DEVELOPMENT OF A NURSING ASSESSMENT TOOL
TO EVALUATE THE HOME HEMODIALYSIS PATIENT

bу

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ABSTRACT

The purpose of this study was to construct a nursing assessment tool to assist the nurse in evaluating the home hemodialysis patient's level of functioning and his need for follow up care.

Relevant variables for inclusion in the tool were isolated from: a review of the literature on the problems encountered by the hemodialysis patient; a review of twenty patient records; nine semi-structured interviews with patients who had been rated by dialysis personnel as having made excellent, adequate or poor adjustments; and a questionnaire submitted to eleven dialysis nurses who were asked to name those factors they used when rating a patient poorly adjusted or well adjusted.

A three category rating system was used for fortyeight items in the tool. A score of one on any item indicated the least need for follow up care and a score of
three the greatest need.

Five dialysis experts agreed the tool contained the appropriate variables which are important in determining the level of functioning and needs for follow up care of the home hemodialysis patient.

A reliability testing using four pairs of nurses to assess twenty patients was significant at the .05 level

indicating the patient rating provided by the tool is independent of the rater.

76 pages

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CHAPTER I

INTRODUCTION TO THE STUDY

I. INTRODUCTION

This study focuses on systematic nursing assessment to identify the needs of the maintenance home hemodialysis patient.

The first artificial kidney was developed by Abel,
1
Rowntree and Turner in 1913, but was never used on humans.

The first dialyzer with practical application for the treatment of uremia was developed by Wilhelm Kolff in 1943.

Maintenance hemodialysis was demonstrated to be a procedure which could lead to the rehabilitation of some 3 patients with terminal renal failure. In 1960 Dr. Belding Scribner and his group at the University of Washington in Seattle implanted the first Quinton-Scribner shunt in the

J. J. Abel, L. G. Rowntree, and B. B. Turner, "on the Removal of Diffusible Substances from Circulating Blood by Means of Dialysis," <u>Transactions Association American Physicians</u>, 1913, pp. 28 - 51.

W. F. Kolff, "First Clinical Experience with the Artificial Kidney," Annals of Internal Medicine, vol. LXII, (1965), p. 608.

Belding H. Scribner, et al., "The Treatment of Chronic Uremia by Means of Intermittent Hemodialysis: A Preliminary Report," <u>Transactions American Society for Artificial Internal Organs</u>, vol. VI, (1960), p. 114

forearm of a patient and began periodic treatments using a pumpless, low flow dialyzer. Other treatment centers were soon established in North America and Great Britain.

The extremely high financial cost of hospital based treatment coupled with the lack of facilities and trained personnel lead to the development of programs which trained patients to dialyze themselves at home.

Home dialysis offers several advantages over 6 hospital based programs. These include; (1) reduced incidence of physiological complications due to more frequent dialysis which was possible because of the lower cost and availability of space, (2) greater independence and self

Wayne Quinton, David Dillard, and Belding Scribner, "Cannulation of Blood Vessels for Prolonged Hemodialysis,"
Transaction American Society for Artificial Internal Organs, vol. VI, (1960), p. 104.

R. A. Baillod, et al., "Overnight Hemodialysis in the Home," Proceedings of the European Dialysis and Transplant Association, vol. II, (1965), p. 99; K. Curtis, et al., "Hemodialysis in the Home," Transactions American Society for Artificial Internal Organs, vol. XI, (1965), p. 7; Joseph W. Eshback, et al., "Unattended Overnight Home Hemodialysis," Transactions American Society for Artificial Internal Organs, vol. XII, (1966), p. 346; C. L. Hampers, J. P. Merrill and E. Cameron, "Hemodialysis in the Home - A Family Affair," Transactions American Society for Artificial Internal Organs, vol. XI, (1965), p. 3; J. P. Pendros and Terrance Pollard, "Eight Years Experience with a Community Dialysis Center," Transactions American Society for Artificial Internal Organs, vol. XVI, (1970), p. 77.

C. R. Blagg, et al., "Home Dialysis: Six Years Experience," New England Journal of Medicine, vol. CCXXCIII, (November, 1970), pp. 1126 - 1131.

confidence for the patient, (3) greater freedom to schedule dialysis at times most convenient for himself, (4) greatly lowered cost of treatment, (5) reduced need for professional services and medical facilities, and (6) less travel time required from home to medical facility which was often many miles away.

A major disadvantage of home dialysis is the increased stress on the spouse of the patient, especially when
the spouse assumes a major part of the patient's care.

There are currently 4,857 patients on hemodialysis in the United States (reported by 88.7 per cent of centers).

8
Of these, 2,001 patients are on home hemodialysis.

In the acute phase of his illness, and during his training period, many services are available to the patient. Once he leaves the treatment center to perform his own dialysis he receives medical consultation and technical backup in response to his own request. No systematic assessment to seek out physiological or social-psychological difficulties currently exists.

Philip W. Shambraugh, et al., "Hemodialysis in the Home - Emotional Impact on the Spouse," <u>Transactions</u>
American Society for Artificial Internal Organs, vol. XIII, (1967), pp. 41 - 45.

Computer Print-Out National Dialysis Registry, Research Triangle Park, North Carolina, January, 1972.

C. Blagg, "Need for Home Follow Up Care," Unpublished Report to Kidney Disease Advisory Committee, Washington-Alaska Regional Medical Program, 1972.

Assessment of patient needs is the first step in the nursing process, considered to be fundamental to professional nursing. Several nursing leaders have examined this process. Lewis describes the process as consisting of a knowledgeable, purposeful series of thoughts and actions 10 to identify patients needs. She sees this process as consisting of assessment, intervention, and evaluation.

Smith also emphasized the need for this process when she stated, "If nursing is to be relieved of haphazard, non-scientific methodology, it must focus on those methods which provide a sound approach to the solving of nursing problems".

McCain looked at the way nurses determined patient needs and concluded that they tend more to use intuition 12 than systematic assessment. She pointed out the difficulties of making reliable and accurate assessments in this way.

This conclusion was also emphasized by Zimmerman and 13
Gohrke in their study of the nursing process. They demons

L. Lewis, "This I Believe About the Nursing Process - Key to Care," <u>Nursing Outlook</u>, vol. XIV, no. 5, (May, 1968), pp. 26 - 29.

Dorothy Smith, Manual for the Use of the Nursing History Tool, College of Nursing, University of Florida, Gainsville, Florida, 1971, p. 1.

R. Faye McCain, "Nursing by Assessment Not Intuition," American Journal of Nursing, vol. LXV, no. 4, (April, 1965), p. 82.

Donna Zimmerman and Carol Gohrke, "The Goal Directed Nursing Approach: It Does Work," American Journal of Nursing, vol. LXX, no. 2, (February, 1970), p. 106.

strated that assessment based solely on intuition carried no assurance that the needs of individual patients are identified. Though assessment by intuition has been widely used it has been pointed out that nurses have felt a strong need for a methodical system of data gathering and patient assessment that is efficient, economical, realistic, and 14 practical.

It is the intent of this study to provide a tool which will assist the nurse to assess the level of functioning of the home hemodialysis patient in a methodical, systematic, and reliable way.

II. PURPOSE OF THE STUDY

The purpose of this study is to develop a reliable assessment tool to be used by a nurse to identify a home dialysis patient's need for follow up care. It would provide an efficient and economical means of rating the level of functioning achieved by the patient in social-psychological and physiological areas.

III. THE PROBLEM

Statement of the Problem

What are those social-psychological and physiological variables which are important in determining the level of

Dolores E. Little and Doris Carnevali, Nursing Care Planning, Philadelphia: J. B. Lippincott Company, 1969. p. 65.

functioning of the home hemodialysis patient? Can these variables be organized into a tool which when used to assess a patient, will give reliable and valid data to assist the nurse to determine his needs for follow up care?

Specific Objectives

The specific objectives of the study are to: (1) determine what a patient regards as important in evaluating his own level of well-being, (2) determine what experienced dialysis personnel feel are the most important measures of patient well-being, (3) construct an instrument which will provide the nurse with a written rating of a patient on these identified variables, and (4) test the instrument for reliability and validity.

Significance of the Problem

Several hemodialysis nurses have pointed out the need for ongoing assessment and follow up care in the home. Komorita and Brand explored problem areas with a group of patients and concluded that the need for psychological and sociological support did not end with the hospitalization period and that this support should be ongoing.

A program of home visits by the dialysis center 16 personnel to the home patient is described by Stewart.

L. Brand and N. I. Komorita, "Adapting to Long Term Hemodialysis," American Journal of Nursing, vol. LXVI, no. 8, (August, 1966), p. 1781.

Betty M. Stewart, "Hemodialysis in the Home: The Value of House Calls by Training Personnel," <u>Nursing Clinics of North America</u>, vol. IV, (September, 1969), p. 432.

She points out that though the patient performs his treatment at home the center personnel continue to be responsible for his well-being and must assure themselves through periodic visits that all is going well for the patient. She does not describe a systematic assessment scheme. Discussing the family of the patient with long term illness, Gaspard points out the severe disruptions that can occur to the entire family unit because of the long term illness of one of its members. She states that nurses must continually assess the needs of these families, plan services carefully and "systematically evaluate their progress toward established 17 goals".

Systematic assessment based on standard criteria allows the nurse and other health care team members to better plan support activities for the patient and his family.

Blagg has pointed out that dialysis centers working with very limited budgets are understandably reluctant to invest funds in follow up care to the patient who is functioning well at home when this would limit their ability to care for new patients. This reemphasizes the

Nancy Gaspard, "The Family of the Patient with Long Term Illness," <u>Nursing Clinics of North America</u>, vol. V, no. 1, (March, 1970), p. 80.

C. Blagg, "Need for Home Follow Up Care," Unpublished Report to Kidney Disease Advisory Committee, Washington-Alaska Regional Medical Program, 1972.

need for efficient and inexpensive methods of determining which patients have the greatest need for follow up care so that staff may be utilized to best advantage.

In addition to detecting needs and planning care there is a need to begin to isolate those factors which most contribute to bio-psycho-social health in the maintenance hemodialysis patient so that some predictive ability might be established.

Meldrum did an extensive retrospective survey of patients in their program attempting to systematically describe the effects of hemodialysis on social functioning. They pointed out that "with increasing cognizance on the part of the public, governmental agencies and the medical profession that dialysis treatment is medically possible, the need of some basis of judgement as to the sociologic as well as medical worth of such treatment is increasingly 19 apparent.

Aydellote describes an exploratory study on a group of fourteen dialysis patients conducted for the purpose of learning more about nursing problems in this group. She points out the need for further delineating

M. Meldrun, J. Wolfram and M. Rubini, "The Impact of Chronic Hemodialysis Upon the Socio-economics of a Veteran Patient Group," Journal of Chronic Diseases vol. XXI, (1968), pp. 37 - 52.

problems.

Referring to dialysis patients, Cummings stated
"the total effectiveness with which medical treatment,
vocational, social and all other rehabilitation goals are
achieved depends largely on the sharpness with which the
nurse observes the difficulties the patient encounters".

21
Systematic assessment could facilitate that sharpness.

A standardized rating scale with good reliability and validity would aid in determining the effect of the manipulation of non-patient variables such as different types of equipment and procedural changes.

The value of a tool which would assist nurses to reliably, conveniently, and efficiently assess a patient's need for follow up care seems well established.

IV. ASSUMPTIONS

This study is based on these assumptions: (1) there are factors, some of which will be common to all hemodialysis patients, which, when considered, will reflect his needs, (2) patients are able to identify many of their needs,

Myrtle Aydelotte, "Nursing Care of Patients Undergoing Hemodialysis: A Study Report," Unpublished Report presented to the Third Annual Veterans Administration Workshop of Chronic Hemodialysis, Chicago, April, 1967.

Jonathan Cummings, Hemodialysis: The Pressures and How Patients Respond, American Journal of Nursing, vol. LXX, no. 1, (February, 1970), p. 76.

and, (3) assessment with the use of a tool allows more systematic collection of data than an informal assessment.

V. DEFINITIONS

Patient

In this study the term will refer to the maintenance home hemodialysis patient.

Maintenance Home Hemodialysis Patient

A person with irreversable kidney disease who must receive periodic hemodialysis to sustain life and who performs this treatment in his home setting without the services of a medical assistant.

Nurse

In this study this term will refer to a registered nurse with experience in the care of hemodialysis patients. $\underline{\text{Needs}}$

The term will be used to designate a requirement of the patient arising from the imposition of his illness on his life and perceived by the nurse as being within the realm of responsibility of the health team to offer assistance to meet.

VI. LIMITATIONS OF THE STUDY

This study is subject to the following limitations:

(1) Only patients being dialyzed on parallel flow dialysis equipment will be included in the study, and (2) Patients will all be residing in Washington State, and from the

Northwest Kidney Center in Seattle which has a unique community support system for renal patients. Therefore, the needs and level of functioning of these patients cannot be generalized except to patients from centers with a very similar philosophy and orientation.

CHAPTER II

REVIEW OF THE LITERATURE

I. PHYSIOLOGICAL PROBLEMS OF THE DIALYSIS PATIENT

Physiological Problems Unrelated to the Dialysis Procedure

General discussions of medical complications can be found in Pendras and Stinson and Hampers and Schupak. These are anemia, hepatitis, renal osteodystrophy, neuropathy, hypertension, congestive heart failure and sexual problems.

One study of anemia in maintenance hemodialysis patients points this out as a persistent problem which results in high risk of hepatitis and iron overload from 2 repeated transfusions. These investigators demonstrated that a majority of patients can be maintained on regular dialysis without blood transfusion by accepting hematocrits in the 17 - 19 per cent range. Iron deficiency will become apparent unless monthly blood loss is less than 250 ml. and

Jerry Pendras and Gerald Stinson, <u>The Hemodialysis</u>
<u>Manual</u>, Seattle, (1969), pp. 1 - 4; Constantine Hampers and Eugene Schupak, <u>Long Term Hemodialysis</u>, New York: Grune and Stratton, 1967, pp. 70 - 146.

C. M. Compty, D. McDade and M. Kaye, "Anemia and Iron Requirements of Patients Treated by Maintenance Hemodialysis," <u>Transactions American Society for Artificial</u> Internal Organs, vol. XIV, (1968), pp. 426 - 432.

dietary absorption of iron is insufficient. Therefore, iron therapy will be necessary in most patients.

Hepatitis, which has been found to be present in a carrier state in some hemodialysis patients, has seemed to be related to frequent blood transfusions which carry the virus. Blumberg points out that even in patients who have had a low rate of transfusion, or none at all, hepatitis is seen. He urges tesing patients for Australian antigen positive blood and of considering non-parenteral routes of transmission, as well as the precautions with blood transfusions.

Renal osteodystrophy seems to have a number of causes in the patient with renal failure, including impaired absorption of calcium in the intestine, secondary hyperparathyroidism, abnormal metabolism of Vitamin D, acidosis, and certain inhibitors of bone calcification circulating in the blood. Bone disease frequently develops and often progresses in patients, even when treated with periodic dialysis.

Uremic neuropathy, which was a serious problem in the first few years of maintenance dialysis therapy, has

A. Blumberg and K. Giger, Letter to the Editor re. Hepatitis and Hemodialysis, New England Journal of Medicine, vol. CCXXCIII, no. 12, (September 17, 1970), pp. 657 - 658.

D. Kim, et al., "Renal Osteodystrophy in the Course of Periodic Dialysis for Chronic Uremia," <u>Transactions</u>
American Society for Artificial Internal Organs, vol. XIV, (1968), pp. 367 - 371.

been shown to be preventable by adequate dialysis.

Tenckhoff after an extensive study of the problem reports,

"Institution of adequate dialysis before motor neuropathy
has developed will prevent this serious complication. If
neuropathy develops or progresses in patients maintained on
dialysis, the amount of dialysis is inadequate and treatment
should be intensified.

Hypertension has continued to be a problem in many patients undergoing maintenance hemodialysis. The use of antihypertensive drugs, restriction of dietary intake of salt and water, and ultrafiltration during dialysis have produced satisfactory results in many patients. Bilateral nephrectomy has been recommended, however, in patients with malignant hypertension or who have been unable to adequately restrict their diet.

Pericarditis develops late in severe uremia and can be reversed with adequate dialysis. When pericarditis is seen in patients already on a maintenance dialysis program.

H. Tenckhoff, R. H. Jebsen, and J. C. Honet, "The Effect of Long Term Dialysis Treatment on the Course of Uremic Neuropathy," <u>Transactions American Society for Artificial Internal Organs</u>, vol. XIII, (1967), pp. 58 - 61.

G. Onesti, et al., "Bilateral Nephrectomy for Control of Hypertension in Uremia," <u>Transactions American Society for Artificial Internal Organs</u>, vol. XIV, (1968), pp. 361 - 366.

the treatment should be increased in frequency or duration.

Congestive heart failure develops as a result of salt and water intake or from failure to remove adequate amounts by dialysis. Long standing hypertension is also implicated. Control of hypertension and blood volume usually results in resolution of this problem.

Sexual problems may be both physiological and psychological. Many women have cessation of menses with uremia, and many men have loss of libido and may be impotent. With institution of regular dialysis and with general improvement in health, these problems are sometimes resolved.

Infertility is the usual rule, though there have been a few successful pregnancies when the husband was the patient and two unsuccessful ones among women patients in the Seattle program.

Pruritis and insomnia are also common problems for the uremic patient. Dialysis may relieve the symptoms, but in some cases it does not. The cause is not well understood.

Constantine Hampers and Eugene Schupak, Long Term Hemodialysis, New York: Grune and Stratton, 1967, pp. 80 - 81.

Jerry Pendras and G. Stinson, The Hemodialysis Manual, Seattle, 1969, Section XII, p. 1.

C. F. Gutch and Martha Stoner, Review of Hemodialysis for Nurses and Dialysis Personnel, Saint Louis: The C. V. Mosby Company, 1971, p. 151.

Physiological Problems Related to the Dialysis Procedure

Complications occurring during the dialysis procedure are well outlined by Pendras and Stinson. They are: Bleeding resulting from any source but worsened by the need for anticoagulation during the procedure; acute hypertension resulting from volume overload, anxiety, or the disequilibrium syndrome; https://pytension and shock resulting from excessive antihypertensive drug therapy; fever caused by infection, pyrogenic reaction, acute bacterial contamination of the blood circuit, gross bacterial contamination of the dialysate circuit or dialysate temperature above normal; nausea and vomiting whose common causes are hypotension. hypertension, dialysis disequilibrium syndrome, anxiety, headache, drug reaction or excessive calcium or magnesium in the dialysate; headache usually caused by dialysis disequilibrium syndrome, hypertension, or anxiety; cardiac arrhythmia caused by hypotension, hypokalemia, excessively low hematocrit, cardiac disease; chest pain commonly caused by angina pectoris or embolism of blood clot or air; muscle cramps caused by rapid sodium and water removal; restlessness caused by anxiety and subclinical motor neuropathy; Shortness of breath caused by volume overload or pulmonary or air embolus; convulsions caused by hypertension, water intoxica-

Jerry Pendras and G. Stinson, <u>The Hemodialysis</u>
Manual, Seattle, 1969, Section X.

tion, dialysis disequilibrium syndrome or chemical abnormali-

Problems with Circulation Access

There are two major types of circulation access for the hemodialysis patient: (1) the Silastic-Teflon cannula, sometimes called the Scribner Shunt or the external A-V 11 shunt, and (2) the subcutaneous arterial-venous fistula. Access to the circulation with the Silastic-Teflon cannula is accomplished by clamping the external tubing and separating it so that direct access is obtained into the artery and vein. Access to the circulation with the subcutaneous fistula is by puncture with 14 - 16 gauge needles.

The Silastic-Teflon cannula can become disconnected or clot. The surrounding tissue may become infected or bleed. Excessive activity involving the extremity must be 12 avoided.

The subcutaneous arterio-venous fistula has fewer complications, but greater skill is required to do the punctures to obtain circulation access.

A study by Achad of the subcutaneous fistula in thirty-three home hemodialysis patients drew the following

Jerry Pendras and G. Stinson, <u>The Hemodialysis</u>
Manual, Seattle, 1969, Section VI.

Martha Read and Mary Mollison, "External Arterio-Venous Shunts," American Journal of Nursing, vol. LXXII, no. 1, (January, 1972), pp. 81 - 85.

conclusions. "Although the subcutaneous arterial-venous fistula remains far from ideal as a permanent access route to the blood supply, our experience indicates that it may be successfully employed in home dialysis, and that it has general advantages over the previously used Silastic-Teflon 13 cannulae."

II. SOCIAL-PSYCHOLOGICAL FACTORS OF THE HOME HEMODIALYSIS PATIENT

Reporting the results of a study of nine patients being dialyzed in a research oriented hospital unit Shea states that the emotional reaction to the need for chronic dialysis may represent the greatest obstacle to successful 14 rehabilitation. She describes these reactions as consisting mostly of irritability, apprehension, insomnia, restlessness, and anxiety. She also reports dietary indiscretion and unnecessary trauma to cannulas.

Wright, reported on 12 patients undergoing hemo-

A. Achad, at al., "Subcutaneous Arterial-Venous Fistula in Home Hemodialysis," <u>Transactions American Society for Artificial Internal Organs</u>, vol. XVI, (1970), pp. 280 - 283.

Eileen Shea, et al., "Hemodialysis for Chronic Renal Failure - Psychological Considerations," Annals of Internal Medicine, vol. LXIII, no. 3, (March, 1965), pp. 558 - 563.

dialysis in a community dialysis center in 1965. They listed some of the stresses of patients as (1) actual or threatened losses which included parts of body function, loss of membership in groups, failure of plans or ventures, changes in way of life or living, loss of home, possessions or financial status, and loss of job or occupation, (2) injury or threat of injury, (3) frustration in drives or derivatives. They note denial as the chief psychological defense in this group of patients.

Norton described patients in the Seattle program in 1967 to be relatively little disturbed, as a whole, by the treatment, which he attributed to the massive support for patients which was provided by the unique arrangement of services, both financial and medical, provided by that 16 community. He states that much more is required for support of these patients than what is ordinarily thought of as medical supervision and advice.

Harry S Abram reports in 1968 his conclusion about 17 the psycho-social aspects of dialysis. He sees the

Robert G. Wright, P. Sand and G. Livingston, "Psychological Stress During Hemodialysis for Chronic Renal Failure,"

Annals of Internal Medicine, vol. LXIV, (March, 1966), pp.

611 - 621.

Charles Norton, "Chronic Hemodialysis as a Medical and Social Experiment," Annals of Internal Medicine, vol. LXVI (June, 1967), pp. 1267 - 1276.

Harry S. Abram, The Psychiatrist, the Treatment of Chronic Renal Failure, and the Prolongation of Life,"

American Journal of Psychiatry, vol. CXXIV, no. 10, (April, 1968), pp 1351 - 1358.

dependency-independency conflict as the most significant stress on the patient. He states that although severe emotional disturbances are not a usual problem in most renal units with a selection process and a treatment-oriented atmosphere, problems of rehabilitation and adjustment require attention and understanding.

Using the MMPI to study a group of patients, Short described denial as an effective mental mechanism used by 18 hemodialysis patients to cope with their stresses. He emphasizes the ineffectiveness of this mechanism for the family and community and the inappropriateness of it for the nurses and the doctors.

DeNour lists some of the stresses he observed as the threat of death, loss of plannable future, dependency on machines, loss of body functions and changes in body image, frustration of drives, and delay of gratification.

He stresses the need for supportive psychological care.

III. ASSESSMENT TOOLS AND PERIODIC EVALUATION SCHEMES
FOR MAINTENANCE HEMODIALYSIS PATIENTS

No complete assessment to identify the needs of

M. J. Short and W. P. Wilson, "Roles of Denial in Chronic Hemodialysis," <u>Archives of General Psychiatry</u>, vol. XX, (April, 1969), pp 433 - 437.

A. K. DeNour, "Psychotherapy with Patients on Chronic Hemodialysis," <u>British Journal of Psychiatry</u>, vol. CXVI, (February, 1970), pp 207 - 215.

the chronic home hemodialysis patient was found in the literature.

Kennedy developed a scoring system for rating patients medically in order to establish a prognosis. He did not attempt a psycho-social or rehabilitation assessment.

Potter used Kennedy's assessment scheme to rate patients in his program and also had the nurse rate the 21 patient in terms of his occupational rehabilitation.

An assessment of patients in an in-hospital program in New York was done in 1965 using such parameters as days spent in hospital, weekly activity records, nightly sleeping time, and three areas of psycho-social adjustment. These were (1) compliance to and acceptance of the therapeutic regimen of maintenance hemodialysis, (2) response to and achievement in constructive activity, and (3) maturity and extent of interpersonal relationships.

MacElveen, in her doctoral dissertation, explored the relationship of cooperation between home dialysis

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A. C. Kennedy, "A Scoring System for Assessing Patients on Regular Dialysis," <u>Lancet</u>, vol. I, (April 5, 1969), pp. 702 - 707.

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D. J. Potter and G. M. Nickos, "Assessment of Patients Undergoing Home Maintenance Dialysis," <u>Arizona Medicine</u>, vol. XXVII, (April, 1970), pp. 76 - 79.

²²

E. A. Friedman, et al., "Psychosocial Adjustment to Maintenance Hemodialysis," New York Journal of Medicine, vol. LXX, (March, 1970), pp. 629 - 637.

patient, his partner, and nurse to adherence to the medical 23 regimen, total activity and morale. She studied twenty-one patients, which was the population of that center, and found significant correlations in these areas.

IV. GENERAL ASSESSMENT TOOLS

Bonney and Rothberg describe a nursing evaluation form which was developed to identify and measure the needs 24 of chronically disabled persons for Nursing service. The tool is divided into three sections: Section I is designed to reflect the patient's physical condition, Section II his level of physical and physiological functioning, Section III is a description of patient behavior. Each of the three sections yield a numerical score. These scores, titled X, Y, and Z scores, are plotted on 3 parallel scales of 0 - 10. They may then be used relative to each other to determine the patient's areas of strength and weaknesses. Reliability and validity studies were not reported.

Williams reports the development of the Patient
Profile which was designed to measure the nursing needs of

Patricia MacElveen, Exploration of the Cooperative
Triad in the Investigation of Home Dialysis Patient Outcomes,
Unpublished Doctoral Dissertation, University of Colorado, 1971.

Virginia Bonney and June Rothberg, <u>Nursing</u>
Diagnosis and Therapy: An Instrument for Evaluation and
<u>Measurement</u>, New York: The National League for Nursing,
1963.

25 It is based on seven basic needs: Nourishment. patients. Elimination, Rest, Exercise, Social Interaction, Safety, and Therapy. Direct observations of the patient is the suggested mode of data gathering. The observer rates the patient's physical ability to meet his needs as (a) adequate, (b) less than adequate, or (c) inadequate. He then rates the patient's response or attitude to meeting his needs as (a) Positive Interest, which is a goal-directed activity toward meeting his needs; (b) Passive response, which is behavior lacking in interest but willing to go along with others actions or suggestions; or (c) Extreme response which is patient behavior extremely positive or negative toward the meeting of needs. A numerical dependency score was obtained by rating each of the fourteen items on a continuum of 0 - 10. This allowed a total score range of 140 - completely selfsufficient to 0 - completely dependent. Interrater reliability co-efficients of 185 were reportedly obtained when pairs of nurses on eight different hospital units rated a total of 241 patients.

Aydelotte describes a test of patient welfare which consists of three measures: (1) Number of days in hospital, number of fever days, number of post-operative days and doses of narcotics, analgesics, or sedatives, (2) Scaled measures: Patient's mental attitude, patient's physical independence,

Mary Edna Williams, "The Patient Profile,"

Nursing Research, vol. IX, no. 3, (Summer, 1960), pp. 122 - 124.

special aspects of independence, patient's mobility, patient's skin condition, patient's opinion of nursing care given to him, and physicians' evaluation of patient's condition and progress. (3) Sampling measures of per cent of time spent in bed, in chair, up and in communication and occupied is leisure. A "poor" to "good" scale was used for the scaled measures. A committee of experts wrote graduated behavioral statements between these categories and the rater placed the patient in the appropriate place on the scale. The reliability coefficient of the mental attitude rating form was reported to be .73 based on 85 pairs of independent ratings. Reliability of the other measures was not reported. Face validity and significant correlation between the item of Physicians' evaluation of patient's condition and most of the other six indices of patient welfare were the tests of validity.

A patient rating scale was developed by Rich and

Dent designed to measure changes in attitudes toward
27
patients. Six criteria were selected for the instrument:
(1) test-retest reliability, (2) change in response when a
patient changed, (3) interrater agreement, (4) variation in

Myrtle Kitchell Aydelotte, "The Use of Patient Welfare as a Criterion Measure," Nursing Research, vol. XI, no. 1, (Winter, 1962), pp. 10 - 14.

Rosemary Rich and James K. Dent, "Patient Rating Scale," Nursing Research, vol. XI, no. 1, (Winter, 1962), pp. 10 - 14.

response across patients, (5) dimensionality, eg., the degree to which the item is positive or negative, and (6) clarity of meaning. The original rating scale used 28 terms or adjectives such as: cooperative, grouchy, hard to please, a model patient, and asked the rater to check whether this described the patient very well, somewhat, a little, not at all, or no opinion. The scale was revised to include only 22 items when the original tool failed to meet the six criteria. The second scale had good split-half reliability and test-retest reliability. Interrater agreement was low.

Schoening and Iversen discussed three years of 28 experience and revisions of the Kenney Self-care evaluation. It utilizes a 5-point rating scale to measure six categories of self care. Zero, one and three and four are precisely defined categories. Two is a "catch all" category used to contain those patients who do not fit the other four precise definitions. The authors state their data shows patients do not spend any greater length of time in this category than in the neighboring ones and feel the expanded middle portion on the scale has increased its value and made it easier to use.

Summary of the Review of the Literature

In summary, the literature on hemodialysis has

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Herbert Schoening and Iver Iverson, "Numerical Scoring of Self-Care Evaluation," <u>Archives of Physical</u> Medicine, vol. XLIX, no. 1, (January, 1968), pp. 221 - 229.

been examined to elucidate those physiological and socialpsychological parameters considered important in judging
the well-being and needs of the hemodialysis patient.

Various tools used to evaluate hemodialysis patients have
been examined. No completely satisfactory tool was found
in the literature. Other types of general patient welfare
rating systems were reviewed. Problems with obtaining
reliability and validity were noted. Various methods of
scoring were explored.

CHAPTER III

METHODOLOGY

I. OVERVIEW

The following procedure was used to develop an instrument to rate patients on their level of well being and need for follow up care. (1) The literature on hemodialysis was explored to identify specific factors said to be important in determining the patient's level of well being. (2) Patient records were examined to elicit pertinent variables. (3) Dialysis nurses were given a questionnaire in which they stated which factors they used to rate a patient well functioning or poorly functioning. (4) Nine patients were interviewed using a semi-structured interview schedule to obtain their perception of their needs and level of well being. (5) A preliminary tool was constructed and submitted to a panel of experts for validation.

The final instrument was tested for reliability using four pairs of nurses assessing five patients each.

II. SAMPLE

The nine semi-structured interviews were done on 3 patients rated by the staff as having made a poor adjustment to home hemodialysis, three having made an adequate adjustment, and three having made an excellent adjustment.

For reliability testing 20 patients were selected from a group who met the following criteria: over 16 years of age, living in King or Snohomish Counties, English speaking, on dialysis at least six months, and not scheduled for a transplant within six months of the assessment.

The patient sample consisted of eight females and twelve males. The patients consent to participate in the study was obtained. All patients had received their home dialysis training at the Northwest Kidney Center, Seattle, Washington.

III. CONSTRUCTION OF THE PRELIMINARY TOOL

Data Gathering

Variables elucidated in the hemodialysis literature are listed in Chapter II - Review of the Literature. Each of these variables were considered for inclusion in the tool.

A list of patient problems and parameters looked at by the staff were obtained by examining twenty patient records. These were found to be almost identical to the problems outlined in the literature.

Nine patients were interviewed using a semi-structured interview schedule. Three of these patients had been rated by the staff as having made a poor adjustment to maintenance home hemodialysis, three having made a fair adjustment, and three having made an excellent adjustment.

Data from these interviews were examined and a list

of problems and problem statements was compiled. Common problems shared by patients rated as poor and not seen in patients of the other ratings were especially noted.

The most striking differences among these groups of patients were in the following areas:

- 1. Time Spent in Productive Activity. All three patients rated as poor adjustors by the staff were unemployed and disclaimed productive activity except for one or two hours daily. In contrast, all three patients rated excellent by the staff were employed full time and claimed normal levels of activity. Of those patients rated as fair adjustors one was employed full time, one part time and the third claimed a full schedule of housework.
- 2. General Outlook and Relationship with Friends and Family. The three patients in the poorly adjusted category made such statements as these:
 - "I guess I'm hard to live with now, I'm in a bad mood most of the time."
 - "I get up in the morning lots of times and wonder why I bother."
 - "I hate being on the machine and can't seem to get my mind on anything else."
 - "This is a hell of a way to live."
 - "Nobody understands what you have to go through."
 - "People don't like to bother with you when you're sick."
 - "I don't know anyone my own age and I can't meet anyone because they would think I was a freak on this machine."
 - "People expect too much of you and don't realize you're sick."

In contrast patients in the adequate categories made these statements:

- "I'm down in the dumps sometimes but I think that's just natural when you have something like this."
- "I'm just thankful to God that they have the machine."
- "Our friends have been wonderful, I don't know what we would do without them;"
- "My wife still gets pretty nervous but we manage and there are lots of good times."
- "When things don't go well with the machine we kind of get tense and yell at each other but mostly we get along 0.K."

The three patients in the excellent category made these and other statements:

- "Of course if I had a choice, I wouldn't go on dialysis but since I don't, I just regard it like brushing my teeth - something you have to do - and I go on about my business."
- "We just don't let it bother us it's one of those things you have to find time for in your life and that's that."
- "My family is great they pitch in and help and are always there pulling for me."
- "We've had to give up some things we enjoyed together but we have been even closer as a family since I started on dialysis we realized how unpredictable life can be."
- "Everyone, my boss, family, friends have been terrific - they want to do everything they can for us - we really don't need anything but it's nice to know they're there."

A questionnaire was submitted to eleven dialysis nurses. Analysis of their statements concerning patients produced the following list:

Table 1 Well Adjusted Patient

Factors Leading to Good Patient Rating	No. of nurses who included this item (11 nurses total)
Optimistic and cheerful	8
Determined to learn - highly motivated	7
Leads active life - community involve- ment, outside interest	6
Well occupied leisure	3
Adequate dialysis	3
Infrequent backup dialysis .	1
Works full time	3
Good relationship with helper - excellent family support	. 8

Table 2 Poorly Adjusted Patient

Factors Leading to Poor Patient Rating	No. of nurses who included this item (11 nurses total)
History of problem with circulation access	3
General medical complications	3
Failure to dialyze or follow diet according to prescribed regimen	5
Does not work	1
No outside interests	6
Does not actively participate in own care	4
Spouse or helper relationship poor	7
Anxiety-tension-fear	2
Frequent backup dialysis	2

Rationale for Inclusion of and Exclusion of Items in the Tool

Material from the four sources, the hemodialysis literature review, patient record examination, dialysis nurses' questionnaire and the nine patient interviews were combined and considered for inclusion in the tool. The criteria used for inclusion were: (1) a rating can be obtained economically, (2) a rating can be obtained with little inconvenience to the patient, (3) a rating can be obtained quickly, (4) a rating may be obtained by an objective quantification of an item or by a perception of the patient, and (5) a rating can be made on the basis of a straight-forward question with no hidden meaning.

All items on the physiological assessment were included because these problems were discussed in the dialysis literature and were found to be frequently mentioned in the patient records. Many of them were mentioned by the patients as symptoms which they experienced. Wherever the question is not one which can be settled by measurement or observation, the patient's perception of the problem is sought. For example the item on sexual functioning seeks to determine if the patient perceives a problem in this area rather than to determine any actual state of sexual potency.

In some instances much more accurate measurements of physiological functioning are available but they do not meet the criteria of being economical and convenient for the patient. For example, a nerve conduction time is a

far more sensitive measure of degree of neuropathy than the assessment provided for by the tool. The nerve conduction time, however, is expensive and uncomfortable for the patient and is usually available only at large medical centers.

The items under miscellaneous symptoms in the tool, that is: itching, nausea and vomiting, headache, dizziness, muscle cramps, constipation, chills and fever, are not quantified because the degree to which the symptom is a problem seems to depend more on the patient's perception than the actual number of times it occurs.

The technical ability assessment would doubtless be much more accurate if direct observations were made and recorded as is done when a patient's ability is being assessed in his home dialysis training period. Again, this is extremely time consuming and expensive. The brief assessment built into the tool is designed to show the patient's perception of his ability as well as the objective number of times he actually encounters problems or must call for assistance.

The social-psychological adjustment of the patient is far more difficult to measure than the physiological or the technical adjustment because the determination of what constitutes good, adequate, and poor social-psychological adjustment is not so readily apparent.

Hours spent in productive activity was noted in the patient interviews as being a factor which was clearly different in those patients who had been rated as poorly adapted by the staff and those who had been rated as well-adapted. Also it seemed advisable to determine if there had been a distinct change in productive activity since their illness.

No outside interests had been mentioned by six of the nurses when asked to describe the poorly adjusted patient. Six nurses used the terms "community involvement", and "many outside interests", to describe the well adjusted patient.

Role changes and feelings of role loss had been mentioned in the literature. It was decided to simply ask the patient his perception of his ability to function as a husband, father, wife, mother, or family member since measuring role change and feelings of role loss in depth would require extensive probing with the patient. Identifying some feelings of role changes was felt to be adequate in assessing the patient's needs for follow up care.

Statements of general feelings made by the patients in the poor categories and the excellent categories were so characteristically different that this dimension seemed to be very important to measure in assessing the patient's level of well being and need for follow up care. Several statements in the social-psychological assessment were compiled from the actual statements made by patients.

The two items mentioned most often by the nurses in rating a patient well functioning were an attitudinal statement of optimistic and cheerful, and good family

relationships and support. Eight of the eleven nurses named these two factors. Also these general feelings of being in a good or bad mood, of feeling accepted or rejected by others and of having people to help and support them were mentioned frequently by patients in all three categories of adjustment. Nine questions on the assessment form are designed to rate the patient on this kind of dimension.

Failure to follow medical regimen had been mentioned by 5 nurses as a factor in rating the poorly adjusted patient. This dimension is measured by the physiological data but one question asking the patient how comfortably he felt he could live with his restrictions was included in the social-psychological assessment.

IV. THE RATING SCALE

A three point numerical rating scale was devised with no weighting of individual items. All measurements and patient perceptions were divided into the categories of excellent, adequate, and poor designated respectively by the numbers one, two, and three. A rating of one would indicate the better adapted patient and three the poorer adapted one. A maximum total score of 144 would indicate the patient with the greatest number of needs and a minimum total score of 47 would indicate the patient with the least number of needs. However any item receiving a three score would indicate an area in which the patient had some need for follow up care or further assessment.

V. VALIDATION

The preliminary tool was submitted to a panel of five experts which included four dialysis nurses whose experience in dialysis nursing ranged from five to nine years and one physician who had worked intensively with dialysis patients for six years. Each of these experts agreed that the tool had content validity.

VI. PRE-TEST

A pre-test was conducted on two patients to determine communication difficulties with any of the questions. No problems were encountered.

VII. RELIABILITY TESTING

Four pairs of nurses used the validated tool to separately assess five patients each. The rating scale was explained verbally as well as in writing to each nurse. The two-tailed test was chosen to test the independence of the tool from the evaluator. A .05 level of significance was used.

CHAPTER IV

ANALYSIS OF THE DATA

I. VALIDITY TESTING

The preliminary tool was submitted to five experts; four dialysis nurses whose experience in dialysis ranged from five to nine years and one physician who had worked intensively with dialysis patients for six years.

The experts agreed that the tool would measure important differences in patients which would be sufficient to determine their need for follow up care.

One question was modified at the suggestion of two of the nurses. This was regarding participation in social or community organizations and activities which asked the patient to describe his participation as often, occasionally or rarely. It was suggested that this be altered to ask whether his participation was about the same as, less than, or much less than before his need for hemodialysis. This was felt to be more meaningful than the original wording because some patients lack of participation would be a life style rather than an effect of their illness.

II. RELIABILITY TESTING

Four pairs of nurses separately assessed each of five patients. A total of twenty patients were assessed.

The two tailed & test was used to test the hypothesis that the assessment tool provides a rating which is independent of the evaluator. It was significant at the .05 level.

Table 3 Paired Nurses Scores of Functioning Level of
Patient and Differences in Nurse Scores

		·	
Patient Number	Score 3 Nurse A	Score Nurse B	Difference A - B
1	¢4.64	64	0
2	85	80	5
3	52	52	0
4	74	75	-1
5	69	. 73	-4
6	58	58	0
7	65	66	-1
8	106	108	-2
9	66	67	-1
10	80	80	0
11	59	59	0
12	82	83	-1
13	61	61	0
14	51	51	0 '
15	61	63	-2
16	55	56	-1
17	87	83	4
18	62	⊚62 ?	0
19	66	67	-1
20	88	89	-1

Table 4 Statistical Treatment

The Test:

If the assessment tool is independent of the evaluator then the difference $A - B \rightarrow 0$, but if the tool is sensitive to interpretation by an individual nurse, then $A - B \rightarrow 0$ constant.

The Hypothesis: The mean of the difference = \overline{x} A - \overline{y} B = 0. If this is true, then the tool is independent of the evaluator.

The Sample: The number of data points, $\sqrt{}$, was 20. The mean \overline{x} was 0.300. The Standard deviation $S_{\overline{x}}$ was 1.922.

The standard deviation of the means of the samples, $\frac{5}{x}$, is given by $\frac{5}{x} = \frac{5x}{\sqrt{n}} = 0.430$

The variable $\frac{1}{2}$ for the two-tailed $\frac{1}{2}$ test is given by: $\frac{1}{2} = \frac{1}{2} \frac{1}$

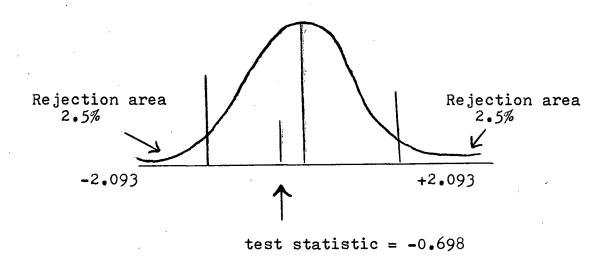
Where for this hypothesis $\mathcal{N}_{\mathbf{o}} = 0$

Inserting the above values we obtain $t = \frac{-0.300}{0.4300} = -0.698$

From the table for the two-tailed \forall test with n = 20 and at the .05 level \forall is given by:

$$(190.025) = 2.093$$

The result is illustrated by the following:



Since the calculated value of talls well within the acceptable range the hypothesis that the tool is independent of the evaluator is verified.

III. ANALYSIS OF RESULTS OF ASSESSMENT

The mean scores of the twenty patients was 69.5.

Twelve of the twenty patients had scores below the mean while the remaining eight patients had scores above the mean.

The age range of the twelve patients scoring below the mean was 17 years to 60 years. The mean age of this group was 41 years. The age range of the eight patients scoring above the mean was 21 years to 61 years. The mean age of this group was 43.5 years.

The lower scoring group had a range of months of dialysis from 6 months to 71 months. The mean length of dialysis of this group was 26.5 months. The higher scoring group had been on dialysis from 8 months to 68 months. The mean length of dialysis was 31 months. This indicates that age and length of dialysis were not factors which accounted for differences in the two groups.

The above information is illustrated in Figures 1, 2, and 3.

The distribution of low scores between the two groups of patients on the pre-dialysis creatinine, BUN, Serum albumin, 24 hour urine volume and usual pre-dialysis blood pressure was quite uniform. For example, 50 per cent of those eight patients whose total scores fell above the mean scored a number one on the item of intradialysis weight gain, while only 40 per cent of those twelve patients whose total scores fell below the mean scored a number one on this item. This indicates that the differences measured in patients did not fall in the category of Adequacy of dialysis and nutritional status in this particular group of patients.

Circulation access problems accounted for some difference in the two groups. Of the twelve lower scoring patients, 25 per cent had problems with circulation access contrasting with 62 per cent of the eight higher scoring patients.

The distribution of low and high scores on the item of Bone Status, both in X-ray evidence and clinical symptoms, was not significantly different between the two groups.

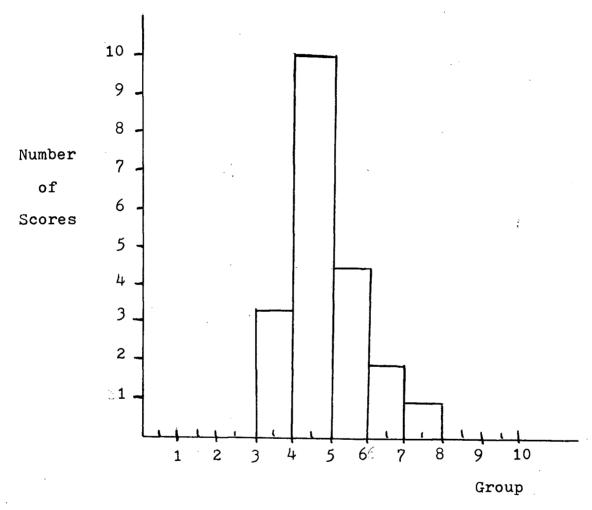


Figure 1 Nurse A Scores Grouped in Interval Size of 14.4

For this set of scores the mean is 69.55; the variance is 194.2475; and the standard deviation is 13.93727. The group size is 14.4

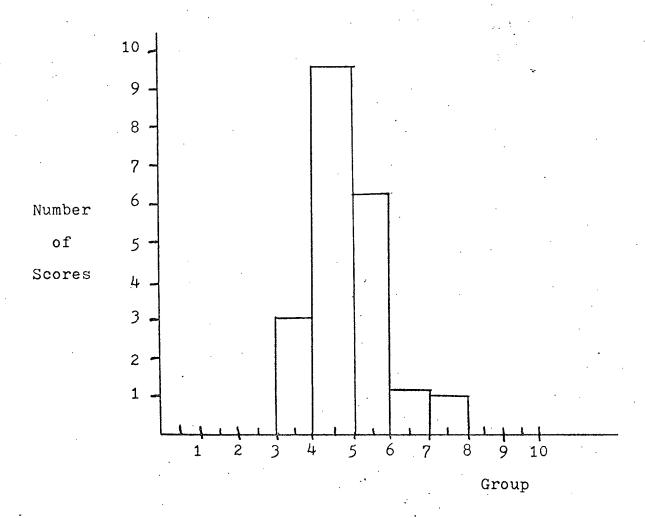


Figure 2 Nurse B Scores Grouped in Interval Size of 14.4

For this set of scores the mean is 69.85; the variance is 189.3275; and the standard deviation is 13.75963. The group size is 14.4.

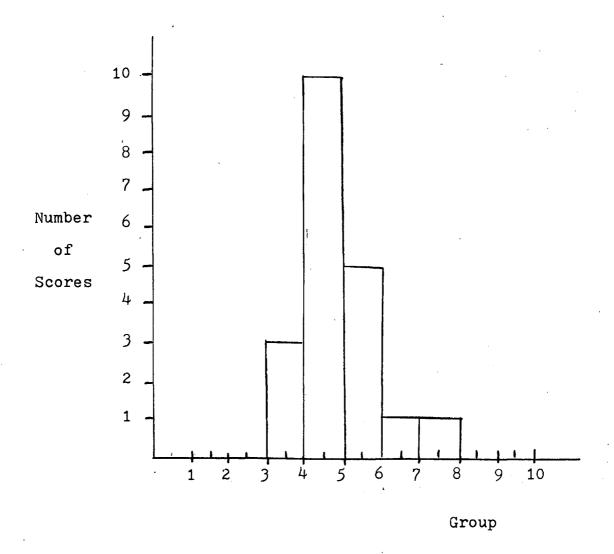


Figure 3 Mean Scores Grouped in Interval Size of 14.4

In this set the mean is 69.7; the variance is 190.91; and the standard deviation is 13.81702. The group size is 14.4.

Cardiac symptoms accounted for a difference in the groups. Eleven of the twelve patients scoring below the mean disclaimed shortness of breath and chest pain while all eight of the other group claimed some shortness of breath and four of the eight claimed moderate to severe chest pain.

Eleven of the twelve low scorers had no evidence of neuropathy as judged by the three items included in that assessment. Six of the other eight patients had moderate impairment and one had severe impairment.

Dissatisfaction with sexual functioning was characteristic of 75 per cent of the higher scoring patients, while only 25 per cent of the lower scoring patients had this complaint.

Response to the sleeping patterns item showed 58 per cent of the twelve lower scoring patients had no difficulty sleeping while 42 per cent had moderate difficulty. Only 25 per cent of the higher scoring patients had no difficulty sleeping while 50 per cent had moderate difficulty, and 25 per cent had severe difficulty.

The distribution of high and low responses on the miscellaneous symptoms was not significantly different between the two groups.

Of the five items on the technical ability assessment, only two showed significant differences in the two
groups. These were the number of technician consultations
required for machine malfunctions and the degree of confidence the patient had in his own ability to handle dialysis

procedures. Eighty per cent of the twelve lower scoring patients rarely required technician consultation while 75 per cent of the eight higher scoring patients required technician consultation three to six times yearly and over. One hundred per cent of the twelve lower scorers declared a feeling of confidence in handling dialysis procedures. Only 25 per cent of the higher scorers claimed to feel confident while 50 per cent felt somewhat uneasy and the other 25 per cent felt uneasyemost of the time.

The social-psychological data accounted for the greatest difference between the two groups of patients. Of the twelve patients scoring less than the mean, 100 per cent had productive activity over three hours daily and 80 per cent of these had productive activity over six hours daily. Of the eight higher scoring patients only 37 per cent had productive activity more than three hours daily.

Family relationships were said to be harmonious and satisfying by 80 per cent of the 12 lower scorers. Seventy-five per cent of the higher scorers stated family relationships were marked by tension and misunderstandings or were severely dissatisfying.

Recreational activities were said to be enjoyed often by 90 per cent of the twelve lower scorers while the remaining 10 per cent enjoyed them occasionally. Thirty-seven and a half per cent of the higher scorers enjoyed these activities often, while 25 per cent did occasionally, and the remaining 37.5 per cent claimed to rarely enjoy

recreational activities.

All of the twelve lower scorers said they had people to turn to for help when they needed it while only 60 per cent of the higher scorers felt this way. Moderate anxiety on the part of family members as a consequence of the patient's dialysis was said to be present by 25 per cent of the lower scoring patients. Seventy-five per cent of the higher scoring patients claimed moderate to severe anxiety on the part of family members.

When the patients were asked about their perceived ability to function in their family roles, 92 per cent of the lower scorers felt they could function as well or better than before their illness. Sixty per cent of the higher scorers felt less able to function in their normal roles than prior to their illness.

All of the patients in the lower scoring group felt generally optimistic in spite of their restrictions. Seventy per cent of the higher scorers, however, chose to say they felt down in the dumps and somewhat fearful about the future as their response to this item.

All of the patients in the lower scoring group said they felt comfortable about discussing their dialysis when meeting new people or talking with acquaintances if the subject should arise. Two of the eight higher scorers said they felt somewhat uncomfortable doing so and one said he would prefer to keep it a secret as his illness made him feel unacceptable to others.

Comparison of percentage scores on selected variables is shown in Figure 4.

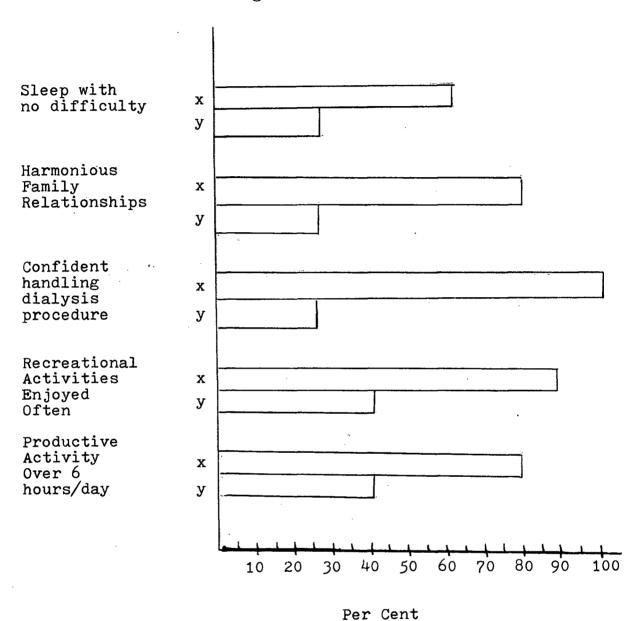


Figure 4 Comparison of Percentage Scores on Selected

Variables of Group x (Total score fell below
the mean) and Group y (total score fell above
the mean)

CHAPTER V

SUMMARY, CONCLUSIONS, AND RESEARCH IMPLICATIONS

I. SUMMARY

The purpose of this study was to construct a nursing assessment tool to identify the home hemodialysis patient's level of functioning and need for follow up care. Items which would rate the patient on physiological and social-psychological variables as well as technical abilities were included.

Data about those variables important to measure were obtained from several sources; review of hemodialysis literature, examination of patient records, questionnaire to dialysis nurses and semi-structured interviews with nine patients.

Items were included if a rating met the criteria of being obtained economically, quickly, objectively, directly, and with little inconvenience to the patient.

A three point numerical rating scale was used with no weighting of individual items. A one score indicates the most adequate level of functioning and a three score the least adequate. Individual scores are tallied to obtain a maximum total score of 144 indicating the patient with the greatest needs or a minimum score of 47 indicating the patient with the least needs.

Five dialysis experts including four nurses and one physician examined the tool. Face validity was established for determining the adequacy of the patient's level of functioning and his need for follow up care services.

A reliability test was conducted with four pairs of nurses using the validated tool to assess twenty patients. Reliability was verified when the two tailed *test, used to test whether or not the ratings obtained with the assessment tool were independent of the nurse obtaining the rating, was significant at the .05 level.

Analysis of the total scores showed a mean score of 69.5. Twelve patients' total scores fell below the mean while eight patients' total scores fell above the mean. These two groups of patients were compared on the several dimensions within the tool. The greatest areas of difference were in the social-psychological variables and in two areas of technical assessment. Differences in physiological variables as a whole were not as pronounced. Patients whose scores fell above the mean tended to have less confidence in their ability to handle dialysis procedures, require more technical backing, have more problems with circulation access, sleep less well, have feelings of role dysfunction, engage in less productive activity, and enjoy recreational activities less often than the group whose total scores fell below the mean.

Distribution of scores on blood chemistries, twentyfour hour urine volume, bone status, intradialysis weight gain, incidence of blood leaks, and failure of dialyzer to test out was not significantly different in the two groups of patients.

II. CONCLUSIONS

An assessment tool has been developed with good reliability and face validity. More extensive validity testing is required to demonstrate if the categories into which the patient falls, indicating his need for follow up care are appropriate in most cases.

More work needs to be done to eliminate non-relevant items, that is items which do not contribute to showing differences in the patients. If this were done then, theoretically, the mean could be made to represent the average patient and greater than one standard deviation from the mean could be used as the criteria for rating a patient's adjustment as excellent or very poor. Since only one patient score among the higher scores in this sample was outside one standard deviation, there was not an adequate base from which to do this.

Assessing patients with the tool required about twenty minutes per patient. Patients were receptive to the questions and answered them carefully and thoughtfully. Often the patient gave more information than was requested. This indicates the tool has good possibilities for expansion into a comprehensive assessment tool from which a nursing care plan could be developed.

III. RESEARCH IMPLICATIONS

Now that reliability of this assessment tool has been verified it should be used to assess a statistically significant sample of hemodialysis patients. From this assessment the most important variables could be identified. Validity testing is a problem since there is no independent standard against which to measure the patient ratings. There is little difficulty, however, in establishing by reports of the staff, those patients who fall at the extreme ends of the continuum of poor adjustment to excellent adjustment. If deviations from the mean are a good criteria then this test of validity would be useful. One could perhaps then assume that the tool would be equally sensitive in the middle areas.

This assessment tool is not intended, in its present form, to be used as an instrument from which nursing care plans are developed. It is intended as an instrument to assist the nurse in evaluating which patients most need further assessment and follow up care. Much more work is necessary in the areas of weighting individual items and excluding non-relevant items.

BIBLIOGRAPHY

BIBLIOGRAPHY

A. BOOKS

- Bonney, Virginia, and June Rothberg. <u>Nursing Diagnosis and Therapy: An Instrument for Evaluation and Measurement</u>. New York: The National League for Nursing, 1963.
- Gutch, C. F. and Martha Stoner. Review of Hemodialysis for Nurses and Dialysis Personnel. Saint Louis: The C. V. Mosby Company, 1971.
- Hampers, Constantine and Eugene Schupak. Long-Term Hemo-dialysis. New York: Grune and Stratton, 1967.
- Little, Dolores E. and Doris Carnevali. Nursing Care Planning. Philadelphia: J. B. Lippincott Company, 1969.
- Pendras, Jerry and G. Stinson. <u>The Hemodialysis Manual</u>. Seattle, 1969.

B. PERIODICALS

- Abel, J. J., L. G. Rowntree and B. B. Turner. "On the Removal of Diffusible Substances from Circulating Blood by Means of Dialysis," <u>Transactions Association American Physicians</u>, (1913) pp 28 51.
- Abram, Harry S. "The Psychiatrist, the Treatment of Chronic Renal Failure, and the Prolongation of Life,"

 American Journal of Psychiatry, vol. CXXIV, no. 10, (April, 1968), pp 1251 1358.
- Achad, A., M. Haimov, A. Hering and E. Schupak. "Subcutaneous Arterial-Venous Fistula in Home Hemodialysis,"

 <u>Transactions American Society for Artificial Internal</u>

 <u>Organs</u>, vol. XVI, (1970) pp 280 283.
- Aydelotte, Myrtle Kitchell. "The Use of Patient Welfare as a Criterion Measure," <u>Nursing Research</u>, vol. XI, no. 1, (Winter, 1962), pp 10 14.
- Baillod, R. A., et al "Overnight Hemodialysis in the Home,"

 <u>Proceedings of the European Dialysis and Transplant</u>

 <u>Association</u>, vol. II, (1965), p. 99.

- Blagg, C. R., R. O. Hickman, J. W. Eschbach, and B. H. Scribner.

 "Home Hemodialysis: Six Years' Experience," New
 England Journal of Medicine, vol. CCXXCII, (November, 1970), pp 1126 1131.
- Blumberg, A. and K. Giger, Letter to the Editor re Hepatitis and Hemodialysis, New England Journal of Medicine, vol. CCXXCVII, no. 12, (September 17, 1970), pp 657 658.
- Brand, L. and N. I. Kamarita, "Adapting to Long-Term Hemo-Dialysis," American Journal of Nursing, vol. 66, no. 8, (August, 1966), pp 1778 - 1781.
- Compty, C. M., D. McDade and M. Kaye. "Anemia and Iron Requirements of Patients Treated by Maintenance Hemodialysis," <u>Transactions American Society for Artificial Internal Organs</u>, vol. XIV, (1968), pp
- Cummings, Jonathon W. "Hemodialysis: The Pressures and How Patients Respond," <u>American Journal of Nursing</u>, vol. 70, no. 1, (January, 1970), pp 70 76.
- Curtis, K., et al. "Hemodialysis in the Home," <u>Transactions</u>
 American Society for Artificial Internal Organs, vol.
 XI, (1965), p. 7.
 - DeNour, A. K. "Psychotherapy with Patients on Chronic Hemodialysis," <u>British Journal of Psychiatry</u>, vol. CXVI, (February, 1970), pp 207 215.
- DeNour, A. K., J. Shaltiel and J. W. Czoczkes. "Emotional Reactions of Patients on Chronic Hemodialysis,"

 Psychosomatic Medicine, vol. XXX, no. 5, (September-October, 1968), pp 521 533.
- Eschbach, Joseph W., et al. "Unattended Overnight Home Hemo-dialysis," <u>Transactions of the American Society for Artificial Internal Organs</u>, vol. XII, (1966), p. 346.
- Friedman, E. A., et al. "Psychosocial Adjustment to Maintenance Hemodialysis," New York Journal of Medicine, vol. LXX, (March, 1970), pp 629 637.
- Gaspard, Nancy. "The Family of the Patient with Long Term Illness," <u>Nursing Clinics of North America</u>, vol. 5, no. 1, (March, 1970) pp 77 84.
- Hampers, C. L., J. P. Merrill and Elizabeth Cameron. "Hemo-dialysis in the Home A Family Affair," <u>Transactions</u> American Society for Artificial Internal Organs, vol. XI, (1965), p. 3.

- Kennedy, A. C. "A Scoring System for Assessing Patients on Regular Dialysis," Lancet, vol. I, (April 5, 1969), pp 701 - 702.
- Kim, D., et al. "Renal Osteodystrophy in Course of Periodic Dialysis for Chronic Uremia," <u>Transactions American Society for Internal Organs</u>, vol. XIV, (1968), pp 367 371.
- Kolff, W. J. "First Clinical Experience with the Artificial Kidney," Annals of Internal Medicine, vol. LXII, (1965), p. 608.
- Lewis, L. "This I Believe About the Nursing Process Key to Care," Nursing Outlook, vol. XVI, no. 5, (May, 1968), pp 26 29.
- McCain, Faye. "Nursing by Assessment Not Intuition." American Journal of Nursing, vol. 65, no. 4, (April, 1965), pp 82 84.
- Meldrum, Maxine, Joydelle Wolfrom and Milton Rubice. "The Impact of Chronic Hemodialysis upon the Socio-Economics of a Veteran Patient Group," Journal of Chronic Diseases, vol. XXI, (1968), pp 37 52.
- Norton, Charles E. "Chronic Hemodialysis as a Medical and Social Experiment," Annals of Internal Medicine, vol. LXVI, (June, 1967), pp 1267 1276.
- Onesti, G., et al. "Bilateral Nephrectomy for Control of Hypertension in Uremia," <u>Transactions American Society for Internal Organs</u>, vol. XIV, (1968), pp 361 366.
- Pendras, J. P. and Terrance Pollard. "Eight Years Experience with a Community Dialysis Center," <u>Transactions of the American Society for Artificial Internal Organs</u>, (1970) p. 77.
- Potter, D. J. and G. M. Nickos. "Assessment of Patients Undergoing Home Maintenance Dialysis," <u>Arizona Medicine</u>, vol. XXVII, (April, 1970), pp 76 79.
- Quinton, Wayne, David Dillard and Belding Scribner. "Cannulation of Blood Vessels for Prolonged Hemodialysis,"

 Transactions American Society for Artificial Internal
 Organs, vol. VI, (1960), p. 104.
- Read, Martha and Mary Mallison. "External Arteriovenous Shunts," American Journal of Nursing, vol. 72, no. 1, (January, 1972), p. 81.
- Rich, Rosemary and James K. Dent. "Patient Rating Scale,"

 Nursing Research, vol. XI, no. 3, (Summer, 1962),

 pp 163 171.

- Sand, Patricia, G. Livingston, and R. G. Wright. "Psychosocial Assessment of Candidates for a Hemodialysis Program," <u>Annals of Internal Medicine</u>, vol. LXIV, (March, 1966), pp 602 - 610.
- Schoening, Herbert and Iver A. Iverson. "Numerical Scoring of Self-Care Status: A Study of the Kenney Self-Care Evaluation," Archives of Physical Medicine, vol. XLIX, no. 1, (January, 1968), pp 221 229.
- Scribner, Belding H., et al. "The Treatment of Chronic Uremia by Means of Intermittent Hemodialysis: A Preliminary Report," Transactions American Society for Artificial Internal Organs, vol. VI, (1960), p. 114.
- Shaldon, Stanely and M. D. Contab. "Independence in Maintenance Hemodialysis," <u>The Lancet</u>, vol. 1, (March, 1968), pp 520 - 523.
- Shambraugh, Philip W., et al. "Hemodialysis in the Home Emotional Impact on the Spouse," <u>Transactions</u>

 <u>American Society for Artificial Internal Organs</u>,
 vol. XIII, (1967), pp 41 45.
- Shea, Eileen, et al. "Hemodialysis for Chronic Renal Failure Psychological Considerations," Annals of Internal Medicine, vol. LXIII, no. 3, (March, 1965), pp 588 563.
- Short, M. J. and W. P. Wilson. "Roles of Denial in Chronic Hemodialysis," <u>Archives of General Psychiatry</u>, vol. XX, (April, 1969), pp. 433 437.
- Simms, Laura. "The Clinical Nurse Specialist: An Experiment,"

 Nursing Outlook, vol. XXXII, (August, 1965), pp 26 28.
- Stewart, Betty M. "Hemodialysis in the Home: The Value of House Calls by Training Personnel," Nursing Clinics of North America, vol. 4, (September, 1969), pp 431 442.
- Tenckhoff, H., R. H. Jebsen, and J. C. Honet. "The Effect of Long-Term Dialysis Treatment on the Course of Uremic Neuropathy," <u>Transactions American Society for Internal Organs</u>, vol. XIII, (1967), pp 53 61.
- Williams, Mary Edna. "The Patient Profile," <u>Nursing Research</u>, vol. IX, no. 3, (Summer, 1960), pp 122 124.
- Wood, S. "Hemodialysis in the Home," <u>Canadian Nurse</u>, vol.65, no. 4, (April, 1969), pp 42 44.

- Wright, Robert G., P. Sand and G. Livingston. "Psychological Stress During Hemodialysis for Chronic Renal Failure,"

 Annals of Internal Medicine, vol. LXIV, (March, 1966), pp 611 621.
- Zimmerman, Donna Stulgis and Carol Gohrke. "The Goal-Directed Approach: It does Work," American Journal of Nursing, vol. 70, no. 2, (February, 1970), pp 306 310.

C. UNPUBLISHED REPORTS

- Aydelotte, M. K. "Nursing Care of Patients Undergoing Hemodialysis: A Study Report," Unpublished report presented to the Third Annual Veterans' Administration Workshop on Chronic Hemodialysis, Chicago, April, 1967.
- Blagg, Christopher R. "Need for Home Follow Up Care," Unpublished report to Kidney Advisory Committee, Washington - Alaska Regional Medical Program, 1972.
- Computer Print-Out National Dialysis Registry, Research Triangle Park, North Carolina, January, 1972.
- MacElveen, Patricia M. Exploration of the Cooperative Triad in the Investigation of Home Dialysis Patient

 Outcomes. Unpublished Doctoral Dissertation, University of Colorado. 1971.
- Smith, Dorothy. Manual for the Use of the Nursing History

 Tool. Third Revision, College of Nursing, University
 of Florida, Gainsville, Florida, 1971. (Mimeographed)

APPENDIX A

NURSING ASSESSMENT FORM FOR MAINTENANCE HOME
HEMODIALYSIS PATIENT

NURSING ASSESSMENT FORM FOR MAINTENANCE HOME HEMODIALYSIS PATIENT

I.	Physiological Assessment	1	2	3
	Adequacy of Dialysis and Nutritional Status			
	Pre-dialysis Creatinine			
	(1) Female: below 9; Male: below 10 (2) Female: 9 - 12.9; Male: 10 - 13.9 (3) Female: 13 or over; Male: 14 or over			
	Pre-dialysis BUN			
	(1) below 80 (2) 80 - 100 (3) over 100			
	Serum Albumin	1		
•	(1) 3.7 Gms % or above (2) 3.0 - 3.6 (3) 2.9 or below			
	24 Hour Urine Volume			
	 (1) > 500 cc per day (2) 250 - 500 cc per day (3) < 250 cc per day 			
	Intradialysis Weight Gain			
	Dry weight $<$ 65 Kg. Maximum = $2 - 2\frac{1}{2}$ Kg. Dry weight 65 - 80 Kg. Maximum = $2\frac{1}{2} - 3$ Kg. Dry weight 80 - 100 Kg. Maximum = $3 - 3\frac{1}{2}$ Kg.			
	(1) rarely exceeds maximum(2) exceeds about 50% of the time(3) usually exceeds maximum			
	Average Pre-dialysis Blood Pressure			
	 (1) systolic below 160; diastolic below 90 (2) systolic 160 - 190; diastolic 90 - 100 (3) systolic above 190; diastolic above 100 			
	Circulation Access			
	Subcutaneous Fistula Puncture			
	(1) \$\ifsize 25\% \text{ of time do extra puncture for access}\$\$(2) \(\frac{25}{5} - 50\% \text{ of time do one or more extra puncture} \)\$\$(3) \$\inc 50\% \text{ of time do one or more extra puncture}\$\$\$	9		

Fistula Flow	1	2	3
(1) Arterial or venous pressure monitor alarm (unrelated to blood pressure) occurs during dialysis less than 25% of the time (2) occurs 25 to 50% of the time (3) occurs greater than 50% of the time or the necessity of keeping the arm completely immobile to prevent alarm			
External A-V Shunt			
Number of infections over past six months (1) none (2) one to two mild infections cleared with treatment (3) more than two mild infections or any severe infection which resulted in revision or permanent skin damage in cannula area			
Bleeding Episodes (1) no bleeding in last six months (2) chronic small leaking of blood at exit sites or one to two episodes of moderate blood leaking at exit sites or very small hematoma formation in the last six months (3) 3 or more moderate blood leaking episodes or any severe bleed or large hematoma formation in the last six months			
Clotting Episodes (1) 0 - 1 in last six months (2) 2 - 4 in last six months (3) more than 4 or any one which resulted in revision of shunt			
Bone Status			
X-Ray Evidence			
 (1) mild to moderate demineralization (2) severe demineralization (3) sub-periosteal erosion and/or vascular calcification plus any degree of demineralization 	•		
Clinical Evidence			
(1) no bone pain (2) bone pain (3) pathological fracture within past year			

•		<u> </u>	
Anemia and Cardiac Status		2	3
Hematocrit			
(1) average > 25% (2) 20 - 25% (3) < 25%			
Shortness of Breath and/or Fatigue			
(1) no s.o.b. or fatigue with normal activity (2) moderate s.o.b. or fatigue with normal activity (3) severe s.o.b. or fatigue with normal activity			
Cardiac Symptoms			
(1) no chest pain or irregularity (except occass-			
ional skipped beat) (2) chest pain on exertion - mild to moderate			
(3) severe chest pain on exertion and/or taking digitalis or quinidine			
<u>Neuropathy</u>			-
(1) no neurological symptoms			
(2) numbness in feet(3) interference with walking			
Exam for Distal Motor Nerves			
(1) pull down toes with difficulty			
(2) toes pull down easily(3) patient cannot extend toes			1
Exam for Proximal Motor Nerves			
(1) stands on toes easily			
(2) stands on toes with difficulty(3) unable to stand on toes			
Sexual Functioning		·	
(1) satisfied with degree of function			
(2) not optimally satisfied - some difficulty (3) very dissatisfied with degree of function		!	
Menstrual Cycle			
(1) normal for age			
(2) irregular menstruation: moderate to excessive bleeding; or absence of menses if bothersome			
to patient (3) severe or prolonged bleeding with menses			
	L		- 1

	1	2	3
Sleep Patterns			
 (1) no difficulty sleeping (2) some or moderate difficulty sleeping (3) severe difficulty sleeping so that functions poorly next day 	·		
Miscellaneous Symptoms			
Itching			
(1) absent(2) moderate(3) severe			
Nausea and/or Vomiting			
(1) rarely(2) moderately often(3) severe and troublesome			
Headache			
(1) mild to moderate and occurs rarely(2) moderate to severe occurs occasionally(3) severe and occurs often			
Dizziness or Feelings of Disequilibrium			
(1) absent (2) occasional (3) often			
Muscle Cramps			
(1) rarely(2) intermittently(3) often			
Constipation or Diarrhea (circle one or both)			İ
<pre>(1) rarely (2) intermittently (3) often</pre>			
Chills and Fever			
(1) rarely(2) intermittently(3) often			

II. Technical Ability Assessment	1	2	3
Machine malfunction Requiring Technician consultation			
 (1) occurs rarely or about 3 times yearly (2) occurs between 3 and 6 times yearly (3) occurs frequently - more than 6 times yearly 			
Rebuilding Dialyzer because of Failure to Test Out			
(1) rarely necessary(2) often but less than 25% of the time(3) over 25% of the time			
Incidence of Blood Leaks on First Dialysis after Rebuilding			
(1) rare(2) occurs but less than 25% of time(3) over 25% of the time			
Feel Frustrated over Technical Problems			
(1) only rarely(2) moderately often(3) most of the time			
Degree of Confidence in Ability to Handle Procedures			
 (1) very confident (2) confident most of the time but somewhat uneasy on occasion (3) uneasy most of the time 			
III. Psychosocial Assessment			
Hours Spent in Productive Activity (employment, housework, studies, etc.)	•		=
(1) 6 or more hours daily (2) 3 - 6 hours (3) 0 - 3 hours	-		i
Present Work Level is			
(1) same as before my illness(2) slightly less than before(3) much less than before			
Enjoy Recreational Activities			
(1) often(2) occasionally(3) rarely			

	1	2	3
Which of these Statements Most Describe Your Own Feelings?			
(1) Though I would rather I did not need dialysis I am glad that it is available and feel it is all worth while to have this chance to extend my life.			
(2) I find myself wondering fairly often if I made the right choice in deciding to prolong my life by dialysis.			
(3) I regret my decision to start on the kidney and feel my life is no longer worth while.		_	
How does Dialysis Affect Your Family?			
(1) have accepted(2) moderately anxious(3) very anxious			
When Meeting New People or Talking with Acquaintances			
(1) I make no effort to bring up my illness but am very comfortable talking about it if the subject should arise.			į (
(2) I feel somewhat uncomfortable in discussing my illness.			
(3) My illness makes me feel different and not accepted by others and I prefer to keep it a secret.			
I Find that I can Live Within My Present Restrictions (such as diet, regular dialysis, reduced physical activity) Comfortably.			
(1) yes(2) about half the time(3) no			
Which of These Statements Best Describe Your Own Feelings?			
(1) People who are on dialysis should do the most they can for themselves but accept help from family and friends when needed.			
(2) People who are on dialysis have a right to			
expect that others will help them. (3) People who are on dialysis should not be expected to take care of themselves.			
	L		

	1	2		3
Participate in Social or Community Organizations and Activities				
(1) about the same as before(2) less than before(3) much less than before				
Feel Able to Function as a Husband, Wife, Mother, Fathe Family Member, (circle those that apply)	r,			
(1) as well or better than before my illness(2) not as well as before my illness(3) poorly				
Family Relationships are				
 (1) for the most part, harmonious and satisfying (2) marked by frequent misunderstandings and tension - are less than satisfying (3) completely disrupted, antagonistic or severely 				. :
dissatisfying				Į,
Relationships with Friends and Relatives are				
(1) good and mutually satisfying(2) somewhat strained since my illness(3) very strained or absent or disharmonious				
There are People to turn to for Help when I Need it		\top		
(1) yes (2) not always (3) no				
Which of these Statements Most Describes Your Feelings About Your Situation				
(1) Though I know I will continue to have to live with restriction I enjoy life and greet most				
days with reasonable optimism. (2) Knowing that I must continue to live with restrictions I find myself fearful about the				
future and find less enjoyment in life. (3) Knowing that I must continue to live with restrictions I find myself down in the dumps much of the time with little enjoyment in life			***	

Which of these Statements Best Describes the Way You	1	2	3
Feel Most of the Time?			
 (1) Reasonably comfortable and at peace with myself and others (2) Uncomfortable and somewhat down in the dumps or in a bad mood (3) Very uncomfortable, angry and annoyed or very down in the dumps and depressed 			
In General I Find My Life			
(1) satisfying(2) less than satisfying(3) very dissatisfying			

APPENDIX B

NURSES QUESTIONNAIRE

NURSES QUESTIONNAIRE

The purpose of this exercise is to elicit information from those who work closely with dialysis patients regarding their reasons for placing a patient in the categories of functioning well or functioning poorly. Try to think of those things which are really the most important in formulating your opinion. These can include medical reasons, social or psychological reasons or anything which you think substantially contributes to the patients being placed in the category.

1. Think of one patient you know well whom you feel is poorly adjusted or doing poorly in general on dialysis. Describe this person briefly (do not mention his or her name) and state why you feel this person is doing poorly rather than well.

2. Think of one patient you know well whom you see as doing very well on dialysis. Please describe this patient and your feelings about why you feel he should be rated as doing well.

APPENDIX C

SEMI-STRUCTURED PATIENT INTERVIEW SCHEDULE

SEMI-STRUCTURED PATIENT INTERVIEW SCHEDULE

General Introduction

I am mostly interested today in finding out from you which parts of your life and health have been most affected by your need for treatment on the artificial kidney - that is - what mostly seems to cause you trouble and what seems to make things easier for you. I have a few questions in mind but first I would like to hear from you whatever you feel like telling me so I make sure I find out what is really important to you.

Questions

In what way is your life different now than it was before you needed hemodialysis? Occupation, leisure activities, sleep, community involvement, family relationships, friendship circles, etc.

How have these changes affected the way you feel about yourself or your life?

How do you feel physically most of the time now? Emotionally? What things bother you the most about your present state? What things seem to help you the most?

What single improvement in your present situation would make life on hemodialysis more tolerable to you?

APPENDIX D

VALIDATION FORM

VALIDATION FORM

Data derived from this assessment form would be adequate to determine the relative state of well being of the maintenance home hemodialysis patient and would point out his need for follow up care.
agree•
agree but feel the following changes should be made:
disagree for the following reasons:
Signature:

APPENDIX E

INSTRUCTIONS TO NURSES PARTICIPATING
IN THE RELIABILITY TESTING

The purpose of this assessment tool is to rate the patient on each item so that a total score will reflect his need for follow up care. This tool is not intended as a depth analysis of a patient's problems but only as a way of reflecting in which areas he has the greatest needs as well as showing his relative level of functioning.

The patient has been told that he will be rated by two different nurses. The reason for this is to provide two scores on each patient so that the scores may be compared statistically to demonstrate whether or not the ratings provided by the tool are independent of the person doing the rating.

Please do not use any prior knowledge you may have of a patient to answer the questions, but record the response the patient gives. If a patient waivers on the answer you may clarify for him, but, please have him make the final decision on the category.

Each item has a choice of three responses numbered 1, 2, 3. Please place a check under the appropriate number in the column to the right opposite the item. If the patient chooses the number two response to an item then place a check mark under the number two column opposite that item.

In all cases the number one response is designed to represent the better level of functioning, the number three response the poorer.

The highest total score should reflect the patient with the greatest need for follow up care while the lowest total score should reflect the patient with the least need.