical regimen of hemodialysis, are strengthened. The increased facility of the family in coping with occasional emergencies further promotes the development of confidence, self-assurance and

independence in the management of this type of care. Home dialysis can reduce the mystery of medical treatment, and, rather than reinforcing the sick role and dependence of the patient upon the expertise of others, can foster the independence and control of the patient and partner over their own situation and the treatment thus involved.

The characteristics of the well-adjusted long term consumer of dialysis tend to be: a desire to survive, using one's abilities and available resources constructively and maximally; a definite pride in productivity and achievement; independent questioning, rather than passive acceptance; concern about oneself rather than self-sacrifice; minimal tendency toward despair--rarely experiencing hopelessness or helplessness; empathetic rather than sympathetic attitudes towards other patients, that is, not always identifying with other patients,--the recognition of his uniqueness (Newmann, 1979). Oberly (1979) states that the common linkage between these people is a strong desire to be independent, to remain productive, and to lead as normal a life as possible.

When the patients have been trained and the home is ready, they are established there, and ongoing medical and nursing care, social, psychological and/or physical, as well as all the necessary equipment, must be provided by the training center. A prime objective of the training unit is to insure that after training, the patients will be able to cope by themselves at home in carrying out the dialysis procedure (Macniven, 1976). Such ongoing care, on the whole, then

must be the responsibility of the main training center, even though the patient is established at home.

Kolodner (1976) also observes that initially, when a patient is begun on home dialysis, the training unit offers greater supportive supervision and back-up resources. However, after the patient is stabilized in the home, the initial support is reduced, and the great burden of care rests with the patient, partner and family.

In a study done by Wick and Rye (1977) in which 61 patients were interviewed concerning rehabilitation, stress, finances and psychological impact of home dialysis, the question "What causes you the most stress in home dialysis?", was answered in numerous ways. Needle insertion, machine problems, fear of complications, and blood leaks were the most frequently mentioned. Table 1 lists the most frequently mentioned stresses, and the percentages of patients reporting these stresses.

Table 1

Stresses of Home Dialysis (Wick and Rye, 1976)

Stress	Percentage of Patients Reporting
Needle Insertions	25%
Machine Malfunctions	21%
Fear of Complications	18%
Blood Leaks	16%
Stress on Family	13%
Time Involved	16%

N=61

The most dominant home training stress found in the survey was anxiety, which resulted from many factors. The major anxiety producing factors included insecurity about the future, the apparently awesome and largely unknown responsibility of home dialysis, and the need to be dependent on the machine and loved ones. Continuous support and patience during training are vital, being particularly important during needle insertion and the handling of stressful situations such as blood leaks and needle problems, the most frequently identified technical difficulties.

Inevitable problems arise within the family unit, and many centers are not prepared to adequately and effectively deal with these problems through the use of adjunct support systems. Because of the time-consuming, and occasionally unpredictable nature of the treatment, it is very important that patient and partner act as a team. If there is continuous resentment or tension between them, the procedure can become an ordeal where each feels he is sacrificing rather than sharing the time together (Oberly, 1979).

Wick and Rye (1977) state that they had an overwhelmingly positive response from the patients and partners regarding the need for better communication, continuing education and group support sessions. Many felt abandoned and isolated from the staff and physicians after going home. Those who did not feel isolated or abandoned were those who remained in close telephone contact with the staff and physicians, or who had contact with a member of the home-training staff who maintained

some of the machinery. Home visits, although time-consuming, help in assessing patients' needs and progress. Wick and Rye further explained that soon after the patient goes home and at least yearly thereafter, unless situations arise in which immediate first hand observation of the home environment seems necessary and advisable, home visits should be made. Between visits, frequent and regular telephone contact should be made.

This type of back-up is available in most home dialysis situations, but not always feasible for the home training center when patients reside at great distances from the center, even though telephone contact is usually maintained.

Although there is a definite economic-financial, as well as a physical-psychological advantage to home dialysis over in-center dialysis, there is a reluctance of Congress and the Department of Health, Education and Welfare to push any legislation in favor of home dialysis (Blagg, 1977; Kolodner, et. al., 1976). Cost varies from \$8,000 to \$15,000 per year for the home patient, versus \$23,000 to \$35,000 for the center patient. Several of the items such as supplies and certain types of equipment necessary for home dialysis are not covered by Medicare reimbursement, which is the main assistance for end stage renal disease patients. Lack of coverage places the home patient at a financial disadvantage (Bochner, 1977). Blagg has found that the number of patients on home dialysis has been decreasing within the last five years, and is approximately 25 per cent of the

total number of dialysis patients, although different regional statistics tend to slightly vary this figure. Medicare currently reimburses 80 per cent of home dialysis costs, not to include any oral medications, and reimbursement begins after the first three months of dialysis.

The patient at home is in a unique situation, and his needs are quite different from those of patients being routinely dialyzed in a hospital or center. In essence, the patient is responsible for his own care. The knowledge and confidence with which home patients perform their dialysis treatment must be provided by the home dialysis training center with paramount importance placed upon management of home dialysis with minimal anxiety. This must be accomplished through the maintenance of open communication between the training center and the patients and their families, so that once in the home they do not feel abandoned (Oag, 1976).

Data from the European Dialysis and Transplant Association (Kolodner, et. al., 1976) shows that patients treated by the use of home dialysis have a lower morbidity, and mortality rate than those patients treated in-center, or transplanted. Wick and Rye (1977) maintain that even though the potential success of home dialysis treatment is a feasible alternative for many patients, in order for the patient to reach his maximum potential home based care must offer the necessary continuing support to the patient and his family. One of the major reasons for the failure of some home dialysis treatment attempts is the almost complete transfer of professional functions to family

members without proper allowance of respite from this burden. Home care, as a viable treatment modality for end stage renal disease, can be an effective and beneficial one, but only with the continued assistance and support of professional personnel.

CURRENT MONTANA DIALYSIS INFORMATION

Montana Health Systems Agency data currently shows that, in the state of Montana, the incidence of end stage renal disease appears to be somewhat less than the national figure of 50 per million. Between 1976 and 1978, 63 new end stage renal disease patients were treated in Montana, for an average annual incidence rate of 32.8 per million.

Public Law 92-603, section 2991, requires the organization and coordination of all facilities into networks of care, thus providing for Medicare eligibility. The state of Montana is serviced by end stage renal disease Network Coordinating Council No. 2, based in Seattle, Washington. Portions of northern Wyoming also refer patients to Montana, and most transplant candidates from Montana are referred to the University of Washington, the University of Oregon, the University of Colorado, or the University of Minnesota.

At the present time there are four acute general hospitals which do provide end stage renal disease care. These hospitals have hemodialysis units and are St. Patrick's Hospital, Missoula; St. Peter's Hospital, Helena; Columbus Hospital, Great Falls; and Billings Deaconess Hospital, Billings. All four facilities provide acute and chronic hemodialysis care, as well as peritoneal dialysis services.

Home training programs for hemodialysis patients are presently offered in two of the four facilities--St. Peter's Hospital, Helena, and Billings Deaconess Hospital, Billings. Columbus Hospital in Great Falls has developed and opened a training program this year. Many of the potential home dialysis patients in the western half of the state receive training from Sacred Heart Medical Center in Spokane, Washington as well as centers located in Seattle, Salt Lake City and Denver.

The idea of kidney self help groups has been initiated in Montana. The first group, the Five Valleys Chapter of the Montana Kidney Patients Association located in Missoula was organized to fulfill several specific purposes:

- a.) To provide an organization of mutual assistance among kidney patients and their families.
- b.) To work with elected representatives at the local, state and federal levels to influence legislation helpful to kidney patients.
- c.) To educate the general public as to aims and needs of the group.
- d.) To encourage the public to sign organ donor cards.
- e.) To encourage the public to support programs, legislation, etc., of benefit to kidney patients.
- f.) To cooperate with other organizations dedicated in whole or in part to similar objectives.
- g.) To encourage and maintain a personal exchange of ideas and methods for the promotion of the rehabilitation of those with kidney problems.
- h.) To ultimately help return every kidney patient to a well adjusted and productive life (Article-2, Constitution, Montana Kidney Patients Association, 1979).

Table 2

End Stage Renal Disease Utilization Statistics for
Montana Facilities, 1977 (HSA Bulletin, 1978)

	St. Patrick's, Missoula	Columbus, Great Falls	St. Peter's, Helena	Billings Deaconess	State Total
Patient Census (June, 1978)					
Transplants	6	3	1	13	23
Center Dialysis	1	6	9	17	33
Home Dialysis	15	7	3	6	31
Total	22	16	13	36	87
Utilization Statistics					
Total No. of Dialysis Stations	2	4	3	7	16
Potential No. of Dialyses Which Can Be Performed	847	1747	1310	3058	6989
Current Utilization	115	1319	815	2127	4376
Percentage of Potential Use	9%	53%	44%	49%	44%

The future plans devised by the Montana Health Systems Agency in relation to end stage renal disease (ESRD) supports increased emphasis on home dialysis, but realizes that in-center units must continue to be located in facilities around the state. An estimate of service needs has thus been devised:

- 1.) Each year at least 33 patients out of every million persons will develop ESRD. This is based upon three years experience in Montana.
- 2.) Twenty per cent of all ESRD patients will have transplants. In Montana, about 26 per cent of ESRD patients have had transplants.
- 3.) About 40 per cent of transplant patients will reject their new kidneys and be required to undergo chronic dialysis.
- 4.) Among those individuals eligible for dialysis, at least 50 per cent can be placed on home dialysis. The remaining 50 per cent will remain on in-center dialysis.
- 5.) Each ESRD patient will undergo dialysis approximately 156 times per year, based on three dialyses per week for 52 weeks.
- 6.) A fully utilized dialysis station should perform approximately 436 dialyses per year, assuming an average of two treatment runs per day, six days per week, and adjusted for an optimal utilization of 70 per cent.

These assumptions are based on the last three years' experiences of Montana facilities as reported to the ESRD network in Seattle. Further, based on these assumptions and reported figures, it is projected that Montana could use an additional eight dialysis stations by 1985. However, HSA recommends that before any applications of the

need estimates can be utilized, more in depth studies should be undertaken. The general goals proposed by HSA are:

- 1.) Home dialysis programs should be promoted in Montana. There is strong indication that the need for in-center dialysis facilities will increase through 1985. Because of the high cost of hospital based ESRD services, and the geographic barriers limiting access to these hospital facilities in Montana, the need for home dialysis is evident.
- 2.) Programs for the prevention of ESRD should be developed in Montana.
- 3.) All modes of treatment and rehabilitation should be available to all individuals with ESRD. (HSA Bulletin, 1978)

CONCEPTUAL FRAMEWORK AND RATIONALE FOR THE STUDY

Through the process of adaptation, man may constructively and consistently cope with internally or externally imposed conditions in order to meet his needs (Murray and Zenter, 1975). Adaptation refers to the process of utilization of coping behaviors by an individual when faced with new, different, or threatening stimuli (Byrne and Thompson, 1972). Adaptation permits forward movement of the individual by minimizing or negating the effects of the adverse forces which may accompany change. Physiological adaptation, or the internal adaptation of the organism itself in the preservation of its integrity, and psychological adaptation, the behavioral adequacy in attaining appropriate human relationships, are inextricably bound (Murray and Zenter, 1975). Engel (1962) contends that adaptive behavior helps the person to adjust or cope with variable circumstances, and is at a maximum

when a sense of discovery, or purposefulness of the self is perceived, thus facilitating the achievement of a balanced satisfaction of needs.

Man is further seen as a complex, intertwining, adaptive network of behavioral subsystems working synergistically to achieve behavioral stability (Wu, 1973). When usual adaptive behaviors are unavailable to the individual due to a change or alteration in the internal/external environment, the individual experiences a breakdown or loss of order and predictability in himself and his relations with others.

According to Caplan (1961), crisis occurs when a person faces an obstacle to important life goals that is, for a period of time, insurmountable through the utilization of the usual methods of problem solving. Caplan (1964) further states that four developmental phases develop in a crisis situation: an initial rise in tension as habitual problem solving techniques are tried; a lack of success in coping as the stimulus continues and more discomfort is experienced; a further increase in tension which results in mobilizing internal and external resources; and if the situation is not eventually resolved, a further increase in tension and a major disorganization of the system. The individual must then work to re-establish equilibrium by learning new skills or new behavior, altering the environment, or withdrawing from the environment to seek a more suitable one (Vickers, 1968).

A loss of order and predictability, which can precipitate behavioral instability is dependent upon the nature of the predispositional event. Any event that is perceived as hazardous is likely to cause

instability and consequent crisis (Rapoport, 1965). Murray and Zenter (1975) further maintain that the body usually stabilizes or regains internal constancy through automatic regulatory mechanisms without conscious effort, and consequently the person is usually more concerned about others and the external environment than his body, unless the malfunctioning body part interferes with daily activity. Illness fosters the inability to satisfy basic needs for food, fluid, oxygen, elimination, release of sexual tension, sleep, exercise, and can be responsible for the loss of a valued body part and a threat to self image (Wu, 1973). It can be a very powerful stimulus to the experience of instability.

In any discussion of end stage renal disease, all of the considerations related to adaptation and stability of the individual in terms of a highly altered life situation, must be taken into serious account. The dialysis patient must be highly motivated to live if he/she is to effectively adapt and cope with the many demands and personal losses he/she may confront. The real and potential losses are many, including life itself, body image, sexual performance, self esteem, physical and mental capacities, self-sufficiency, independence and control, personal and financial status, home and material possessions and group memberships (MacElveen, 1972; Brand, 1966; Shea, et. al., 1962; Wright, et. al., 1966).

Santopietro (1975) has identified the major emotional needs of dialysis patients as the need for self concept, the need to grieve,

the need for safety and control of the environment, the need for acceptance and love, and the need to establish optimum levels of wellness and functioning. Wright et. al., (1966) has divided the basic psychological stresses of dialysis patients into actual or threatened losses; injury or threat of injury, and frustration of instinctive desires and needs. The major needs and stresses appear to correlate very closely with each other, and take into account not only the physiological adaptive needs, but the psychological needs as well.

The grieving process accompanies renal failure, and the sense of loss experienced by both patient and spouse must be recognized by the medical staff during this period of patient adjustment. This process may be dealt with by the spouse, family members or friends in three general ways: 1.) With sympathy, which plays into the patient's sense of helplessness; 2.) With apathy, suggesting that they really don't care, and causing an increase in the patient's sense of loneliness; 3.) Or with empathy, the midpoint between sympathy and apathy. This will lead to effective caring by recognition of the problem by the patient, and the ability of the individual to share his or her feelings and ideas without a sense of pity (Newmann, 1979).

Wu (1973) believes that a basic alteration in the self concept of the individual can occur due to the new and confusing bodily state, as well as the under mining of a previously cogent, secure, and safe environmental existence. Disruptions and continued life changes are

numerous and very labile, and the losses which will occur due to alteration of future plans and dreams, activities and achievements, and time and freedom, must be viewed as an invasion of the total life of the hemodialysis patient (MacElveen, 1972).

Home dialysis, through the active encouragement and participation of the patient in his treatment can be seen as an enhancement to the coping and adaptation of the patient to this profoundly altered environment. The health care staff can play an important role in the influence and outcome of the individual's adaptation (Rusk, 1978). Veverbrants (1972) contends that medically, the patient can increase the frequency of dialysis as necessary, and psychologically, although home dialysis may cause anxieties and disruption of the family unit, the actual return to the family, as well as the freedom to schedule dialysis into everyday life, and the gain in self confidence experienced by the patient, are seen as quite advantageous. However, in order for home dialysis to be successful following the two to three month supervised patient training, continued assistance, support, and training must be provided by the home dialysis training center. Frequent home visits, particularly in the early months of home dialysis, linked with continued counselling, are needed to help in the adjustment to home dialysis (Brown et. al., 1978; Blagg, 1977; Sandle, 1972).

All of the major needs and stresses of the home dialysis patient must be dealt with. As studies by MacElveen (1975) and Brown (1978) have shown, maintenance hemodialysis as a chronic stress can exert a

profound effect on all aspects of the individual's physical and psychosocial integrity. Independence can be fostered only if the patient is able to successfully adapt to the home environment and assume responsibility for his care. Brown et. al. (1978) and Rusk (1978) further support the idea that an integration of home visits, as well as regular holidays must be provided for the patient and partner involved with maintenance home dialysis.

The dialysis assistant/partner in most families is the spouse of the patient, and studies by Streltzer (1976), Brown (1978), and MacElveen (1972) have indicated that the spouse must accomodate to many changes and stresses related to the home dialysis situation. Single persons, on the other hand, typically return home or remain at their parents home. In such situations, the most significant other person is usually the mother of the patient, or perhaps a hired helper. These relationships are characterized by an increased dependency, and unless the patient is firmly established in adulthood, the demands of this chronic illness can precipitate a regressive return to the maternal-child symbiotic bond (Peirce, 1975). For the patient, home dialysis may provide several advantages, but for the spouse, it can be the portent of many disadvantages, such as less free time, decreased mobility, and increased responsibility. The presence of the dialysis machine in the home further may serve as a constant reminder of these disadvantages.

MacElveen and Alexander (1977) and Oberly (1978) reiterate the fact that even though the end stage renal disease patient has the opportunity to live many productive years on home dialysis, there are many radical, personal adjustments to be made in order to accomodate this change in the total life situation. At each state in the family cycle specific goals, responsibilities and developmental tasks must be addressed and dealt with, in order for the family members to meet their needs and satisfy the requirements for continued growth and development as a family unit. There are particular aspects of life on home dialysis which may impose strong inhibitions on the successful growth and functioning of the family unit. One of these stresses is the reduced energy levels of those on dialysis. Physical activities requiring strength or endurance are limited. Meeting the dialysis schedule assumes increased demands on family resources of time, household space, money and energy. Role adjustments and changes in the relationships with other family members occur. Some required adjustments and renegotiations of tasks may be necessary for the family; and unpredictable health emergencies can occur in addition to the accommodation to a constantly limited state of wellness. Large investments of time on dialysis can restrict many social and recreational activities thereby excluding friends and relatives, and becoming a stressful influence on the home dialysis family.

Smith, Malmquist, and Hagberg (1974) have emphasized the fact that the stress of home dialysis markedly affects the spouse as

dialysis assistant. Subsequent assessment indicates a definitive need for psychological and psychiatric evaluation of the home dialysis patient in order to anticipate difficulties as they arise, and to give the patient and family needed psychotherapeutic support.

MacElveen (1977) and Malmquist et. al., (1974) further identify the need in terms of the vulnerability of particular families, and the fact that continued support, and periodic monitoring of the family, and its members requires primary prevention. Families can be altered to changes in the structure and function within their unit, and may be able to better relate the influence of the patient's disease either directly or indirectly to the progression of their own developmental status.

Supportive contacts for the spouse and family are a major need, and in order to give both the patient and partner, a complete rest from the procedure in the home, it has been suggested by several authors (Brown, 1978; Streltzer, 1976, among others), that it would be particularly beneficial to the family if the home training center would provide two to three weeks per year of in-center dialysis, and alleviate where possible the psychological stresses inherent to the spouse and family in the home situation.

The patient's fear of injury, loss of safety, need for identity, and intense spouse/family interaction with home dialysis are all major components in the life change situation required by this type of care, and as such serve as a basis for problems which can occur most

intensely during the initial adaptive months of home dialysis. The importance of back-up support by the home training center cannot be over-emphasized during this time. The center should provide continuous assistance to patients in potential emergency situations at home, as well as care and provision of supplies, maintenance of machinery, psychological, dietary and financial counselling, medical and surgical intervention if necessary, and routine home visits by the training staff (Blagg, 1977).

Newmann (1979) lists some of the major factors pertaining to the success and effectiveness of a home dialysis program:

- 1.) The health care staff is dedicated to it. Doctors, nurses and technicians markedly influence patient attitude and support.

Those who believe strongly in the advantages of home dialysis have developed excellent training and follow-up programs which are generally well received and supported by patients. There are relatively few home dialysis consumers followed by physicians who are not wholly in favor of a home program, and unable to provide the type of care needed in terms of physical and psycho-social interventions.

- 2.) A thorough and individualized training program. This enables patient and partner to function as a team which in turn is greatly beneficial in the reduction of stress and anxiety experienced by patient and partner. Experienced home patients can be effectively utilized to help new trainees cope with stress.

3.) Follow-up from the medical team. Follow-up serves as a useful tool to monitor the experience and responsibility of the home dialysis team as a successfully functioning unit, which uses home dialysis constructively and maintains a special sensitivity to each partner's needs.

Adaptation to change must be continually fostered by support from the home training center, especially during the first six months the patient is on home dialysis. Studies by MacElveen, et. al. (1975) have shown that by the end of six months, 89 per cent of home trained patients felt at ease, not only with home dialysis, but also in their ability to handle most emergencies. Assessment, and constant reassurance must be an ongoing process. Information must be consistently provided regarding supplies and equipment since technology is rapidly changing, and reeducation in newer and better methods must be part of a continuous, comprehensive program. The relationships of the professional and training staff with the patient and family are instrumental in providing complete care to the home patient, and in developing a decrease in the threat of injury due to any mechanical problems, blood access problems or any other environmental risks. They must also foster the confidence, trust and motivation necessary for a home dialysis patient to continue to adapt and to live in his/her altered situation.

In summary, the literature reviewed indicates that the ability of the home dialysis patient to adequately cope with the dramatic

alteration in life situation is contingent upon several major factors: patient motivation; individual and family coping strategies; developmental status of the individual and family unit; and adequate support from family and involved medical personnel, particularly those individuals responsible for the provision of home dialysis training. Continued support and assistance from the home training center appears to function as a major determinant in the effective resolution of adaptational changes related to the home dialysis experience.

However, if the home dialysis training center is not easily accessible to the home patient due to distance, and other related factors, the problems encountered by these patients could present increased resolutorial difficulties. The necessary crisis and coping strategies required for successful adaptation of the home dialysis patient to his altered environment might then be less effective in this situation. Through a study of problems and concerns of home dialysis groups more adequate methods of support may be identified for the home patient, and more effective methods of treatment could eventually be utilized.

CHAPTER 2

METHODOLOGY

STATEMENT OF PURPOSE

The purpose of the study was to describe problems of home dialysis in rural and urban populations to discover how distance was perceived by both groups and whether or not distance from a center influenced adaptation to treatment. The following questions were asked:

1. What are the most frequently encountered problems of home dialysis patients residing more than 50 miles from their home training center?
2. What are some of the resolutions patients have used in coping with distance from the center?
3. Are there differences in the kinds of problems and resolutions experienced by dialysis patients who live in proximity to the training center, and those who reside at a distance from the training center?

RATIONALE FOR THE STUDY

The author's previous work with dialysis patients and MacElveen's (1972) study stimulated the author's interest in problems of home dialysis patients. In reviewing the literature it became apparent that problems of home dialysis for people distant from training centers had not been studied. No studies were found which considered patients' perceptions of distance from the center, or distance to travel for

assistance, or how rural patients coped with medical, technical or interpersonal problems. A study comparing rural with urban patients could provide new information and contribute to knowledge of how rural people cope with chronic disease.

There is a population of home dialysis patients living in Western Montana who were home trained in other states. There is no training center within 50 miles of the Montana group, and the distance to a center is 200 miles or more for most Western Montana patients. Due to lack of immediate access to assistance and support of the home training center, these patients have been forced to function quite independently.

Another population of home dialysis patients lives in the Spokane area where the Sacred Heart Medical Center home dialysis training center is located. The Spokane patient population made a good comparison group since a large percentage (60%) of the Montana group received their training there.

RESEARCH DESIGN

An exploratory descriptive method of study was selected because little was known of patients' perceptions of their problems and no studies were found which focussed on distance from the center as it related to adaptation to home dialysis. The investigator elicited patient's perceptions of a variety of problems encountered during the initial months of home dialysis as well as those problems still occurring at the present time; the resolution of these problems; and individual interpretation of proximate and distant.

The investigator was present during dialysis, attended meetings, interviewed patients and spouses or partners formally and informally and observed home dialysis patients and their support network under varying conditions. A trip to a Spokane center meeting provided limited observations of the urban comparison group at a joint meeting with the rural group.

An attempt was made to utilize patients' perceptions of their problems. Extensive interviewing of one patient contributed to development of the categories used in the checklist. Use of present categories was necessary to have comparable data from both groups, the one interviewed and the one that responded to the questionnaire. Both groups would have been interviewed if that had been possible.

DEFINITION OF TERMS

- 1.) End stage renal disease: Chronic inability of the kidney to filter and remove from the bloodstream and body, the waste products of cellular metabolism; conserve essential substances; regulate the composition of body fluids; and secrete hormones (Cameron, 1976).
- 2.) Home dialysis: Chronic maintenance dialysis done in the home of the patient.
- 3.) In-center dialysis: Chronic maintenance dialysis done in a hospital or dialysis center specifically designed to provide this treatment for the patient on an outpatient basis.

- 4.) Proximate to the home training center: Residence within 50 miles from the home training center.
- 5.) Distant from the home training center: Residence greater than 50 miles from the home training center.
- 6.) Home dialysis training center: A specialized dialysis center with the primary objective of training the patient fully and completely to perform all aspects of the dialysis treatment at home.
- 7.) Problems: Those occurrences causing the patient undue interruption with the normal dialysis treatment. Problems are identified as mechanical, medical and psycho-social.
- 8.) Resolution: The ability of the patient to adequately rectify these mechanical, medical and psycho-social problems with or without support from the home training center.

SAMPLE AND SETTING

A sample of 15 home dialysis patients was selected from Missoula and the surrounding areas (within a 150 mile radius) to represent those home dialysis patients distant from the home training center, since there is no training center in Missoula or the immediate area. The sample is the total population of home dialysis patients listed under the care of the Missoula area nephrologist, and was the group available for interview at the time of the study. This number of home dialysis patients is also the same number indicated by the Montana Health

Systems Agency data for dialysis patients residing in this vicinity. There was a 100 per cent response rate from this population.

These patients were trained at home training centers in other states, then returned to Montana to continue home dialysis without proximate support from the home training center. Patients in this area have been home trained in Denver, Colorado; Seattle, Washington; Spokane, Washington; and Palo Alto, California, and receive medical emergency back-up support from St. Patrick's Hospital in Missoula.

Another sample of 18 home dialysis patients was contacted from eastern Washington to represent those patients proximate to a home training center, since there is a home training center in the city which provides support and back-up to these home dialysis patients. The Washington sample of 18 home patients was also the total population of home patients residing within a 30 to 50 mile radius of the city. These patients were selected and contacted by the training center itself in order to maintain strict confidentiality. There was a 33 per cent response rate from this population.

DATA COLLECTION METHODS

The instrument utilized in the collection of data was a checklist of various problems which could possibly occur while the participant is on home dialysis. The checklist included problems in these categories: Mechanical Problems; Medical Problems; and Other (Psycho-social Problems), (Appendix A).

The specific variables selected for each category were a compilation of problems identified in previous dialysis studies particularly those studies directly related to home dialysis. Various written materials related to dialysis treatment and management were also utilized in order to facilitate selection of a series of pertinent problems.

The respondents were asked to indicate which of these problems he/she had encountered, and then to rate them in importance based on a five point scale, one being the least important, and five being the most important. The respondent was also questioned as to what resolutions to these problems might have been beneficial to him/her, and what resolutions actually were utilized to meet the demands of problems encountered at home.

A separate form requesting demographic data (Appendix B) was also utilized, and questions regarding place of home training, length of time on home dialysis, training time, dialysis partner, frequency of dialysis, distance from the training center, type of dialyzer, type of blood access site, age, sex and occupation were addressed. Questions regarding perceptions of the respondent concerning proximity of care were included.

Names of patients for the Missoula and surrounding area sample were obtained from the nephrologist in Missoula, and from the Five Valleys Kidney Association of Montana. Each respondent was contacted by phone in order to obtain verbal permission for an interview. The

checklist, questionnaire, consent form (Appendix C) and explanatory cover letter from the author (Appendix D), were then mailed to each respondent one week prior to the scheduled interview to allow each participant time to read and contemplate the materials.

Each prospective participant was guaranteed complete confidentiality in all aspects of the study. Interviews took place with prior verbal agreement from each prospective respondent, and approval of the health service agency directly responsible for the care of each respondent. Each prospective respondent was also required to sign a consent form which indicated voluntary participation in the study, and provided an explanation of the confidentiality agreement.

In most cases, respondents, partners, and in some instances, other members of the family were seen in their own home environment. The checklist and questionnaire were devised as guides for the interview. They were implemented in the form of a guided conversation in order to encourage free flowing and open communication. Interviews were conducted by the author during actual dialysis in about half of the cases, and each interview ranged in duration from 40 minutes to two hours.

The Washington sample of respondents were questioned by mail. The artificial kidney center associated with this sample was unable to provide the author with a list of the names of their home dialysis patients due to strict confidentiality requirements. However, in order to facilitate obtaining the required and necessary information

from the sample, the administrative director of the training center, with the cooperation of the physician in charge of the center, forwarded a letter of endorsement and explanation of the study to each prospective participant. Each home patient received the letter with the revised checklist enclosed (Appendix E), the questionnaires, the author's cover letter of explanation (Appendix F), the consent form, and a self-addressed stamped envelope directed to the author. Each respondent was then asked to indicate consent and participation by voluntary completion of the enclosed materials, and response by mail to the author. In this manner, the author did not see the names of any of the respondents until the completed forms were received, and only if respondents chose to reveal their identities.

DATA ANALYSIS

The literature was reviewed to determine categories of problems commonly occurring in home dialysis. A profile of common problems was developed for the purpose of comparison within each sample and between the populations. Data has been presented in written, graphic and table forms. Descriptive statistics, means and percentages were applied to the data.

CHAPTER 3

DISTANT HOME HEMODIALYSIS PATIENTS: DESCRIPTION AND FINDINGS

DISTANT HOME HEMODIALYSIS PATIENTS: DESCRIPTION

The selected population for interview consisted of 15 home hemodialysis patients who resided in the western Montana region. The characteristics of the sample are listed in Table 3.

The respondents ranged in age from 24 to 68, with a mean age of 51.8. All but two respondents were between 45 and 68 years of age, the youngest, 24 and 32 years of age. Twelve of the respondents were men, three were women.

The length of time on home hemodialysis varied from seven months to ten years, with a mean length of time on dialysis of three and one half years. No relationship was found between the length of time on home dialysis and the age of the participants. None of the participants had ever been on in-center dialysis other than for home training purposes.

The amount of actual time per week spent on dialysis varied from six hours per week to 18 hours per week, with most of the respondents in the 12 to 15 hour range. The mean amount of time spent on dialysis per week was 13.4 hours, which is average for maintenance hemodialysis patients. Several of the respondents stated that they were quite flexible in the arrangement of those hours in terms of preferred and suitable days of the week. Those who were employed, or whose spouses

Table 3

Profile of Distant Patient Population

Age:	Range = 24 - 68 years Mean = 51.8 years	Amount of Dialysis Time Per Week:	Range = 6 - 18 hours Mean = 13.4 hours
Sex:	Female = 3 Male = 12	Access Site:	Fistula = 14 Cannula = 1
Place of Training:	SHMC, Spokane = 10 Seattle V.A. = 3 University of Colorado, Denver = 1 Stanford Univ. Medical Center Palo Alto, CA = 1	Original Site:	Yes = 10 No = 5
Distance to Home Training Center:	Range = 200-1200 mi. Mean = 415 mi.	Length of Time on Home Dialysis:	Range = 7 mo. - 10 yrs. Mean = $3\frac{1}{2}$ years
Dialysis Partner:	Spouse = 13 Mother = 1 Daughter = 1	Occupation:	Retired = 4 Unemployed = 4 Full-time = 1 Self-employed = 3 Homemaker = 3
Length of Training Time:	Range = 4 wks. - $3\frac{1}{2}$ mo. Mean = 2 mo.	Membership in Local Kidney Association:	Yes = 10 No = 5
Supplies and Equipment:	Home Training Unit = 11 Supply Company = 4	Adequate Support from Home Training Center:	Yes = 13 No = 2
		Use of Patient Group for Support	Yes = 10 No = 5

N = 15

were employed were not able to be as flexible as the others, and had established a consistent routine. Most respondents dialyzed on weekdays; only one used a combination including Saturday.

A few of the respondents also said they had come to the decision concerning dialysis hours themselves, by experimenting a month at a time with the number of dialysis runs per week, and the amount of time per dialysis, and then comparing monthly blood levels of urea nitrogen and creatinine. In this way, the respondents effectively adjusted their own times according to their body's needs and responses. Some respondents stated that they actually needed less dialyses than initially ordered by their physicians. Experimentation with the dialysis schedule indicated a definite pursuit of a treatment regime based on independently acquired information, and in some cases was negatively regarded by the medical staff. Knowledge of the disease process and the dialysis treatment appeared to be of great importance to most of the respondents and provides the basis for one important coping strategy: making one's own decisions about timing of dialysis. A strong desire to function independently in terms of dialysis treatment, and total life situation were also noticeable characteristics of this group.

One respondent was employed full-time, and has been on dialysis for the longest period of time (10 years). Two respondents were farmers and maintained a somewhat flexible part-time self-employment compromise at home. The rest of the male respondents were divided

evenly between retirement (4), and unemployment (4), and the three female respondents were all homemakers, and had not been employed outside the home in recent years. Of the retired, unemployed and female respondents, seven of the spouses were employed full time, and among these were spouses who had to work to maintain financial needs (4), and spouses who wished to work (3).

For the purpose of this study, those respondents considered gainfully employed were the individuals maintaining full-time employment, self-employment, and homemakers. Those respondents considered unemployed were retirees, and younger individuals who were unemployed. Based on this categorization, the unemployment percentage was 53 per cent. This appeared quite high in comparison with the group studied by Wick and Rye (1977) in which the unemployment rate was only 16 per cent for the total sample. Although somewhat high, the age distribution of respondents (mean age 51.8 years), and the fact that retirees were counted in the unemployment statistics, must be considered. If the retirees were excluded from the unemployed category, the figure would decrease to 26 per cent. Two of the younger respondents were either employed or seeking employment.

Seven of the respondents indicated Missoula as their community of residence, and the other eight respondents lived in small rural communities from 11 to 120 miles outside Missoula. Respondents had used four places for home dialysis training. One kidney center in Washington was the most frequently cited center, cited by ten of the

fifteen respondents. Another kidney center in Washington was the second most frequently utilized center and two more distant kidney centers which were in Colorado and California were each used by one person. None of the respondents had been trained within the state of Montana, although at the present time there are small home dialysis training units in Billings, Helena and Great Falls. However, all three of these units are relatively new and have only been operational as training centers for the past two or three years.

The distances in miles from the respondents' community of residence and the home dialysis training center varied from 200 miles of one-way travelled mileage, to 1200 miles. The mean mileage travelled from place of residence to the home dialysis training center was 415 miles. This appeared to be an exceptionally large figure. None of the literature cited previously in this study made clear reference to the actual distances between patient residence and the home training center. However, Wick and Rye (1977) did state that home visits were not feasible in terms of time and cost, if long distances (unspecified) were involved. Consequently, it is difficult to evaluate what would be considered "average" distance from patient residence to training center.

Closely related to the actual distance in miles to the training center was the respondent's perception of the distance as "close" or "far away" from their residence in terms of accessibility. Table 4 presents the distribution of these responses in conjunction with the

Table 4

Comparison of Actual Distance to HDTC, and
Perception of Distance by Respondent

		Numerical Designation for Each Respondent														
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Distance in Miles To Home Training Center		250	557	250	200	200	200	550	200	200	400	1200	900	210	300	308
		Close	Close	Close	Far Away	Far Away	Close	Close	Close	Close	Far Away	Far Away	Close	Close	Far Away	Far Away

actual one way distances each respondent must travel to reach the home training center. Nine of the respondents regarded accessibility as close, or convenient for them since the center could be reached in a half-day to one-day drive, or in two to three hours by air. The other six respondents regarded the distances as far away, but not necessarily inconvenient for them in terms accessibility. Those who felt that the training center was far away also stated that the most difficulty with travel was in the winter, and although some felt it was a "hassle" to get there, their particular training center was the best available to them at the time they needed it. Some of the respondents who reside outside Missoula also stated that the distance to the Washington training center was no more difficult than travel from their home to Missoula for treatment.

All but one respondent indicated the spouse as the home training partner. The one exception was unmarried, and had his mother as his home dialysis partner. However, since hemodialysis training, two respondents have changed their dialysis partners. One respondent and spouse were separated, and dialysis has continued without assistance. Another respondent trained one of his daughters to assist him with home dialysis treatment since his spouse returned to full time employment, and her work hours did not effectively coincide with his dialysis hours. All the respondents indicated satisfaction with their current home dialysis partners, but mentioned that occasional relief for the partner from dialysis duties would be particularly beneficial.

The length of training times at the home dialysis training center were recounted ranging from three and one-half months to four weeks, with the mean amount of training time as two months.

The machines used for home dialysis training were the Drake-Willock negative pressure hemodialysis machines. This type of machine was consistently used in all the various training centers in the study, as well as many of the training centers cited in the literature. One respondent was trained on a Redy hemodialysis machine. The Redy machine is a smaller and more portable machine which has an internal water filtering mechanism, allowing the system to be connected directly to tap water, rather than to special de-ionized water systems. The Redy machine was used for training the respondent at Stanford University Medical Center, on an experimental basis, and the participant stated she liked it very much and wished to lease it for home use following training. Another respondent in the Missoula area has since switched from the Drake-Willock machine to the Redy machine after four to five years. He took a full six week course in the Redy machine mechanics directly from the Redy Company in order to effectively operate and maintain the equipment since any repairs had to be done by a company representative from Oklahoma City, Oklahoma. Both respondents felt that the machine allowed for greater travel mobility and required less storage space.

Five of the respondents indicated that their dialysis machines were paid for. After 30 months of leasing the machine from the home

training center, the machine is paid for, or the machine may be purchased outright. Subsequently the machine is taken in to the training center for an operational re-check and "tune-up" every one to two years. If there are or have been any real mechanical problems, the respondent may trade the machine in for a newer or more adequately functional model at no extra charge. If the machine was not functioning properly at the initial installation, it was immediately replaced by the training center.

Ten of the respondents were accompanied home by a nurse or technician from the training center for the first home dialysis and initial connection and operationalization of the dialysis equipment in the home. The other five respondents had no nurse or technician present for this purpose, and all but one respondent in this group felt the need for assistance. The respondent who did not indicate a need had taken his camper-trailer to his training center prior to training since it was to be used as his home dialysis facility. He connected the machinery in his trailer at the training center, had one dialysis run there under technical supervision, and then transported the connected machinery back to his home. Supplies and equipment were obtained by the respondents directly from the home training center or ordered from a dialysis supply company.

All but one of the respondents had a fistula of some type as the blood access site for hemodialysis. Eleven respondents had arterio-venous fistulas in one or both arms; two respondents had saphenous

vein graft fistulas; and one respondent had a bovine graft fistula. The respondent who did not have a fistula, had an external shunt/cannula access site in his arm which did not require needle insertion for dialysis, but instead was connected directly to the blood tubing and dialysis machine. The other access sites all required direct needle insertion in order to connect the patient to the dialysis machine. The needle insertion procedure varied among the respondents as to the use of one or two needles for dialysis. Those respondents recently trained at Sacred Heart Medical Center in Spokane exclusively utilized the single needle connection equipment, although one respondent trained in Spokane several years ago utilized the double needle technique. The other respondents also used the double needle technique. The single needle procedure requires an adapter for the blood pumping apparatus on the machine, so that blood being removed from the body for dialysis will not be combined with blood returning to the body from dialysis. Those respondents who utilized the single needle insertion technique disliked the use of double needles when dialysis occurred in a center. The local hospital which provides hemodialysis in emergency situations for the home dialysis patients, did not have the proper equipment for the single needle utilization procedure, and most of the single needle respondents expressed concern and reluctance to utilize the facility for this reason.

Five of the participants did not have their original fistula at the present time. Ten of the respondents not only had their original

fistula, but have had no infections, clots or other problems with the access site. The other five respondents have had revisions of the original site due primarily to clotting or poor blood supply for dialysis purposes. Infection was not a major reason for the loss of any of these sites.

Only two respondents indicated that they felt a lack of support from the home training center. Both respondents stated that their calls were not answered promptly enough by the center staff when a question would arise at home regarding the dialysis run. All of the other respondents believed their home training center gave them adequate support, particularly in terms of the initial assistance provided by the center for the first treatment at home. Most respondents believed that center staff were supportive, but would prefer some form of ancillary support more proximate to their homes.

Ten of the respondents were actively functioning members of a kidney association in Montana, a local support group organized for renal patients, their families, interested friends, and medical personnel. The organization functions were described as a group effort to relieve some of the isolation factors renal patients in the western part of Montana experienced due to distance from their home training center, and the lack of home dialysis support facilities in the area. This group, which had approximately 60 members at the time of the study, kept in touch not only with each other, but with recent advances and developments in renal disease by utilizing guest speakers and

professionals in their monthly meetings. In addition to the monthly informative meeting, the group met on a regular basis for various social activities. Of the ten active participants in the association, all of them stated that they utilized the club for support, and that this support was of great value to them physically, in assisting with dialysis problems, and psychologically in terms of the sharing of experiences, feelings and activities.

All home dialysis patients in the western region of the state were contacted by this group. Of the five respondents who did not belong to the kidney association, two of them expressed great dissatisfaction with their home training center and indicated a feeling of isolation and aloneness in their situations. The other three respondents felt no real need for membership and no time to attend the various functions of the group. One respondent had recently moved into the area, and had not been contacted by the organization. Patients from other areas of the state who learned of the existence of the group, or were referred to it, when they began dialysis were also offered this support. The choice of joining the support group is the decision of each individual. The group is also endorsed by the area nephrologist and medical community.

All but one respondent answered that they preferred home dialysis to in-center dialysis primarily because it increased flexibility of scheduling and increased independence in life style. The one respondent who did not prefer home dialysis considered the treatment to be too

much of a burden upon the spouse.

SUMMARY

The major differences apparent in the investigation of this sample in comparison to some of the other home dialysis populations cited in the literature were related to psycho-social functions and were not related to the actual mechanical/physical aspects of home dialysis. The distances indicated between residence and the home training center were substantial, and the methods of coping with these distances involved a great deal of innovative and independent activity. The presence of the patient organization within the vicinity served to provide necessary support and assistance in the effective management of the home dialysis situation for the majority of this sample. This indigenous support network has provided a great deal of needed assistance in the absence of a proximate training center.

Another characteristic of importance related to this sample involved the respondents' perception of distance. Most respondents indicated that distances of 200 or more miles were considered "close", while a 900 mile distance was convenient for one respondent. Distance perceptions may be related to the rural orientation of the sample, and the fact that in a large state such as Montana, substantial distances are usually involved in most travel situations. The perceptions may not be unique to kidney patients however; further investigation regarding attitudes toward distance and travel to health care would

be of interest in relation to both healthy and chronically disabled persons.

FINDINGS: RESPONSES TO IDENTIFIED STRESSORS

Interviews were conducted with 15 hemodialysis patients who live more than 200 miles from a center. A checklist of 24 identified stressors was sent to each home prior to a formal interview. Stressors were arranged as a problem checklist and included problems likely to be encountered by home hemodialysis patients. The list of stressors was developed from review of the literature and a series of interviews held over a period of months with one informant, a home hemodialysis patient.

The author expected that the Montana sample would indicate and identify more dialysis related difficulties and problems due to their distance from the home training center, and their consequent lack of immediate support from that center. This group of patients was expected not only to describe greater anxiety related to the mechanical/technical aspects of dialysis than the group located within proximity to the training unit, but was also expected to demonstrate less effective adaptational and coping strategies. Feelings of isolation and related anxiety were also expected to be above average. The author strongly suspected that urban area residents (the proximate sample) would be more highly integrated and better adapted to home dialysis due to the accessibility of immediate support and assistance from the home

training center. Based on these expectations, the author also believed that a home training center located in the Missoula area would serve to substantially alleviate many of the difficulties experienced by the Montana sample.

IDENTIFIED STRESSORS

Each respondent was interviewed concerning the dialysis problem checklist. Discussion and identification of major, as well as minor problem areas occurred. The identified stressors were divided into three major sections: Medical Problems; Mechanical Problems; and Psycho-Social (Other) Problems. Problem ratings were categorized in two basic groups according to numerical designation. For the purpose of this study, those problem ratings within the range of three to five were considered "high" problem areas, and those ratings existing in the zero to two range were considered to be "low" problem areas.

The most frequently identified problems according to the respondents were: machine malfunctions; needle insertion difficulties; low blood pressure on the machine; headaches, cramping, nausea and vomiting during the run; high blood pressure off the machine; diet; dependency on partner; finances; sleep disturbances; sexual difficulties; depression; fear and anxiety; disruption of family during home training; and mobility and recreation. These problems were considered most serious during the initial three to six months on home dialysis, but, in some cases were still in existence.

Figure 1 illustrates the list of problems presented in descending order of composite group rating scores. The composite scores were compiled by determining the sum of the points allotted to each problem by each respondent. The profile shows that a greater number of psych-social and medical stressors were identified by the distant group as high problem areas. Mechanical difficulties were rated by the respondents as less serious and more easily manageable than the other identified problems. This finding is not consistent with the initial expectations of the author concerning problem identification outcomes. Mechanical difficulties were expected to receive higher rating scores than many of the other problems due to their technical nature and the distance between patient and training center. Even though machine malfunctions received a high composite score, resolution of these malfunctions was not totally related to assistance from the training center.

MEDICAL PROBLEMS

Those stressors categorized as medical problems are actual physical problems encountered by most dialysis patients related not only to the dialysis treatment, but also to the end stage renal disease condition.

Table 5 presents the problem ratings computed for the category of Medical Problems, and indicates the distribution of responses per rating designation of zero through five for each medical problem listed on the checklist.

Figure 1

Identified Stressor Profile in Descending Order
of Composite Scores (Range = 0-75),
Distant Sample

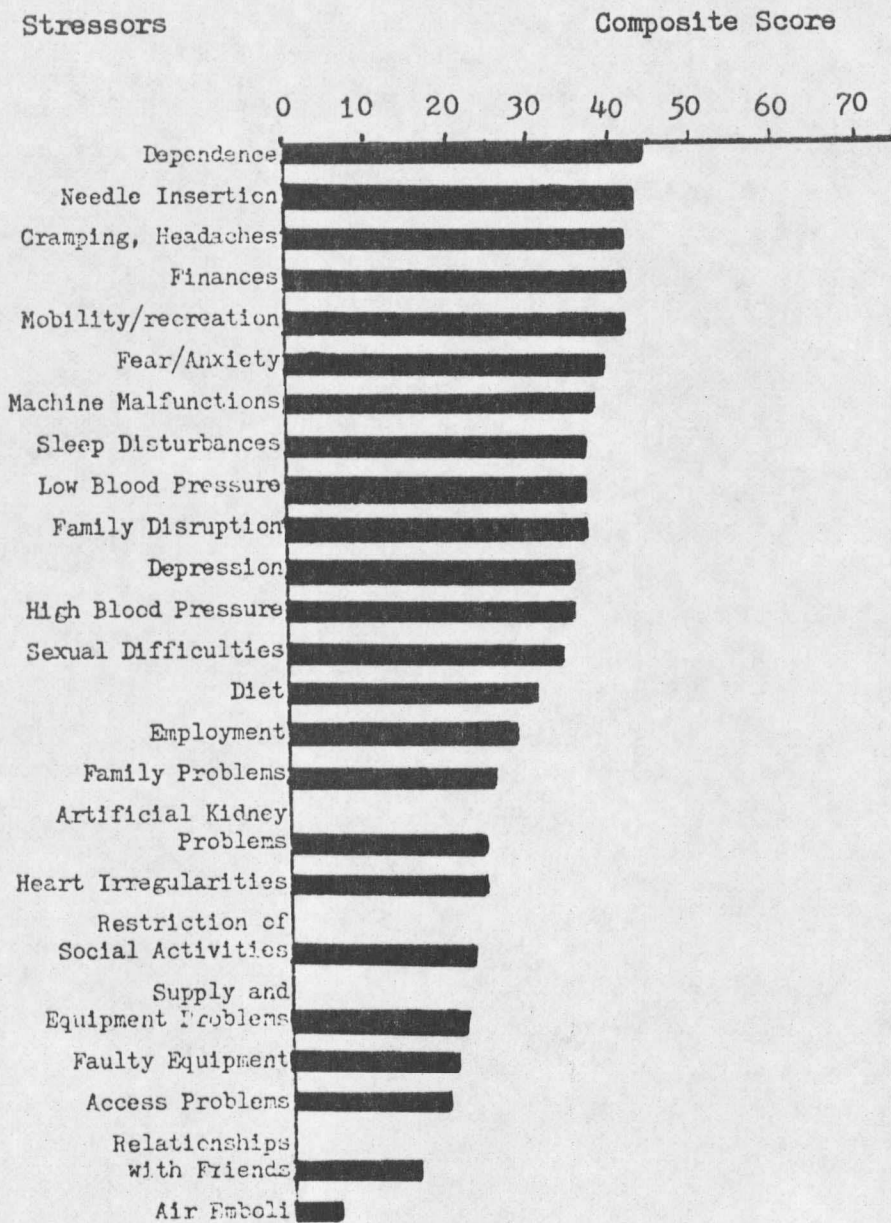


Table 5

Number of Responses Per Rating Designation -
Medical Problems

Medical Problems	Rating Designations*						Composite Group Score	Mean Score
	5	4	3	2	1	0		
Needle Insertion	4	3	0	4	3	1	43	2.87
Headaches, Cramping, Etc.	3	1	5	2	4	0	42	2.80
Low Blood Pressure While on Machine	3	1	1	5	4	1	36	2.40
High Blood Pressure	3	2	1	3	3	3	35	2.33
Heart Irregularities	2	2	1	0	3	7	24	1.60
Access Problems	1	0	1	3	3	7	17	1.13
Air Emboli	0	0	0	0	6	9	6	0.40

N = 15

*3-5 = High; 0-2 = Low

Overall Rating Total = Sum of: Each Rating Designation
 $\times$
 Number of Responses Per Designation

Needle Insertion

Needle insertion difficulty was identified as the most serious problem with a composite score of 43. The mean rating score was 2.87. Respondents had a variety of reasons for rating needle insertion high. One respondent stated that he was not trained adequately by the training center in the actual performance of the procedure before being allowed to go home and utilize it on his own. Other respondents stated that either the fistula itself was not developed enough for use initially, or that nervousness and anxiety contributed to difficulty in this procedure. All the respondents were required to do repeated punctures at home until the blood flowed properly. The repeated punctures which were required as "practice" in order to learn the procedure were described by respondents as unpleasant experiences. Large hematomas, a result of poor punctures, were quite common and sometimes required medical care. Two participants returned to the training center for further assistance and/or revision of the access site.

Many of the spouses who actually performed the needle insertion were very fearful initially of the procedure and were particularly concerned that they would cause pain to their partners. Of the five respondents who routinely did their own punctures, three also rated needle insertion as a serious initial difficulty.

The respondents who rated needle insertion as low, were either quite comfortable with the procedure prior to coming home on dialysis,

or found that the few difficulties they did experience at home doing repeated punctures were easily resolved with patience and practice.

Nine of the respondents discussed the difficulty with in-center dialysis in relation to the needle insertion procedures, stating that they did not like to be run on double needles if they used single needles at home, and vice versa. Respondents also stated that hospital personnel had caused problems for them, such as large hematomas, clots, and completely punctured fistulas when attempting to insert needles. Hospital personnel often did not allow the respondent to do his own needle insertion. The attitude of the respondents toward needle insertion techniques and procedures used during in-center dialysis was quite negative because of lack of individualized treatment.

Headaches, Cramping, Nausea and Vomiting During the Run

The second most highly rated medical difficulty was the occurrence of headaches, cramping, nausea and vomiting during the dialysis run. This was given a composite score of 42, with a mean score of 2.80. Nine respondents rated this problem as high.

The above symptoms are closely related physiologically to a drop in blood pressure during dialysis. The occurrence of low blood pressure in an individual during dialysis treatment, and occasional persistence of this condition for a few to several hours post dialysis, was given a composite score of 35 with a mean score of 2.30. Low blood pressure is closely related to the amount of fluid the respondent was

attempting to remove from his/her body, and thus, the amount of pressure which must be exerted on the artificial kidney in order to accomplish this task. With increased fluid weight gain between dialysis runs, increased amounts of negative or positive pressure have to be used in order to remove the fluid weight gain. Usually a significant increase in machine pressure is accompanied by a decrease in blood pressure. Symptoms occur as a result.

Two of the respondents stated that their low blood pressure was a direct result of dialysis itself and had no real basis as far as increased machine pressure was concerned, since they utilized no negative pressure while on the machine. They stated that they were "totally wiped out" after each dialysis run.

Three of the respondents who rated low blood pressure as a severe problem did state that it occurred when they "ran themselves too hard" in an attempt to take off excess fluid or when they unintentionally took off too much fluid. Infusion of saline directly into the blood lines connected to the patient, or an oral intake of sodium chloride (salted crackers), were the two primary treatment methods for this condition.

Most of the respondents believed that the cramping and other physical symptoms were a direct result of low blood pressure while on the machine. However, four of the respondents stated that they had a significant amount of cramping without the presence of low blood

pressure. Quinine tablets, tylenol and/or massage of the affected area were mentioned as the primary methods of treatment for cramping.

Headaches, nausea and vomiting were indicated by all the respondents as symptoms of low blood pressure. If these symptoms were present the low blood pressure was treated accordingly.

The remaining respondents who rated these medical conditions as low, stated that symptoms occurred more frequently during in-center dialysis due to the unwillingness of hospital staff to individualize dialysis treatments according to the needs of the dialysis patient. The in-center staff was described as maintaining strict adherence to unit routines rather than attempting to provide dialysis treatment to accommodate each patient. Those respondents who rated low blood pressure as serious for them at home also believed that the condition was aggravated in the hospital setting, and that frequently hospital personnel "refused to listen to them" and to what constituted normal for them.

High Blood Pressure

High blood pressure was rated as a composite 33. The mean score was 2.33, with six of the respondents rating it as high. Four of these respondents stated that their blood pressure was extremely high prior to the initiation of dialysis treatment and had occurred in conjunction with their renal disease. It was now regulated by dialysis, but had been difficult to control during the initial months of dialysis. Two

respondents expressed concern that their blood pressure was very high prior to the onset of dialysis treatments and remained high between treatments. These respondents were intermittently treated with anti-hypertensive medications.

Of the remaining nine respondents who rated high blood pressure as a problem of low importance, six stated that high blood pressure was a serious problem prior to beginning dialysis, but was not yet very well controlled. Only one respondent stated that high blood pressure had never been a problem.

Other Medical Problems

The last three medical problems listed included heart irregularities, access site difficulties, and air emboli. Heart irregularities, given a composite score of 24, and a mean of 1.60, was rated high by five respondents. Two respondents stated that they had recurrent chest pain and heart arrhythmias if their blood pressure became too low while they were on the machine. They also stated that ectopic beats occur occasionally when they are off the dialysis machine, but not to the same degree as during a dialysis run. One respondent stated that this was a severe and frightening problem for him due to his distance (80 miles) from a city, and his lack of access to any medical care within 30 miles. He stated that he was threatened enough by these episodes that he would consider moving to the city in the future. The other respondent who rated this problem as high felt that irregularities were annoying, but not threatening. One respondent

stated that he had a myocardial infarction last year, and was very careful regarding his heart. He indicated that he was more concerned about episodes of chest pain, than the occurrence of intermittent cardiac arrhythmias.

Treatment of heart irregularities included saline infusion to raise the blood pressure; experimentation with various types of artificial kidneys to determine if one type caused less cardiac irritability than others; and premature termination of the dialysis run to bring about cessation of the symptoms.

Difficulty with the access site ranked low by most respondents. The composite score was 17; the mean 1.13. Only two persons gave it a high rating; both of these respondents had initially begun hemodialysis with external cannulas, and had great difficulty with repeated cannula infections and clotting. After several months, both received fistulas and had no further problems. Four respondents who rated access difficulties low stated that they had either had revisions of the initial access site, or a new one surgically placed due to poor blood flow through the old fistula. Some of the respondents had their original fistula declotted without revision or surgical replacement. Of the remaining eight respondents who rated this problem as low, none had any difficulty with the access site. One respondent had a permanent external cannula, and had no difficulty with this access site. Fistula infections occurring at home were virtually non-existent for all respondents, but hospital borne infections were mentioned as a common

occurrence during dialysis training or in-center dialysis.

Air Emboli

The problem of air emboli had a very low composite score of 6. The problem was almost non-existent due to the intense and careful surveillance of the machine and blood lines during the run, by either the respondent or partner. Air emboli are more likely to occur during removal of the patient from the dialysis machine, when air pressure instead of a saline flush is used to push the blood from the dialysis lines into the patient. Sometimes this may happen too quickly, and the recipient receives a bolus of air. Prevention is accomplished through very careful monitoring of the returning blood as well as "double clamping" or extra clamping of the blood lines leading back to the patient. None of the respondents interviewed used this air pressure technique as a routine measure, although it is quite commonly used in many dialysis centers.

The six respondents who indicated air emboli as a minor problem expressed concern that it could be a potential hazard if an unforeseen and unobserved lead occurred in any part of the dialysis system. One respondent mentioned that this situation had almost occurred at home, but that he had been able to prevent any air from entering his system. He stated that it had been a very frightening experience.

Additional medical problems identified by the respondents included increased bleeding after dialysis (rated low by one respondent);

neuropathy, or progressive nerve degeneration and loss of sensation in the extremities due to the continuous presence of toxins circulating in the bloodstream (rated as high by one respondent and low by another); itching (rated as high by three respondents); and clotting problems with the artificial kidney causing fiber rupture in the kidney (rated as high by one respondent).

Most of these problems were treated medically by the respondent and his/her local physician or training center physician. Increased dialysis time sometimes aids in resolving neuropathy and itching, whereas increased bleeding or clotting is treated with variation in sodium heparin dosage during dialysis. Respondents stated that they worked cooperatively with the physician on some of these problems, and were satisfied with this solution.

Summary

Needle insertion, symptoms caused by low blood pressure during the dialysis run, and high blood pressure were the significant medical problems identified and discussed by this sample. Other important concerns which were emphasized by the respondents included lack of individualized care provided in the hospital or in-center dialysis, and general mistrust of some hospital procedures. Many of the respondents stated that they were not given the opportunity to participate in their care when present in the hospital or in-center setting and maintained that the attitude demonstrated by the health care staff

was not only an affront to their ability to function independently in the home, but could also promote the occurrence of medically hazardous situations.

It was apparent that these respondents wished to maintain knowledge and independence related to their medical care, and to continue to function independently in the management of many of their identified medical problems.

MECHANICAL PROBLEMS

Mechanical Problems are those difficulties directly related to the functioning of the dialysis machine, artificial kidney and ancillary supplies required for effective operation of the dialysis equipment.

Table 6 presents the individual problems ratings and the composite scores for each problem listed under the category of Mechanical Problems. It represents the distribution of responses of each respondent.

Machine Malfunctions

Machine malfunctions were given a composite score of 37 with a mean of 2.50. Machine malfunctions were considered a serious problem by most respondents. Difficulty with the machine was attributed to inadequate training, being isolated without anyone nearby who could assist with mechanical difficulties (as was the first home hemodialysis patient in the area) and a machine which did not operate well initially. Home hemodialysis patients who were not accompanied home by a kidney team member to set up and assist with the initial run had more

Table 6

Number of Responses Per Rating Designation -
Mechanical Problems

Mechanical Problems	Rating Designations*						Composite Group Score	Mean Score
	5	4	3	2	1	0		
Machine Malfunctions	3	0	5	0	7	0	37	2.46
Artificial Kidney Malfunction	1	1	2	1	7	3	24	1.60
Supply and Equipment Problems	2	0	0	0	11	2	21	1.40
Faulty Equipment	0	0	2	4	6	3	20	1.33
Power Failure	0	0	0	2	8	5	12	0.80

N = 15

*3-5 = High; 0-2 = Low

Overall Rating Total = Sum Total of: Each Rating Designation
X
Number of Responses Per Designation

difficulty than those who received such assistance. Some patients continued to experience difficulty with operation of the kidney machine after the technician had gone home.

Mechanical malfunctions were serious for those who experienced them. Three respondents had to either call a mechanic from the company to come to their homes to repair a non-functioning machine part, or order a new piece of equipment directly from the company.

Communication problems were identified by several respondents as a factor in continuing difficulty with their machines. Calls for assistance were not answered rapidly. One patient with a language problem was unable to obtain assistance in communication with the unit. Difficulties with malfunctioning and communication were alleviated when other patients in the area began to help each other.

Initially, one respondent had been on home peritoneal dialysis, but stated that it was very unsuccessful not only in terms of actual dialysis effectiveness, but also in terms of mechanical difficulties. After several months he began home hemodialysis training and did well. He mentioned that the hemodialysis machine had an average number of malfunctions and that he had no difficulty contacting the training unit concerning these problems.

The respondents who rated the problem as low stated that they either had very few actual problems with the dialysis machine, or that they called another patient in the area if assistance was needed. The machine was electronically and mechanically simple for several

respondents to operate and maintain due to their own technical aptitude and expertise. One respondent stated that he had farm machinery much more difficult to operate than the dialysis machine.

The pattern of assistance among patients appeared to provide a very effective means of dealing with many of the problems related to machine malfunction. The presence and active support of other patients seemed to facilitate the use of successful coping strategies.

Artificial Kidney Malfunctions

The artificial kidney is a separate apparatus which is connected to the kidney machine and to the patient's bloodlines. This piece of equipment is composed of a filtering membrane across which the actual exchange of waste products and toxins from the patient's bloodstream occurs. It consists of connection segments which attach to the dialysis machine, and connection segments which attach to and from the patient. The artificial kidney can be cleaned, re-sterilized and re-used up to three additional times, although all artificial kidney manufacturers recommend use for only one dialysis run. It is believed that with repeated usage, the kidney becomes less effective as a filtering mechanism.

Artificial kidney malfunctions, or defects within the artificial kidney causing leaks or faulty connections, was given a composite score of 24 by the respondents. The mean score was 1.60. Four respondents rated artificial kidney malfunctions as high. The problems

identified were blood leakage with one particular type of kidney, and several defective artificial kidneys which arrived in one boxload. Several respondents had used a type of kidney no longer in use today when they first began home dialysis, and stated that they had experienced continuous blood leakage problems. Leakage was usually due to poorly fitting connection segments. Respondents stated that they would try to return blood to themselves if possible, and restart dialysis if the leaking occurred early enough in the dialysis run. If not, they would terminate the dialysis run until the next day. Frequent occurrence of leaks caused inconsistent and poor dialysis, and increased blood loss. Artificial kidneys have been improved so that equipment is safer and leakage seldom is a problem.

Another respondent who rated the problem as high said that they had received several defective artificial kidneys in one boxload. Artificial kidneys are usually supplied in boxes of 10 to 20 kidneys. Most home patients order several boxes of the kidneys at one time, depending on how frequently they dialyze and how often they order supplies. Arrival of an entire box of kidneys which were defective had occurred only one time.

Other respondents who rated artificial kidney malfunctions as low stated that they had occasionally experienced problems with leaks, but had usually discovered them very early in the dialysis run. One respondent stated that he preferred certain brands of artificial kidneys

to others due to a high percentage of leaks he has discovered in specific types of kidneys. The majority found that the problem was manageable and infrequent in occurrence.

Faulty Ancillary Equipment

The problem of faulty ancillary equipment was rated low with a composite score of 20, and a mean of 1.30. Ancillary equipment such as intravenous tubing sets, needles and syringes, alcohol preptic pads, and liter bottles of normal saline for infusion were included in this category. Two respondents rated this difficulty as high, stating that they had intermittently received poorly functioning equipment. Blood tubing with poorly fitted connections for the machine, and I.V. tubing sets (one set had several small holes in the line) were the specific articles of faulty equipment in both cases and precipitated annoyance rather than any medical complications.

The remaining twelve respondents rated faulty ancillary equipment as low and also stated that the problem was of infrequent and intermittent occurrence. Some stated that they had received dull access needles. If the respondents discovered that there were any particular types of equipment at fault, they did not hesitate to try a different brand and to notify the company concerning the precise nature of the difficulty.

Equipment Delivery Problems

Supply and equipment delivery problems received a composite score of 21, and a mean score of 1.40. The two respondents who rated this difficulty as high stated that there were problems in receiving their dialysis supplies. Both indicated some insecurity in the fact there was a nationwide fuel shortage, and a resultant trucking strike. They feared that these circumstances might jeopardize their reception of supplies and equipment since they ordered supplies every two months. The respondents also stated that their supply of normal saline infusion had frozen en route to Missoula this past winter. (Saline freezes at temperatures of 25⁰F or less.) The freeze produced some difficulty since they were then required to purchase saline from a local distributing source and pay substantially more money for the product. These respondents live 40 miles from Missoula, and stated that they would attempt to borrow supplies from some of the Missoula patients if necessary. They could also have the needed supplies shipped by air freight instead of carrier.

The thirteen respondents who rated supply and equipment problems as low stated that they were quite satisfied with the current delivery status. Two of the group also mentioned frozen saline and said they attempted to avoid this problem by ordering saline only once or twice a year in large quantities.

It is interesting to note that most respondents ordered supplies and equipment on a six month basis rather than more frequently. Those

respondents who do order supplies and equipment more frequently may be utilizing a short term coping mechanism in an attempt to avoid a long term commitment to dialysis treatment. Denial of the need for long term dialysis could be a way of coping with kidney disease. Other factors must also be considered such as economic necessity. Borrowing needed supplies, equipment and machine parts from each other was a frequently utilized option, and again exhibited the pattern of support among the patients.

All supplies and equipment are routinely shipped from the training center or company by common carrier, unless an emergency situation develops. Air freight is then the designated mode of transportation. Four of the respondents were required to pick up their supplies at the carrier warehouse but the rest of the respondents had them delivered directly to their homes by the trucking carrier. None of the respondents voiced dissatisfaction with this particular arrangement, although those respondents who routinely received their supplies at the warehouses stated that extra time and assistance were required.

Power Failure

Electrical power failure, and subsequent difficulty with dialysis received a composite score of 12, with a mean of 0.80, a very low score. All respondents rated the problem low. None believed that it was or could be a serious situation. Many stated that the power company had their names and telephone numbers and would notify them if there were

to be anticipated power shut-down. Five respondents stated that they had actually been contacted by the power company under such circumstances, and they were then able to adjust their dialysis schedules accordingly.

Three respondents stated that they had experienced unanticipated power outages due to storm activity or accidental disruption of the necessary power supply. They had hand pumped their blood from the machine into their systems without any difficulty. Hand pumping the blood in order to remove the patient from the dialysis machine posed no particular difficulty to those respondents who had access to assistance from the dialysis partner at the time the outage occurred. However if the problem occurred when the respondents were alone, or to a respondent who routinely dialyzed alone, it would be a procedure which would require skillful coordination.

Many of the respondents had well-water in their homes and required electricity in order to obtain a water supply. If the water supply is compromised, the dialysis run must be terminated due to inability of the machinery to function in dialysis.

Most of the respondents believed that they were well trained for this possibility, and had responded well in simulated circumstances during training.

No other mechanical difficulties were identified by the respondents.

Summary

Machine malfunction and related technical difficulties were anticipated by the author to be very serious problems for respondents isolated from the home training center. However, even though machine malfunction was ranked as a significant difficulty, most of the problems and related stresses were resolved effectively by respondents.

There appeared to be a definite pattern of mutual respondent reliance. Respondents had developed a network of assistance and support among their patient group. The network provided an effective means of dealing with many of the stressors related to home dialysis. Calls to the training center were also cited as resolutions to problems in some cases, but most of the respondents sought and received help from other patients in the area rather than from the home training center. The patient network facilitated the development and utilization of effective coping behaviors and adaptational strategies.

Some of the patients residing in outlying areas, indicated feeling of isolation. In some cases, patient support was not available, and more difficulty with coping and adaptation could be expected from these individuals.

The mechanical/technical problems associated with home dialysis appeared to be generally manageable by the group studied with much of the management directly related to indigenous patient support.

Some of the findings related to this sample were inconsistent with the author's initial expectations, and described an overall

situation which was somewhat unanticipated. Many of the coping mechanisms and adaptational strategies utilized were devised in order to overcome factors of distance and isolation, and have functioned as effective methods of adaptational adjustment. The group has demonstrated some very effective means of functional and independent adaptation to a unique circumstance rather than exhibiting increased behavioral disorganization and instability resulting from a lack of proximate training center support. The home training center initially proposed by the author may not provide the only means of adequate resolution of some of the identified distance related problems.

PSYCHO-SOCIAL PROBLEMS (OTHER PROBLEMS)

Psycho-social problems are those problems directly related to the interpersonal and intrapersonal adjustment required for long-term adaptation to home dialysis and end stage renal disease. The category includes many of the stressors associated with the following: personal adaptation; spouse/family interaction and adaptation; social interaction; and general life style alteration.

Table 7 presents the problem rating distribution per respondent of the zero through five rating designations. It also includes the composite score for each problem as well as the mean score.

Dependence on Partner

The most highly rated problem listed under the category of Psycho-Social Problems was dependence of the respondent on the dialysis

Table 7

Number of Responses Per Rating Designation -
Psycho-Social Problems

Psycho-Social Problems	Rating Designations*						Composite Group Score	Mean Score
	5	4	3	2	1	0		
Dependence	5	3	0	1	5	1	44	2.93
Finances	6	1	0	2	4	2	42	2.80
Mobility/ Recreation	3	3	2	4	0	3	41	2.73
Fear/ Anxiety	4	2	1	3	2	2	39	2.60
Sleep Disturbances	4	1	1	2	5	2	36	2.40
Disruption of Family	3	1	4	1	3	3	36	2.40
Depression	2	1	4	2	5	1	35	2.33
Sexual Difficulties	3	0	1	5	4	2	32	2.13
Diet	2	1	1	5	3	3	30	2.00
Job	3	1	1	2	1	7	27	1.80
Family Problems	2	0	2	1	7	3	25	1.67
Restriction of Social Activities	1	0	2	3	5	4	22	1.47
Relationships with Friends	0	1	1	2	4	7	15	1.00

N = 15

*3-5 = High; 0-2 = Low

Overall Rating Total = Sum of: Each Rating Designation
X
Number of Responses Per Designation

partner. This difficulty was given a composite score of 44, and a mean score of 2.93. It is the most highly rated problem indicated on the checklist.

Eight respondents rated this problem high. Of those respondents rating dependence on the partner as high, six stated that they could not dialyze without the dialysis partner to assist them. They cited the most necessary function of partners as their ability to connect and disconnect them from the dialysis equipment. Two of those respondents stated that they really knew very little about the machine and its operation, and that the partner did all of the machine connection and operation related to dialysis. Both of these respondents indicated that they were attempting to do more of the procedure recently, in order to remove some of the burden from the spouse/partner.

One respondent who works full-time requires that his dialysis equipment be set up and ready to be utilized immediately when he returns from work in order to successfully allow dialysis time in his schedule. His spouse has accommodated him for several years, yet no problems were identified by the respondent or his spouse. The spouse reflected the impression that total commitment to her husband was her responsibility, and that she fully accepted it.

Three respondents stated that they depended upon the partner to assist with the dialysis procedure, but if necessary, they could probably function alone. One respondent discussed initial dependence on the spouse, but since marital separation, dialysis has been done

without a partner or assistant. Children could assist if necessary.

The respondents who rated dependence low believed that it existed in varying degrees, but did not constitute any kind of problem for them. All respondents believed that dialysis was confining or restrictive for the partner. However, some of the partners did not share this feeling with the respondent. Several partners were present for the interview, and their attitudes ranged from feeling unrestricted to feeling severely confined. One partner stated that home dialysis was restricting in terms of a career that the individual had worked very hard to develop, while several other partners expressed the attitude that dialysis assistance was their total responsibility. All partners interviewed with the respondents (nine) believed that they played a tremendous part in the overall care of their spouse or loved one, and shared the responsibility willingly in order to promote and maintain the respondent's optimum wellness.

Thirteen of the respondents expressed a desire for the partner to "take a break" a few times a year and consequently modify some of the continuous routine of dialysis care. There appeared to be very little bitterness or resentment exhibited by any of the spouses or partners interviewed, although in a few cases, some undertones of dissatisfaction were expressed. The respondents appeared to depend a great deal on the dialysis partner, and this finding might be partially attributed to the absence of a local training center. It may be that transfer of dependency by the client from the dialysis center to the

dialysis partner occurs with increasing isolation from a center. In a large rural state such as Montana, the patient and partner become the parties solely responsible for effective and adequate dialysis treatment on a routine basis. It seems as if this circumstance could foster increased dependency between the partners. Effective coping strategies related to dependence appeared to focus on acceptance of shared responsibility by partner and patient.

Financial Problems

Financial problems were the next most highly scored difficulty, receiving a composite score of 42, and a mean score of 2.80. Seven respondents rated this problem as high.

Most home dialysis patients currently maintain 80 per cent coverage by Medicare. However, coverage is not effective until the recipient has spent three consecutive months on maintenance hemodialysis. The remaining 20 per cent of dialysis costs must be met by the home dialysis patient, either by private insurance or by out-of-pocket payment.

A variety of reasons for financial difficulties were discussed by the respondents. Many respondents complained of costs not covered by insurance or of gaps in insurance coverage, especially for the initial three month period.

One individual incurred a very large medical debt during the first three months of dialysis and had no private insurance to carry

these costs. The person consequently amassed a very large hospital and physician bill and had no financial means to provide payment. The person was self-employed at the time and had no ideas concerning settlement of these costs. Other respondents had been partially covered by various private insurance plans. The non-reimbursable 20 per cent of dialysis costs not covered by Medicare were a problem for many respondents due to difficulty with private insurance firms accepting coverage of these costs, or complete lack of coverage.

Another family discussed the fact that they were drawing upon their savings to provide payment of these costs, and were beginning to diminish their financial resources. They had no answers as to what would occur when the resources were depleted.

Financial difficulty related to travel costs to and from the training center, and the considerable cost of housing during the time of home dialysis training (from 4 weeks to $3\frac{1}{2}$ months) were also discussed by the respondents. Two respondents had travelled to more distant training centers because of available housing during the training time. Both respondents had friends or relatives who could provide a temporary residence for them. Training centers are usually reluctant to accept patients from distant areas, but will agree to do so if the circumstances indicate a difficult situation for the patient and if the individual arranging for patient transfer were able to convince the center of the need.

An added financial stress cited by four of the respondents concerned a lack of gainful employment. Even with total insurance coverage of dialysis costs, a definite financial strain was incurred. If both spouse and respondent were unemployed, financial assistance would probably be provided by retirement or welfare compensation. Vocational rehabilitation had also absorbed some of the costs.

Another reason for financial strain was related to the building or revision of an area in the home to be used for dialysis. Eleven of the respondents had a separate room for the dialysis treatment and storage of dialysis supplies.

The remaining respondents who rated financial problems as low indicated that they maintained complete insurance coverage and had satisfactory supplemental incomes. Two of them did mention some initial difficulty with the insurance coverage.

Financial strain was specifically related to the cost of travel to and from the center, which was done up to twice a year unless there was an emergency, and the high cost of housing during the time of dialysis training. Most of the respondents have sought financial assistance of some kind, although for some, finances appeared to pose a very difficult problem with no immediate available resolution.

Mobility, Vacation and Recreation

Mobility, vacation and recreation received a composite score of 41, with a mean score of 2.73. Eight respondents rated this problem

as high. They indicated feelings of severe restriction in terms of vacations and travel, and discussed the difficulty in obtaining transient in-center dialysis. These respondents also had no means of transporting their own dialysis equipment or de-ionized water systems during travel. Several respondents stated that they had children or relatives residing in various parts of the country, and that they found it difficult, if not impossible to visit them. The in-center dialysis training unit arranged most transient dialyses for the patients but arrangements had to be made at least one to two months in advance. Depending on travel destinations, there might not be adequate dialysis facilities in the area. Four respondents did state that they travelled, but believed that it required a great deal of "hassle" and prior arrangement to do so.

One respondent who scored this problem as high, stated that recreation was a major frustration. The individual described himself as a very active person, and felt very restricted physically due to an inability to participate in highly active sports and recreational pursuits. The respondent remains active, but not to the degree which was previously enjoyed, and has found this to be a particularly difficult adjustment.

The seven respondents who felt that mobility, vacation and recreation were not problems for them appeared to have one of three reasons for the low rating. A reason cited by one respondent was the lack of need or desire to travel. Other respondents stated that the family

resided in the vicinity and they found that they could take an occasional two to three days off dialysis for travel purposes. Another reason discussed by some of the respondents was the availability of in-center dialysis enroute to their travel destination and at their travel destination, and their willingness and ability to pursue this alternative. They did not indicate that it was a problem to arrange for transient in-center dialysis. The fourth reason cited by respondents was the ability to take their machinery and equipment with them on trips and vacations. The respondents had camper-trailers or vans, and were able to set up and transport the necessary equipment in these vehicles, including the de-ionized water tanks. Under these circumstances, freedom of travel was much more feasible, and the respondent much less restricted. Mobile equipment provided an innovative and effective coping strategy for these respondents.

Many of the respondents who rated travel and mobility as a high priority, voiced a desire to own a recreational vehicle for such purposes, but did not have the available financial resources. Those respondents who were able to utilize this mode of dialysis-travel were very pleased with the results and maintained flexibility in terms of travel and accommodation to dialysis treatment "on the road".

Fear/Anxiety

Fear/anxiety received a composite score of 39, with a mean score of 2.60. Eight respondents rated it as high. Those respondents rating

the problem high stated that fear/anxiety was largely an initial reaction related to the change in their life situation due to renal disease, and to the beginning of self-sufficient home dialysis. The respondents also discussed anxiety in terms of home training, and the initial months of actual home dialysis treatment. Two respondents stated that they felt particularly anxious since they were among the first patients in the area to dialyze at home. Other respondents whose residences are 80 to 100 miles from the local back-up center stated that they felt quite isolated and fearful during dialysis due to lack of any experienced dialysis help in the immediate vicinity. Three respondents indicated anxiety concerning the course of their disease process, and the uncertainty which faced them in the future. Those most recently begun on home dialysis expressed strong feelings of anxiety at home. The reasons for these feelings stemmed from fear of being unable to handle or cope with unusual situations during dialysis runs. Needle insertion was also cited as an anxiety provoking problem for these respondents.

A few of the respondents who rate fear/anxiety as low stated that they were so glad to return home following training that anxiety was not a problem at all. They stated that they felt totally prepared and confident in each other's abilities to carry out the treatment procedures. Some of the respondents stated that they felt slightly reluctant initially, but once established at home felt very comfortable.

Of the nine spouses interviewed, over half of them stated that their initial anxiety level was much higher than that of the dialysis partner due to their feelings of responsibility for needle insertion and monitoring.

Those respondents who resolved their initial anxiety reactions (which constitutes all but the most recently trained patients) did so through repeatedly successful performances of necessary procedures, by seeking and accepting assistance from other home dialysis patients, and through communication and contact with the home training center when appropriate. Respondents stated that these strategies served to increase levels of confidence and decrease feelings of fear and anxiety.

The author expected distance from the home training center would increase fear and anxiety, and that the anxiety would not be greatly reduced by the passage of time. Most respondents who rated anxiety as high stated that they gave this rating based on their feelings during the first six months of home dialysis, and had since resolved many of their fears. Reasons for anxiety cited by some of the respondents who had recently begun home dialysis related to the absence of available medical assistance and the possible occurrence of unforeseen or unusual difficulties during dialysis.

Many of the respondents indicated that they were quite comfortable with dialysis even initially, due to their utilization of support from other patients in the vicinity, and contact with the training unit.

Those respondents residing at a distance from the larger community appeared to have higher anxiety levels than many of the respondents residing within the larger community. These patients were not only isolated from the training center, but also from other dialysis patients who could offer support and assistance.

Results concerning fear/anxiety were consistent with reference to the initial reactions of many of the respondents, but unexpected in terms of resolution after a period of time.

Depression

Closely related to fear/anxiety in terms of psychological reactions regarding an altered life situation, was depression. Depression received a composite score of 35, with seven respondents rating it as high. The mean score was 2.33. The respondents stated that their overall level of depression was much higher during the initial grieving process. Also, feelings of depression and frustration occurred quite commonly during home training partly due to the tension and anxiety manifested in learning the dialysis procedure and due to the realization of the long-term implications involving maintenance dialysis. One respondent stated that physical condition was responsible for some of the depression, and that continuing concern and anxiety about finances were also causative factors. Two respondents stated that they felt much more depressed following particularly difficult dialysis runs. They would feel very "washed out" afterward, and less able to

cope with the demands of everyday life. Another respondent believed that feelings of depression had increased over the years, and had not been as severe initially. The individual explained that this was probably due to the full realization and experience of the life-style restrictions caused by the illness.

The remaining respondents who rated depression as low stated that the problem was much worse initially, but that time and improved physical condition had assisted in decreasing the occurrence of depressive feelings. Two respondents discussed that they had known for many years that they would have to begin dialysis at some time in the future, and had begun to accept this circumstance long before it actually occurred. They expressed feelings of relief and satisfaction based upon their ability to successfully manage their lives under present conditions, and also related feelings of gratitude for being alive and able to function.

Most of the respondents indicated that they experienced intermittent bouts of depression even in a well-controlled situation, and that at these particular times, family and friends--often other kidney patients--were of immeasurable importance in offering encouragement and support.

Disruption of the Family During Training

Disruption of the family during training was given a composite score of 36, with a mean of 2.40. Six persons stated emphatically

that home training was disruptive to the family unit, particularly if there were children living at home. All six respondents with children at home stated that this was the primary difficulty, and that it was a serious problem to have to leave children at home and find care for them for an extended period of time. One respondent stated that he belonged at home assisting with the farm work, and he and his partner's absence during home training placed an extra burden on those family members remaining at home. Other respondents discussed disciplinary difficulties which erupted when older children were left at home with minimal supervision. Another respondent found that the patient's elderly mother who resided in a rest home became quite confused and bothered by the patient's absence. Leave from employment to attend training was also identified as a cause for disruption and concern to the respondent.

Those respondents who rated disruption of family as low either had no children living at home at the time of dialysis training, or they did not have any pressing obligations at home.

Some of the respondents found means of returning home each weekend during training to spend time with their families if children or other members were involved. One couple utilized this option, and although it required extra time, travel and financial investment, they found it was worthwhile in terms of maintenance of family stability.

Disruption of the family during training is an important consideration in relation to the initial family acceptance of the home dialysis situation. Anxiety and concern on the part of the partner and patient during training in regard to the family could have a definite effect upon successful completion of dialysis training. In some cases, assistance from friends and relatives provided the needed relief from these concerns, but in other cases family related problems only served to increase the anxiety level of the patient and partner. The fact that the patients were required to reside in the vicinity of the training center for an extended period of time during training may have served to foster more problems in terms of family disruption.

Sleep Disturbances

Sleep disturbances were scored as 36, with a mean of 2.40. Six respondents indicated this problem as high. The actual disturbances of sleep experienced by the respondents was believed to be due to physiological as well as psychological processes. Those who rated the problem as high expressed feelings of disturbance due to repeated occurrence of sleeplessness, and found little relief in use of sedative treatment. Three respondents cited nervousness as a primary reason for sleep problems, and one respondent stated that severe itching aggravated the nervousness and insomnia. Two respondents stated that lack of physical activity and idleness during the day were a major reason for their sleep disturbances.

Physiologic causes for increased irritability and nervousness are derived from the continuous presence of toxins in the bloodstream, and the eventual changes these toxins effect upon the nervous system. In addition to the physiologic manifestation is the combination of all the problems inherently involved in the entire dialysis life situation. Worries and fears concerning the disease process itself, treatment of the disease, employment and financial and family problems could accumulate and combine with physical difficulties to produce an extremely aggravating condition. Four of the respondents mentioned anxieties as major contributory factors related to physiologic problems.

The respondents who rated sleep disturbance as low stated that they either had no difficulties at all with sleep or that it was a very infrequent occurrence and easily manageable through the use of prescribed sedative medication. One respondent had sleep difficulties when on dialysis initially due to the presence of an external cannula in the arm, and a well established habit of sleeping on the arms. The individual now has an A-V fistula, and no longer has difficulty with body positioning.

Sexual Difficulties

Sexual difficulties received a composite score of 33 with a mean of 2.13. Several respondents rated the problem as high. Those who rated sexual difficulties as high were male respondents who stated that their sexual relationships with spouses had changed. Lack of

sexual desire due to fatigue and other physiologic changes as well as all of the psychological adjustments to illness were described by the respondents as reasons for sexual changes and difficulties. Most respondents stated that the difficulties had largely resolved themselves over time and that the high rating given to the problem was due to initial difficulties. Respondents did not consider sexual adjustments to be responsible for any major changes in their marriages. Resolution was related to recency of dialysis, with time being the primary variable related to eventual resolution.

Five of the respondents rating the problem as low also had found sexual adjustment more of a problem initially due to body image changes, but believed that the problem had been resolved. A few couples believed that their relationships were now much closer due to their sharing in dialysis treatment. The remaining respondents believed that the change in sexual habits which they encountered following the onset of illness was not a drastic one, and that this did not constitute a problem for them. The female respondents stated that sexual habits had not changed to any marked degree since the onset of illness.

Diet

Difficulties with diet received a composite score of 29, with four respondents indicating a problem with diet as high. The mean score for diet was 2.00. Diet was considered to be a problem by the respondents primarily due to the restrictions of sodium and potassium

in the renal diet. Respondents indicated a definite lack of choice of food variety, and emphasized difficulties with food management in places other than their own homes. Most canned goods, as well as a great many foods processed and prepared in commercial establishments contain large amounts of sodium. Light salt or salt substitute cannot be utilized as an alternative due to its high potassium content. The respondents found that the diet was definitely limiting, and also mentioned that it was a problem to have to prepare "special food" for them in addition to the food prepared for the rest of the household members. Some of the respondents discussed the increased frustration associated with unrelenting cravings for previously enjoyed foods. For these respondents, the problem of diet had not improved with time.

The respondents who rated diet as low indicated various methods of dealing with an adjusted diet. Several of the respondents consumed their favorite foods occasionally and found that this intermittent consumption of non-diet food posed no problems for them. Home canning of various fruits and vegetables was also utilized to avoid the high sodium content of commercially prepared products. Another reason cited by respondents for the low problem rating was strict adherence and acceptance of the renal diet. These respondents felt that the diet was a tool to assist them in achieving optimal health and preventing difficulties during dialysis.

Respondents gained anywhere in the range of one to seven pounds between dialysis runs. Several rarely gained more than one to three

pounds. None felt that weight gain was a problem, and all were able to adequately remove the excess fluid weight through dialysis. If, however, fluid exceeded what they normally gained between runs, dialysis became more difficult, and they complained of symptoms of fatigue and discomfort during and post dialysis. None of the respondents were careless about their diets, and all were very aware of dietary balance. Only one respondent felt ill prepared in dietary training, and stated a desire for more comprehensive diet instruction by the training unit.

Family Problems

Family problems, other than those previously discussed, received a composite score of 25 with a mean score of 1.69. This heading was included to encompass all family related difficulties not already listed as problems. Four respondents rated this as high. The respondents stated that problems were related to anxiety and tension during the initial months of home dialysis, and had since resolved. One respondent stated that it was difficult for the spouse to leave a job to accompany the patient to home dialysis training, resulting in some tension in their relationship. Some respondents stated that even though the family relationships suffered some tension and stress initially, their marriages had remained stable throughout and had actually improved under these circumstances. The respondent who stated that their marriage had not worked believed that dialysis was not a major factor and that other problems were present which were responsible for the separation.

The remaining group of respondents who rated family problems as low were families with children. Nine respondents stated that their children had become very involved in the home dialysis procedure itself, and many families had taught the procedure to children at home in order to relieve the spouse or partner of some of the burden, and to assist in emergency situations. Only one respondent discussed a problem with a family member who was unable to tolerate the actual dialysis procedure; a child did not want to be present at any time when the respondent was on the dialysis machine.

All of the respondents indicated a great need for intermittent relief for the dialysis partner. Some suggested in-center dialysis as an option, and others mentioned the need for a nurse or technician in the area to assist them at home during a partner rest period if it was not feasible for other family members to do so. A "vacation" for the dialysis partner was cited as a real necessity by many of the respondents, in order to assist in maintaining stability and positive adaptation.

The problems receiving the lowest composite scores in the Psycho-Social category were restriction of social activities--score of 22, mean of 1.47; and relationships with friends--score of 15, mean of 1.00.

Restriction of Social Activities

Three respondents rated social activity restriction as high, and

again mentioned travel and decrease in recreational and physical activity as a main reason for their rating. Only one respondent indicated feelings of severe confinement in all aspects of recreational and social activity. The remaining twelve respondents stated that there were either no real changes in social activity levels, or that due to the new acquaintances and friendships which were developed with membership in the local kidney association, their social lives had improved. Membership in the support organization appeared to be an important part in the lives of many of the respondents. The organization has served to enhance friendships among its members as well as provide opportunities for increased social activity.

Relationships with Friends

Two respondents indicated that relationships with friends had changed to a significant degree and gave this problem a high rating. One person felt that reluctance on the part of former friends to actively associate with the respondent after the onset of disease was due to being fairly young at the time of the illness (in the twenties), and also due to friends' fears and misunderstandings concerning the illness. The person believed that they were threatened by the occurrence of the illness in someone so close to their own age, and wanted to avoid having to deal with their fears and feelings. The respondent did state, however, that a close friend remained very supportive and had really "stuck by". The other family

who rated the problem as high stated that due to fatigue and changes in the amount of time they could spend with friends, some of their friendships had definitely been sacrificed. The patient also stated that the spouse believed that friendships were more of a problem for the spouse who continued to feel quite restricted in terms of previous social activities and friendships.

Of the remaining group, seven observed no changes in relationships with friends since dialysis had been initiated. One respondent felt that only the closest of their friends had stuck by them during this time, but that they had definitely adjusted to this. Five respondents indicated increased support and encouragement from friends since the onset of illness and dialysis. Many friends assisted with family needs such as caring for the children when the respondent and spouse were in home training, and others offered financial assistance.

Members of the kidney association felt that they had developed some valuable new friendships with each other, and that the bond of concern and sharing within this group has been a mainstay in their lives. The social activities arranged by the group had not only helped to enhance friendships, but also provided a real means of enjoyment and recreation for many members.

Additional Identified Stressors

The only problem added to this list was that of employment. Five respondents stated that this was a serious problem for them due to the

financial difficulties unemployment posed for the dialysis patient and family. This problem was given a composite score of 27 with a mean score of 1.80. The respondents stated that routine employment physicals were almost impossible to pass and continued employment requiring strenuous physical labor was very difficult to sustain. Employment was also restricted in terms of hours of work time and adaptation of work time to dialysis schedules. Some of the partners were required to seek employment in order to attempt to maintain adequate financial balance which placed further stress on the family unit.

Identified Resolutions

When the respondents were questioned as to what would have helped them the most during their initial six months on home dialysis, and what they have felt had actually helped them the most, the responses were very consistent. Fourteen respondents stated that having someone in the vicinity (a nurse or technician) trained in home dialysis procedures and machine functioning who could check on them intermittently would have been of valuable assistance to them. Two respondents stated that a training center was needed in Missoula, while the remaining group indicated that more adequate ancillary support in the vicinity would be adequate.

Two respondents stated that although home dialysis should be strongly supported in Montana, they did not think that training centers should be established throughout the state. They explained that there

was lack of an adequate number of patients to support a well-functioning training unit and comprehensive training program. They believed that the center in Spokane provided excellent home training and support, and that this facility should continue to be used as the home training unit for the western part of the state.

Two respondents were convinced that pre-dialysis consultation for the patient and family was a primary necessity for the home patient, and that such consultation would have helped greatly during the initial adjustment period. All respondents stated that having someone trained in home dialysis who could function as a partner substitute when the partner needed respite would be very beneficial. Most of the respondents were quite reluctant to use the local hospital dialysis facility due to the use of the two-needle method of blood access, and due to a general dislike of in-center dialysis procedures, including the high cost factor.

Respondents residing outside the community with dialysis facilities (30 to 120 miles) tended to feel more isolated, and expressed feelings of greater need for a trained individual to check on them; while those respondents residing within the community stated that they were not only closer to available health care, but also closer to members of the kidney association and other home patients who could provide assistance if necessary.

What actually did assist the respondents in adjustment to home dialysis? For some, repetition and practical, patient trial and error

learning, along with frequent phone calls to the home training unit helped the most. Other respondents believed that contact with and assistance from other kidney patients in the area was very helpful to them, even though many of them were quite confident with dialysis techniques and procedures. Self reliance, self confidence and independence were identified as traits most beneficial to home dialysis training and eventual success with long term home dialysis.

There is one nephrologist who functions as medical provider for most patients in western Montana. Respondents were generally quite satisfied with his care, although some believed that he was overloaded with patients so that provision of highly personalized care was very difficult. Many respondents also found that his dedication to the home dialysis idea had been a tremendous help to them and that the arrangements and support for training provided by the social worker in conjunction with the physician had been very beneficial.

Summary

There were some major problems directly associated with respondent distance from the home training center. These stressors included: dependence on partner; financial problems; fear/anxiety; and disruption of the family during training. The stressors directly related to the distance factor were consistent with the author's expectations concerning respondent outcomes. The unanticipated finding was in relation to the unique methods of coping with the difficulties exhibited by

this group. Many of the coping mechanisms and adaptational strategies utilized functioned specifically to overcome factors of distance and isolation. Rather than increased anxiety and possible behavioral disorganization resulting from the lack of proximate training center support, the sample demonstrated that leadership, self reliance and independence are effective means of adaptation to a unique circumstance.

The respondents did propose several suggestions related to more adequate problem resolution. These included: intermittent respite for the dialysis partner; assistance in the initial months of home dialysis by a trained resource person residing in the vicinity; pre-dialysis consultation for spouse and family; and more personalized care in the hospital or in-center setting. Follow through on their suggestions might even more effectively assist the home dialysis patient and family in adjusting to their altered life style.

CHAPTER 4

DESCRIPTION OF THE PROXIMATE SAMPLE AND FINDINGS

Introduction

The proximate group consisted of respondents who lived within 50 miles of their home dialysis training center, located in a metropolitan center in Washington. Of the 18 home dialysis patients living near the training center, six completed and returned the questionnaires and consent forms which were sent to them by the kidney center.

The proximate sample was selected as a comparison group. Their problems and resolutions were compared to those experienced by home dialysis patients who lived at a distance of 200 miles or more from their home dialysis training center. The same checklist was administered to both groups; the proximate group received it in the form of a mailed questionnaire while the distant group responded to it in the form of an interview.

Population Profile

The major characteristics of the sample are listed in Table 8.

The respondents ranged in age from 49 to 77 with a mean age of 61.8. The mean age is higher than the mean age for the distant sample. Five of the respondents were men, and one was a woman. Four of the five respondents stated that they dialyzed three times per week for four to five hours, and one respondent dialyzed every other day for four hours.

Table 8

Profile of Proximate Patient Population

Age:	Range = 49 - 77 years Mean = 61.8 years	Access Site:	Fistula = 6
Sex:	Female = 1 Male = 5	Original Site:	Yes = 4 No = 2
Place of Training:	SHMC, Spokane = 6	Length of Time on Home Dialysis:	Range = 3 mo.-4 yrs. Mean = $2\frac{1}{2}$ yrs.
Distance to Home Training Center:	Range = 3 - 26 miles Mean = 10.8 miles	Occupation:	Retired = 3 Unemployed = 2 Homemaker = 1
Dialysis Partner:	Spouse = 5 Other = 1	Adequate Support from Home Training Center:	Yes = 6 No = 0
Length of Training Time:	Range = 10 wks.-5 mo. Mean = $3\frac{1}{2}$ months		
Supplies and Equipment:	Home Training Center = 6		
Amount of Dialysis Time Per Week:	Range = 12 - 18 hours Mean = 14.6 hours		

N = 6

Three of the five respondents indicated that they were retired. The female respondent indicated that she was a homemaker, and the other two respondents stated that they were receiving disability payment and unemployment. The unemployment rate for this sample was 83 per cent with retirees counted as unemployed, and 33 per cent without the retirees. The 33 per cent figure is close to that of the distant sample which was 26 per cent without retirees.

The length of time on home dialysis varied from three months to four years, with a mean length of time on dialysis of two and one-half years. This is less than the mean for the distant sample which was three and one-half years.

The length of home dialysis training time ranged from ten weeks to five months with a mean of three and one-half months. The mean length of training time was therefore longer for the proximate sample than for the distant sample (mean training time was two months) and could be related to the fact that the proximate patients did not have to travel nearly as far for their initial training as the distant sample. They were not required to reside away from home for any length of time during training. The respondents who had to travel a great distance for training, and then remain in the area, may have completed home training more quickly in order to expedite the return home.

Five respondents indicated that they lived in the city and one respondent resided in a small town a few miles away. Respondents

received their home dialysis training, equipment and supplies directly from the medical center at which they were trained. Respondent distance from the training center varied from three to 26 miles, with a mean distance of 10.8 miles. The mean for the distant sample was 415 miles. All respondents indicated that they considered themselves close to the training center. In response to the question concerning proximity, two respondents stated that locations within the city limits were close; one respondent stated that locations within 15 minutes of home were close; and two respondents indicated that locations within a 30 to 50 mile radius were close. All respondents stated that locations beyond the described parameters were distant. The comparison between samples in terms of distance perception was very interesting. Montana respondents indicated that a distance of 200 to 900 miles from their place of residence was considered close, and convenient in terms of travel time and availability of the training facility. The other respondents stated that they considered their training centers as distant in terms of mileage, but that this did not necessarily denote inconvenience. Only two distant respondents stated that the training center was distant, and that access to the center was a problem. A major difference in distance perception between the samples was apparent.

Five respondents indicated that the spouse was the initial training partner, and was still the home dialysis partner. One respondent indicated that the spouse had been the original training

partner, but was no longer. No further explanation was offered.

The respondents utilized the Drake-Willock hemodialysis machine, and had fistulas as access sites. Two respondents indicated that the present fistulas were not the original access sites. One respondent stated that he had an external cannula for two years, and then received a fistula due to problems with the cannula. Another respondent explained that difficulty with the fistula due to poor blood flow and consequent clotting and infection problems had been experienced. The patient recently had a Gortex (synthetic) fistula inserted, and was still experiencing difficulties.

All but one respondent utilized the single needle access technique. The other respondent used double needles but gave no explanation regarding the technique.

The respondents all indicated that they were very satisfied with the support and care they had received from their training center.

Summary

These were the characteristics specifically related to the proximate sample. Some of the minor differences that existed between the proximate sample and the distant sample included mean age of the sample, unemployment rates and length of training time. The outstanding differences were individual distance perceptions and time spent training. There were no organizations for the proximate group and no other available assistance except that directly related to the training center.

Since the sample was not directly interviewed, much of the data obtained from the demographic questionnaire was presented, but not explained by the respondents. Consequently, the overall profile of the proximate group was not as complete as that of the distant group.

The two nephrologists responsible for the two groups of patients both believed that the distant group was an "exceptional group of patients". They emphasized the fact that the distant group had functioned very well independently, and in many ways had adapted more readily to home dialysis than kidney patients living in the vicinity of the city. The distant patients were described as a highly motivated group who offered a great deal of support and assistance to each other. The author was told not to expect the same degree of cooperation and support from the proximate group.

FINDINGS RELATED TO STRESSORS

The original expectation was that differences in rating of problems between the two samples would exist in terms of all dialysis related difficulties. The hunch was that the proximate sample would have fewer problems due to their close proximity to the training center, and the accessibility of immediate assistance and support. However, the findings indicated that although there were many similarities in scoring, some major differences also existed. Due to the small size of the proximate group, mean scores rather than composite group scores will be used to describe the identified stressors throughout the text.

in order to compare the samples. Since there were no interviews with the proximate kidney patients, there were no explanations and no elaborations on any of the responses. Please refer to Table 9 or Figure 2 for the individual composite scores.

Table 9 presents the comparisons between the samples based on composite group scores and means for all of the identified stressors. They are listed in descending order of importance according to category. Figure 2 illustrates the overall problem list in descending order of composite scoring.

The most highly rated problems included: machine malfunction; access problems; low blood pressure while on the machine; headaches, cramping, etc.; dependence on dialysis partner; finances; sleep disturbances; sexual difficulties; depression; restriction of social activities; family problems related to home dialysis; and mobility, recreation and vacation. Similarities and differences between the samples existed in all three categories. Major areas of difference were in the following ratings: needle insertion; access problems; finances; and fear/anxiety were all given high composite scores by the distant sample, and low scores by the proximate sample. Sexual difficulties; restriction of social activities; and relationships with friends were scored high by the proximate sample, and received low scores from the distant group. Basic differences in these scores could be attributed to distance from the center and different methods of coping and problem resolution for each sample.

Figure 2

Identified Stressor Profile in Descending Order
of Composite Score (Range = 0-30),
Proximate Sample

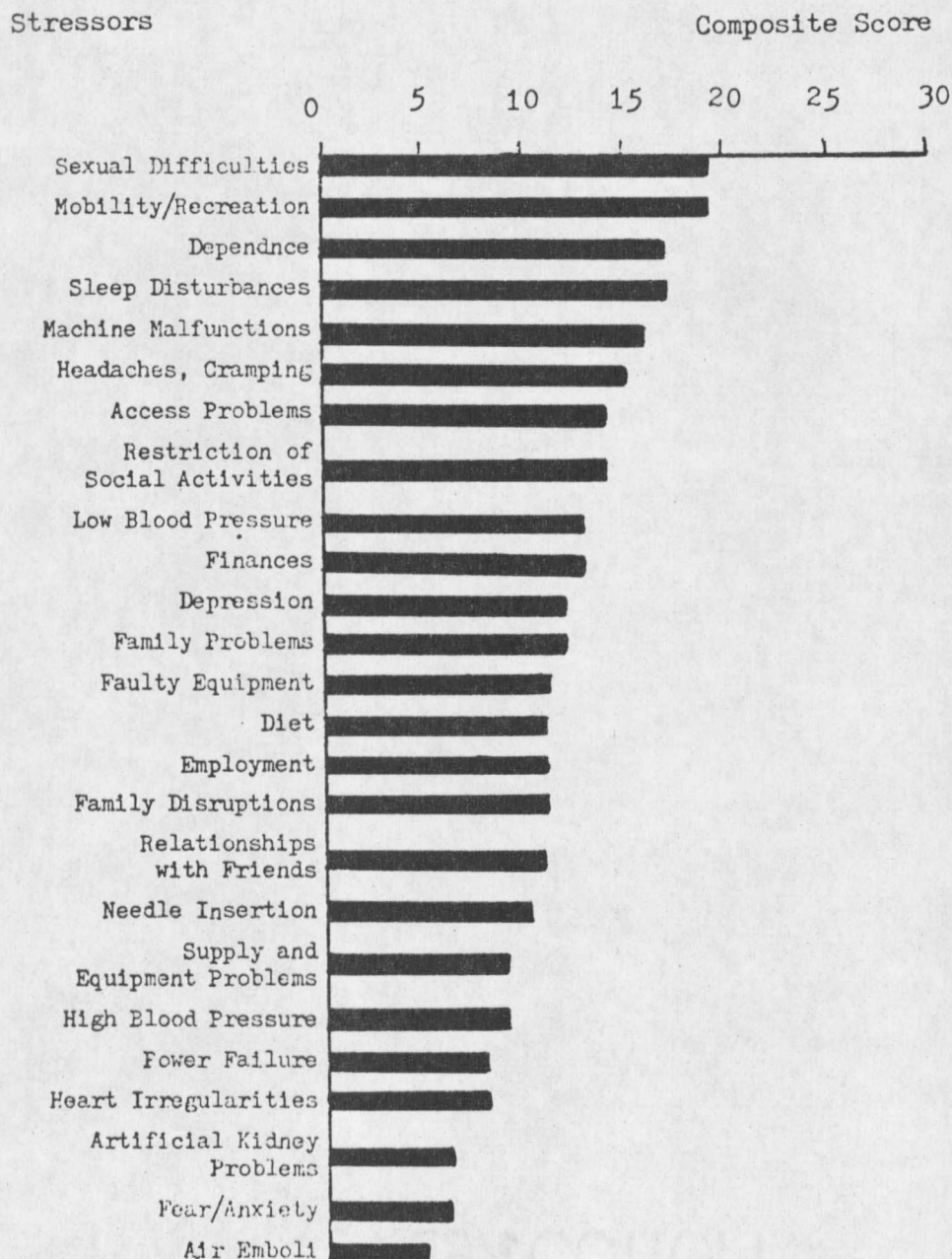


Table 9

Comparison of Composite Scores and Mean Scores
Per Sample, Listed in Descending Order Per Category

Identified Stressors	Composite Scores		Mean Scores	
	Proximate Sample	Distant Sample	Proximate Sample	Distant Sample
MECHANICAL:				
Machine Malfunctions	16	37	2.67	2.46
Faulty Equipment	11	20	1.83	1.33
Supply and Equipment Problems	9	21	1.50	1.40
Power Failure	8	12	1.33	0.80
Artificial Kidney Malfunction	6	24	1.00	1.60
MEDICAL:				
Headache, Cramping, etc.	15	42	2.50	2.80
Access Problems	14	17	2.33	1.13
Low Blood Pressure	13	36	2.17	2.40
Needle Insertion	10	43	1.67	2.87
High Blood Pressure	9	35	1.50	2.33
Heart Irregularities	8	24	1.33	1.60
Air Emboli	4	6	0.67	0.40
PSYCHO-SOCIAL:				
Sexual Difficulties	19	41	3.17	2.73
Mobility/Recreation	19	32	3.17	2.13
Dependence	17	44	2.83	2.93
Sleep Disturbances	17	36	2.83	2.40
Restriction of Social Activities	14	22	2.33	1.47
Finance	13	42	2.17	2.80
Depression	12	35	2.00	2.33
Family Problems	12	25	2.00	1.67
Family Disruption	11	36	1.83	2.40
Diet	11	30	1.83	2.00
Employment	11	24	1.83	1.80
Relationships with Friends	11	15	1.83	1.00
Fear/Anxiety	6	39	1.00	2.60
Proximate Sample N = 6 Range = 0-30				
Distant Sample N = 15 Range = 0-75				

PSYCHO-SOCIAL PROBLEMS

The most highly rated problem in this category was sexual difficulties, which received a mean score of 3.17. Sexual difficulties were scored as low by the distant sample. Possible explanations for this scoring difference might be related to the increased group activity and support available to the distant sample, and the consequent development of more effective coping strategies associated with marriage and family. Perhaps members of this sample were able to communicate more freely with each other concerning difficulties at home, and received advice and support from other group members.

Dependence and sleep disturbances received mean scores of 2.83 and 2.83 respectively. This scoring is parallel to that of the distant sample. Dependence was a highly scored problem for both samples. Since no explanations for scoring were offered from the proximate sample, it is difficult to draw any conclusions regarding dependence and distance from the training center related to this sample. Although no explanations were offered by the proximate group, because of the nature of dialysis treatment, dependence may be a major problem of all dialysis patients regardless of proximity to the center.

Mobility, recreation and vacation received a mean score of 3.17. Restriction of social activities was scored as 2.33 and relationships with friends was scored as 1.83. Individual ratings for these three problems corresponded closely in 50 per cent of the respondents. These three problems were closely related, and all received high composite

scores from the proximate sample. The distant sample rated mobility and recreation as high, but the other two problems as low. The opposition in composite scoring between the samples could be related to the activity of the distant support group, and the increased social interaction available to the respondents due to the group activities. There were probably fewer opportunities for social interactions among the respondents who have no functioning indigenous support group.

Financial difficulties received a mean score of 2.17. Two respondents rated financial difficulties as high. All respondents appeared to maintain adequate insurance coverage. Financial difficulties were cited by the distant sample as much more severe. For them distance related costs were considerably higher than for the proximate patient.

Employment received a mean score of 1.83. The same respondents who rated finance as high also rated this stressor as high. The other respondents rated the problem as low. One respondent stated that his spouse was employed due to necessity, but indicated that this was not a problem.

Depression received a mean of 2.00. The scoring was quite similar to that of the distant sample. However, fear/anxiety was given a mean of 1.00 by the proximate population. The distant sample scored fear/anxiety much higher. This scoring could be attributed to the distance of the proximate group to the training center, and the availability of immediate medical support. There appeared to be a great deal of dependence on support from the training center among proximate patients.

Coping and adaptational skills appeared to be closely associated with the presence and access of the center, and short term coping could account for the decreased amount of anxiety experienced by the respondents. Short term coping consisted of calling the center whenever the patient felt anxious. This fostered a great deal of dependence on the center. The distant group utilized group support as a long term coping strategy. Group interaction outside the home served to reduce intensity within the family and improved the overall perspective for the patient.

Diet received a mean score of 1.83. The ratings between samples were quite similar. Two respondents rated it as high, but no discussion of the rating was available. Both of these respondents also rated mobility/recreation and restriction of social activities as high, and probably experienced diet as a contributory restriction.

MEDICAL PROBLEMS

The most highly scored medical problems were headaches, cramping, etc., and low blood pressure on the machine. Headaches, cramping, etc., received a mean of 2.50. Two respondents rated this problem as high. Low blood pressure was scored as 2.17. One respondent rated this problem as high and also rated headaches, cramping, etc., as high. He appeared to have significant difficulties with both. Low blood pressure and headaches, cramping, etc., appeared to correspond in four of six responses. The physiologic relationship of the problems could account for the corresponding scores. These scores are very close to the ratings designated by the distant sample.

Access problems such as clotting or infection of the access site was given a mean of 2.33. Two respondents rated this difficulty as high. Both respondents described recurrent difficulties pertaining to blood access sites. One respondent indicated that he had received a cannula initially, but was changed to a fistula due to continuous problems with the cannula. The other respondent stated that he had very poor blood flow through his fistula, and had recently had a revision. His new fistula was one composed of the synthetic material Gortex, and has required surgical declotting twice since its installation in December of 1978. This sample appeared to have a few more difficulties with access sites than did the distant sample.

Needle insertion difficulties received a mean of 1.67. One respondent rated it as high. The respondent had also designated access site problems as high, and appeared to have difficulty with both. The low composite score given to this problem by the proximate sample might be attributed to proximity of the training center, and the availability of immediate assistance if needle insertion became a problem at home. The distant sample scored this problem as high, and described repeated difficulties with needle punctures. The lack of assistance from the training center would increase the anxiety concerning the procedure and the problems resulting from an increased amount of trial and error learning.

Heart irregularities and high blood pressure were given mean scores of 1.33 and 1.50 respectively, with one respondent indicating both

problems as high. The remaining respondents may not have encountered either of these problems, or had them well under control. The ratings indicated by the distant sample for these two problems were comparable. However, some respondents identified increased anxiety levels due to the lack of direct access to medical care.

Air emboli received a mean score of 0.67, the lowest of the identified stressors. All of the respondents rated this as low. The saline flush blood return method was taught at Sacred Heart Medical Center and most of the respondents utilized this technique. This rating was consistent with the distant rating.

MECHANICAL PROBLEMS

The category of mechanical problems contains one highly scored problem. Machine malfunction was given a mean score of 2.67. Three respondents rated this problem as high. One respondent stated that he had difficulty with the machine's electrical system and had consequently encountered operational difficulties with the machine. Two respondents cited difficulties with machine components such as the water filtering system and the blood leak detector. In all cases, the kidney center was contacted for assistance, and the malfunctions were resolved. This problem received similar scoring from the distant sample, but the distant sample utilized some different methods of coping. They traded machine parts among each other, and depended upon assistance from other patients for resolution of some of the machine malfunctions.

Faulty ancillary equipment was given a mean score of 1.83, with one respondent rating this difficulty as high. The respondent indicated that a blood leak detector was malfunctioning, and that he received immediate assistance concerning the problem from a center technician. No other types of equipment problems were cited by the respondents.

Supply and equipment delivery problems received a mean score of 1.50 and were cited by one respondent as high. The problem entailed the delivery of a barrel of dialysis concentrate which had several leaks in it. The barrel was immediately replaced by the training center. Another respondent indicated that he had minor problems with equipment delivery. There was no discussion concerning the trucking strike and related difficulties. All supplies could be obtained directly from the center if transportation became a problem. There was more concern on the part of the distant sample due to the distant location of supplies and equipment. Borrowing necessary items from other patients in the area was discussed as an alternative method of obtaining the required equipment if there were transportation problems.

Power failure was scored as 1.33. One respondent considered this to be a serious problem. The respondent stated that he had experienced a few power failures, and that these occurrences had caused some difficulties.

Artificial kidney malfunctions received the lowest score in this category. It received a mean of 1.00. There were no respondents who

rated this stressor as high. The distant sample indicated a few more difficulties with artificial kidney malfunctions, but their scoring was quite similar to that of the proximate sample.

ADDITIONAL PROBLEMS

No additional problems were identified by this sample. The responses regarding the problem resolution questions were very consistent. The respondents indicated that they received direct assistance from the training center in all necessary cases. No other methods of problem resolution were suggested or discussed by the sample. One respondent indicated that patience was an invaluable attribute related to the continuous adaptation to home dialysis. There were no indications of network support linkages among the patient population, and no mention of assistance from other home dialysis patients residing in the area.

SUMMARY

Major difficulties identified by this sample were similar in many respects to those problems cited by the distant sample. The differences in stressor identification between the samples were primarily related to the presence or absence of training center support. The lack of group support from other patients in the city or vicinity also contributed to some differences in problems and their resolutions.

The particular problems of increased difficulty related to the Washington sample such as sexual difficulties, restriction of social

activities, and relationships with friends were closely related to interpersonal situations. The difficulties identified by the distant sample were more closely related to distance from the training center.

The proximate group did not appear to exhibit the traits such as independence, leadership and self-sufficiency that were so prominent in the distant sample. However, it must be remembered that the data collected pertaining to the proximate sample was not as comprehensive as the data gathered in terms to the distant sample.

CHAPTER 5

LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

INTRODUCTION

The purpose of the study was to investigate some of the difficulties concerning home dialysis patients who resided at a distance from their home training center, and to determine what some of the resolutions and coping strategies related to this distance have been.

In previous chapters, the rationale for the study, related literature, and actual implementation of the project were discussed. In the final chapter, the author will present some of the conclusions drawn from the study, some of the implications for nursing, and propose recommendations for further investigation.

LIMITATIONS

Sample Size

The distant sample consisted of 15 home dialysis patients residing at 200 miles or more from the home training center. This was the total population of distant home dialysis patients. All the patients in this sample were interviewed by the author.

The proximate sample consisted of 18 home dialysis patients who resided within 50 miles of the home training center. There were six responses out of the 18 possible respondents, and in this case the checklist and questionnaire were administered by mail rather than by

direct interview. The response percentage (33 per cent) was too small to generalize to the total population of the proximate sample.

Data Collection Instruments

The data collection instruments were developed through the utilization of three major sources of information:

- 1.) Home dialysis problems described by a home patient with whom the researcher worked on an individual basis prior to the study;
- 2.) Dialysis problems directly observed by the researcher during her employment on an in-center dialysis team;
- 3.) Home dialysis problems cited in the literature.

The various problems pertaining to dialysis were then compiled and categorized into the checklist format.

Reliability and validity of the data collection instruments are questionable not only due to the fact that the tool was not pre-tested, but also to the variation in the administration of the tool between samples. The difference between direct interview and mail completion of the tools accounted for a large gap in the description of detail related to the identified stressors. Also, since total populations were utilized in both samples, it was not possible to actually pre-test the research instruments prior to the initiation of the study. This situation could also account for some faults in the accuracy of the tool. There were also a couple of identified stressors which could have been combined in order to prevent overlapping and redundancy of description related to these stressors.

Employment and financial difficulties could be included as "Financial Difficulties" alone. Family problems related to home dialysis could have been omitted. No respondents actually indicated any new or different stressors related to this problem category.

In terms of the sample responses, the distant sample was very open in communicating their problems and concerns. The proximate sample, however, either do not perceive themselves as having many problems, or they are reluctant to share their problems fully with the researcher. It was difficult for them to share specific concerns due to the lack of any previous contact with the researcher, and the difference in the instrument administration.

There were several interactions between the researcher and members of the distant group prior to the study.

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

The three basic questions related to the study were: 1.) What are the most frequently encountered problems of home dialysis patients who reside at a distance of at least 50 miles from the home training center?; 2.) What are some of the resolutions patients have used in coping with distance from the center?; 3.) Are there differences in kinds of problems and resolutions experienced by dialysis patients who live in proximity to the training center and those who reside at a distance from the center?

The researcher had several opportunities to meet with the distant sample in both formal and informal settings. In April, 1979, a workshop for home dialysis patients affiliated with a distant training center was held. Many of the home dialysis patients in the distant sample, as well as some of the members of the proximate sample, attended this gathering. This was the only opportunity the researcher had to directly observe members of both samples. The distant group was referred to several times by physicians and members of the health care staff as the "independent" group. The distant group also displayed a great deal of knowledge related to their treatment, and an outstanding group cohesiveness. The proximate group was more difficult to evaluate. They did not display the group participation so apparent in the distant group. The distant sample was very cooperative during all interviews, and welcomed the researcher with much openness and honesty in all encounters both formal (interviews, and kidney association meetings), and informal (association social gatherings). The researcher was introduced at one of the monthly association meetings, and her project endorsed openly by the members of the association.

The stressors rated most highly by the distant sample included: dependence on partner; needle insertion difficulties; headaches, cramping, etc.; finances; mobility and recreation; fear/anxiety; and family disruption during home dialysis training.

It was the author's initial expectation that the patients living far from a center would experience more stress associated with the

home dialysis situation due to distance from the center. Mechanical and medical difficulties were not as highly rated as some of the psychosocial stressors related to dependence, family disruption, finances and anxiety. Those mechanical and medical stressors related to distance were cited as supply and equipment delivery problems, machine malfunctions and needle insertion difficulties. The stressors were contributory to increased feelings of anxiety by the home patient.

Primary resolutions utilized in coping with the distance related stressors were described in terms of indigenous patient support systems and direct contact with the training center. The patients not only offered assistance concerning their problems to one another on an individual basis, but also developed an actively functioning formal support organization. The Kidney Patients Association of Montana, Five Valleys Chapter was organized to provide some of the necessary local support and assistance for home patients and their families by promoting many social and recreational activities among group members, and by facilitating communication among home dialysis patients and families, the medical community and residents of the state of Montana. Direct contact with the training center for assistance was also utilized by the distant group as a coping strategy, but not to the same extent as active patient support methods. Traits such as leadership, self-sufficiency, independence and self-knowledge were features markedly exhibited by this sample.

The stressors identified by the comparison sample who reside within 50 miles of the training center were similar in certain respects and quite variant in others. Some of the major stressors such as dependence, mobility and recreation, headaches, cramping, etc., were identified as difficulties by both groups and, according to related literature, were problems common to most home dialysis patients. Some of the medical problems such as needle insertion difficulties were given low rating by the more proximate group, due to more rapid manageability in terms of closeness to medical help. There were fewer concerns related to delivery of equipment and supplies and family disruption during training. Fear/anxiety was also a problem of very low rating. These responses were consistent with the author's expectations regarding proximate home dialysis care.

However, some of the psycho-social problems such as restriction of social activities and relationships with friends were more highly scored by the proximate group. Because the proximate group had easy access to the center there was no pressure toward developing a support group or toward involving peers in the solutions of problems. The group experienced a greater degree of social isolation due to their illness even though they were closer to the training center.

Another interesting difference between the groups existed regarding distance perception. The proximate sample tended to regard any location within a 30 mile radius of the training center close, whereas most of

the distant sample perceived distances in the range of 200 to 900 miles as close. Variations in urban/rural distance orientation might explain these interpretations.

Differences in problem resolution were quite apparent between the groups. The proximate sample cited all resolutions to identified stressors in terms of contact with the training center. There were no references to utilization of any forms of patient support networks. The absence of indigenous patient support systems, and the reliance of the group on assistance from the training center may account for increased difficulty with interpersonal interactions. The distant support group increased the flexibility and long term coping of every kidney patient in the area. The difference raises a question about rural people being better equipped to cope with some kinds of stress than urban people because rural people do not have the services available to become dependent on. It is a general belief that rural people wait longer to consult a physician. Perhaps at the current state of medical expertise they are better off in not calling on a medical specialist as frequently as their counterparts in urban areas.

The findings indicate that there are definite differences between the samples in problems and resolutions. It was initially believed that the patients residing within proximity to the training center would not only have fewer dialysis related problems, but would also have better integrated and developed adaptational coping skills. However, the "isolated" or distant group did not necessarily experience

more stressors related to dialysis, just different stressors, and have effected many successful strategies for problem resolution and general adaptation to the distance situation. The group developed independent and innovative coping strategies to compensate for distant location, and developed network linkages based on mutual needs to share concerns and provide encouragement.

Nursing Implications

The patient's personality, life expectations, family situation, and relationship with the health care team all directly influence the degree to which successful adaptation to the home dialysis environment will occur. In order to facilitate effective adaptation to routine dialysis, it is necessary for the nurse to understand the factors related to long term maintenance dialysis. The nurse must have an honest appreciation of the problems encountered by the home patient and must realize that many patients have developed successful coping strategies and self-sufficient life styles in spite of chronic illness.

Nurses working directly with home dialysis patients must constantly seek improved means of assistance for the dialysis patient and family. Group sessions for patients, spouses and families, intermittent home visits, provision of respite for the home dialysis partner, and ongoing emotional support are a necessary part of complete care. This is true particularly in terms of the patient who resides at a distance from the training center.

Those nurses working intermittently with home dialysis patients such as in a clinic or acute care setting must also be continually aware of the unique environment in which home dialysis patients normally function. The nurse must actively seek input from the patient and family concerning their home dialysis, and must then utilize this information to its maximum potential. Totally individualized care must be provided based on the needs and experiences of the home patient. In this way, a mutual rapport between patient and professional can be established.

Because it makes more options available for different patterns of living, every effort should be made to promote and support the development and maintenance of patient support groups. Support of the patient requiring long term care must be provided in terms of the ongoing life alterations experienced by the patient. The health care team must find ways of promoting support from within the professional establishment, as well as from within the patient group.

Recommendations

There have been few studies directly related to the problems and experiences of the home dialysis patient who resides at a substantial distance from the home training center. The Montana sample was a group of patients who functioned in this unique circumstance, and who have developed unique methods of coping with the situation. Based on the findings from the present study, the author proposes several

recommendations. The recommendations relate to improvements in the study, as well as suggestions for improved care of the home dialysis patient. Implications for further study are also included. The author recommends that:

- 1.) More complete data be obtained from the proximate group through inclusion of individual interviews. A larger proximate sample is also necessary in order to provide a more complete comparison between the populations.
- 2.) Comparable projects be conducted in other states with large populations of rural home dialysis patients. Studies could be done regarding rural versus urban population perceptions in terms of home dialysis problems, distance orientation, and development of adaptational skills. Larger populations must be utilized in order to draw adequate comparisons, and the research tool would need to be refined to reduce overlapping of categories.
- 3.) Utilization of the current dialysis capabilities within the state of Montana should be researched with particular emphasis placed on differences between in-center and home dialysis treatment facilities. A project could be done similar to this one, with utilization of a Montana training center instead of an out of state facility.

- 4.) The feasibility of more adequate back-up support for home dialysis patients who reside at distances from the center within the Missoula area should be researched. The researcher believes, however, that although a home training center in the Missoula area would be beneficial in terms of new home dialysis patients, other methods of support seem more feasible. The small number of new home dialysis patients per year does not support the development and maintenance of a successfully functioning comprehensive unit. The use of a mobile unit, such as one used in rural areas of Colorado (Sundahl, 1975) could also be an alternative method of back-up support for home patients.

A mobile unit could be staffed by nurses trained specifically in home dialysis techniques. It would function as a support unit for patients who are experiencing difficulties at home, and would provide intermittent respite for home dialysis partners. Some of the home dialysis patients in the vicinity have obtained extra machine parts and equipment over the years and would perhaps be willing to assist in the development of such a unit. The kidney patients in the local area would be an invaluable aid in the development of such a project.

- 5.) More comprehensive studies need to be done investigating the differences between rural and urban populations in terms of distance interpretation and perception of access to medical care based on these interpretations.
- 6.) The formation, development and inner mechanisms involving patient support networks be examined in relation to adaptational and coping strategies, and as alternative methods of home dialysis back-up support. Specific studies could be conducted concerning kidney patients who have developed their own support groups. They could be longitudinally compared with patients who have no support groups.

The study of many of these areas would not only promote further insight into the dialysis situation in an area such as Montana, but would also provide implications related to the improvement of nursing care for rural residents in general.

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APPENDICES

APPENDIX A

DIALYSIS PROBLEM CHECKLIST

This is a checklist of problems you may have possibly had during your first six months of home dialysis, and may still be having now. Please read through them, and have in mind when we meet for our interview, which of them you may have had or are experiencing now, and how serious they have been to you. On a scale of 1, 2, 3, 4, 5, please rate the ones you have had according to how serious they were or are for you, 5 being the most serious, and 1, the least serious. When we meet for the interview, we can discuss what you think, and you can add any other problems I may not have included. If you have any questions prior to our meeting, please call me at 258-6431.

Please check problems, then place number next to check mark.

Mechanical problems:

- ☐ machine malfunctions
- ☐ artificial kidney malfunctions (such as coil leaks)
- ☐ power failures
- ☐ faulty equipment of any kind (including I.V. sets, needles and syringes, etc.)
- ☐ supply and equipment problems
- ☐ any other problems not included

Medical problems:

- ☐ needle insertion difficulties
- ☐ access problems, including infection of site
- ☐ low blood pressure while on the machine
- ☐ headaches, cramping, nausea, vomiting during the run (Indicate any other problems you have encountered during dialysis runs.)
- ☐ heart irregularities

- ☐ air emboli
- ☐ high blood pressure

Other problems:

- ☐ diet
- ☐ dependence on partner/assistant
- ☐ finances
- ☐ sleep disturbances
- ☐ sexual difficulties
- ☐ depression
- ☐ fear/anxiety (concerning the disease, or concerning dialysis)
- ☐ restriction of social activities
- ☐ disruption of family during training
- ☐ family problems related to home dialysis
- ☐ mobility, vacations and recreation
- ☐ relationships with friends

What might have helped you to resolve these problems more easily?

APPENDIX B

DEMOGRAPHIC DATA

The purpose of this form is to gather some basic information about each participant in the study. There is no need for you to write your name.

Please complete the following:

1. Age _____ Number of dialysis runs per week _____
Amount of time per run _____
2. Sex _____ Occupation _____
3. Length of time you have been on hemodialysis _____
4. Length of time you have been on home hemodialysis _____
5. Community of which you consider yourself a resident _____
6. Place of home dialysis training _____
7. Approximate distance from your home to your home training center

8. Home dialysis partner (list relationship of person to you)

9. Is this the same person with whom you home trained? If no,
explain.
10. Type of dialysis machine _____
Single or double needle _____
11. From whom is the machine leased? Explain.
12. From whom are supplies and equipment obtained _____
13. Type of blood access site _____

14. Is this your original dialysis site. If no, explain.

15. Do you consider your home dialysis training center as close or far away? Explain.

16. What do you consider close? What do you consider far away?

17. Do you feel that you receive adequate support and care from your home dialysis training center? Explain.

18. Length of time spent in home dialysis training _____

(Circle) Prefer: home dialysis
center dialysis

APPENDIX C

CONSENT FORM

I _____ agree to complete the enclosed forms by Teresa E. Snyder, and to participate in the study described in this letter. I understand that any information obtained in this study will be strictly confidential, and will only be used for purposes concerning this study, and that my name will not be used in any way, other than an indication of consent for this study.

Name (printed) _____

(signed) _____

Date _____

APPENDIX D

MONTANA COVER LETTER

Box 459
Bonner, Montana 59823
June 10, 1979

Dear

I am writing this letter to ask for your help. I am a registered nurse working on my Master's Degree in Nursing from Montana State University, and have also worked as a dialysis nurse. During this time, it has come to my attention that there are some very needed improvements in the care of home dialysis patients, especially those people who are situated far away from their home training center, or any back-up center for that matter. I am going to conduct a study dealing with this situation, and hopefully, from the results of the study, some better forms of care can begin to be provided for the home patient.

What I will need to do in order to conduct the study, is interview many home dialysis patients regarding their experiences on home dialysis--particularly those experiences dealing with the first six months of home dialysis.

Your name was given to me by Dr. John Reiter of Missoula as a possible participant for the study. Your assistance in this study is greatly needed, and would be very much appreciated. It is strictly voluntary on your part, and complete confidentiality is guaranteed in all matters concerning the study. Enclosed is a consent form for you to sign, if you would be willing to assist me with this. Please let me know as soon as possible. If you have any questions concerning the study, please feel free to write to me at Box 459, Bonner, Montana 59823; or call me collect at (406) 258-6431. Thank you very much.

Sincerely,

Teresa E. Snyder, R. N.

APPENDIX E

REVISED CHECKLIST

This is a checklist of problems you may have possibly had during your first six months of home dialysis, and may still be having now. Please read through them and decide which of them you may have had or are experiencing now, and how serious they have been to you. On a scale of 1, 2, 3, 4, 5, please rate the ones you have had according to how serious they were or are to you, 5 being the most serious, and 1, the least serious. Place the numbers in the spaces provided before each problem. Please add any other problems I may not have included.

Please place the number next to each problem, and explain why it was a problem and what you did about it.

Mechanical problems:

- _____ machine malfunctions
- _____ artificial kidney malfunctions (such as leaks, faulty connections, etc.)
- _____ power failures
- _____ faulty equipment of any kind (including I.V. sets, needles and syringes, etc.)
- _____ supply and equipment problems

Medical problems:

- _____ needle insertion difficulties (hematomas included)
- _____ access problems, including infection of site or clotting
- _____ low blood pressure while on the machine or immediately after
- _____ headaches, cramping, nausea, vomiting during the run
- _____ heart irregularities
- _____ air emboli

_____ high blood pressure

_____ Please indicate any other problems you have encountered during dialysis runs.

Other problems:

_____ diet

_____ dependence on dialysis partner

_____ finances

_____ employment (Is spouse employed? If so, due to necessity or choice?)

_____ sleep disturbances

_____ sexual difficulties

_____ depression

_____ fear/anxiety (concerning dialyzing at home, or concerning renal disease)

_____ restriction of social activities

_____ disruption of family during training

_____ family problems related to home dialysis

_____ mobility, vacations and recreation

_____ relationships with friends

_____ Any problems not mentioned

What did you or do you usually do if you have a dialysis problem, or question?

What might have helped you to resolve these problems more easily?

What has helped you to resolve the problem?

APPENDIX F

LETTER TO SPOKANE

Box 459
Bonner, Montana 59823
July 11, 1979

I am writing this letter to ask for your help. I am a registered nurse working on my Master's Degree in Nursing from Montana State University, and have also worked as a dialysis nurse. During this time, it has come to my attention that there are some needed improvements in the care of home dialysis patients, especially those people who are situated far away from their home training center, or any back-up center for that matter. I am going to conduct a study dealing with this situation, and hopefully, from the results of the study, some better forms of care can begin to be provided for the home patient.

What I will need to do in order to conduct the study, is to gather information from many home dialysis patients, both close and far away from their home dialysis training centers, regarding their experiences on home dialysis--particularly those experiences dealing with the first six months of dialysis.

Your assistance in this study is greatly needed, and would be very much appreciated. It is strictly voluntary on your part, and complete confidentiality is guaranteed in all matters concerning the study. Enclosed is a consent form for you to sign, if you would be willing to assist me with this project. Please let me know as soon as possible. Also enclosed are the two forms I will need to have you complete, and return to me in the self-addressed, stamped envelope. The consent form can also be included in this. If you have any questions concerning the study, please feel free to write to me at Box 459, Bonner, Montana 59823; or call me collect at (406) 258-6431. If there are no questions, please fill out the enclosed forms and return them to me as soon as possible. Thank you very much.

Please return by 15 August, 1979. Thank you.

Sincerely,

Enclosures: 3

Teresa E. Snyder, R. N.




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