



Social support and quality of life among rural hemodialysis patients
by Karleen Marie Anderson

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University

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Abstract:

This study examined the relationship of social support, quality of life, and selected demographic variables of rural in-center hemodialysis patients. The demographic variables selected for inclusion were age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases. Social support was measured by using the Personal Resource Questionnaire (PRQ) by Brandt & Weinert (1985). Quality of life was measured using the Quality of Life Index (QLI) by Perrons & Powers (1985). The questionnaires were personally distributed to potential participants in three dialysis centers in Montana. The sample included 31 in-center hemodialysis patients. The PRQ, QLI, and demographic data were descriptively analyzed for the entire sample. Scores for the PRQ and QLI were summed for each participant. The means were entered into a Pearson r correlational analysis program to determine variable relationships.

A strong positive relationship was found between the variables of social support and quality of life. No relationship was found between any of the demographic variables and social support or quality of life. The unmarried participants in the study had lower mean social support scores than the married participants.

The findings in this study emphasize that assessment of the role of social support for the dialysis patient should be a priority in the provision of nursing care for dialysis patients.

SOCIAL SUPPORT AND QUALITY OF LIFE
AMONG RURAL HEMODIALYSIS PATIENTS

by

Karleen Marie Anderson

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This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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ABSTRACT

This study examined the relationship of social support, quality of life, and selected demographic variables of rural in-center hemodialysis patients. The demographic variables selected for inclusion were age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases. Social support was measured by using the Personal Resource Questionnaire (PRQ) by Brandt & Weinert (1985). Quality of life was measured using the Quality of Life Index (QLI) by Ferrons & Powers (1985). The questionnaires were personally distributed to potential participants in three dialysis centers in Montana. The sample included 31 in-center hemodialysis patients. The PRQ, QLI, and demographic data were descriptively analyzed for the entire sample. Scores for the PRQ and QLI were summed for each participant. The means were entered into a Pearson r correlational analysis program to determine variable relationships.

A strong positive relationship was found between the variables of social support and quality of life. No relationship was found between any of the demographic variables and social support or quality of life. The unmarried participants in the study had lower mean social support scores than the married participants.

The findings in this study emphasize that assessment of the role of social support for the dialysis patient should be a priority in the provision of nursing care for dialysis patients.

CHAPTER 1

INTRODUCTION

Background and Rationale for Study

End-stage renal disease (ESRD) has become a major health problem in today's society. The majority of deaths related to renal failure occur in the most productive years of adulthood. Each year in the United States, over 55,000 deaths are attributed to ESRD (Eddins, 1984).

End-stage renal disease is a chronic, debilitating disease which requires persons to make extensive changes in their life-style in order to survive. Persons having ESRD must choose between hemodialysis, peritoneal dialysis, and/or renal transplantation as treatment choices. Other life-style changes include adaptation to a complex dietary and medical regime with strict fluid retention and medication requirements. Loss of freedom and fear of premature death add to the stress of having ESRD and may result in poor adaptation to the necessary changes. Since poor adaptation can be life threatening, compliance with the treatment regime is essential.

Many research studies have been conducted to determine the variables that influence the ability of ESRD patients to adapt and comply with dialysis treatment. Results from these

studies indicate that some form of social support is needed for dialysis patients to deal with the stresses and anxiety created by chronic illness. Social support assists ESRD patients to develop and use adequate coping mechanisms and behaviors to deal with chronic illness (Harris, Hyman & Woog, 1982; Piltz-Kirkby & Fox, 1982), comply with a complex medical regime (Eddins, 1985), and promote adaptation to dialysis as a life-saving treatment for prolongation of life (Winkes, 1983). Support or lack of support from family characterizes the climate in which end-stage renal disease patients must function (Stark, 1985) and determines social well-being (Simmons, Anderson & Komstra, 1984). Simmons et al. indicated that social well-being should be included with physical and emotional well-being in order to conceptualize quality of life.

Quality of life has become an increasingly important variable in deliberations about patient care, medical ethics, new technology, mechanisms of financing and reimbursement, and goals of the health care system (Levine, Groog & Sadilovsky, 1985). In the 1960s dialysis treatment was available for only a few. Committees of health practitioners decided the "ideal" candidates for dialysis and those selected were responsible for paying the full cost of hemodialysis or transplantation. A dramatic impact on the care of ESRD patients occurred in 1973 when Medicare coverage was extended to ESRD patients under 65 years of age through the End-Stage Renal Disease

Program. The emphasis on economic needs that once were the determiners of happiness and satisfaction shifted to factors related to quality of life--family life, friendships, work conditions, personal attributes, and the nature of the social and physical environment.

Research studies have been conducted to examine the quality of life for patients undergoing dialysis treatment. These studies examined quality of life from several perspectives. They included the measurement outcome of treatment success (Stout et al., 1987), the determination of the impact of chronic illness (Laborde & Powers, 1980), the questioning of the objective benefits patients derive from rising health care expenditures (Evans et al., 1985), the exploration of how patients feel about their lives (Simmons et al., 1984), the comparison of the costs of various treatment options for ESRD patients (Hawthorne, 1986), and the problems encountered in defining and measuring quality of life (Ferrons & Powers, 1985).

Purpose of Study

No studies were found that directly examined the relationship of social support and the quality of life of ESRD patients. Therefore, the purpose of this study was to examine the relationship of social support and quality of life and selected demographic variables of rural in-center hemodialysis patients. The demographic variables selected for inclusion

were age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases.

The research questions to be addressed included the following:

1. What is the relationship between social support and quality of life among dialysis patients in rural in-center hemodialysis facilities?

2. What relationships exist between the demographic variables of age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases and level of social support?

3. What relationships exist between the demographic variables of age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases and perceived quality of life?

Significance to Nursing

Lazarus (1983) has been quoted to say:

What is missing in health care is an appreciation of the whole person in the context of his or her environment, which includes goals, obligations, wishes and fears, social ties, meanings and sense of future. In short, it includes all the factors in living that carry heavy emotional loading when a person is threatened by illness (Mapes, 1985, p. 33).

Within the provisions of health care to chronically ill dialysis patients, increased knowledge of the relationship of social support and quality of life could potentially help improve the nursing care of dialysis patients. Nurses could

facilitate increased support of the patient by family and dialysis personnel, improve communication techniques with the patient, and better assist in planning interventions for health care of dialysis patients.

Psychological and social factors should be considered in the overall management of patients with ESRD for a relationship with success of the treatment. Assessment of quality of life and social support for dialysis patients could be important in measuring the outcome of treatment success. Information obtained by psychosocial profiling could assist in making informal decisions regarding the choice of treatment for ESRD and measuring specific patient needs.

Conceptual Framework

The concepts of importance related to this study were social support and quality of life. Social support theories are compared and followed by a discussion of issues related to quality of life.

Social Support

Social support has been described in several ways and can be defined as a set of concepts rather than a single concept. None of the theorists support a single definition.

Weiss (1974) suggested that social support is a combination of relational provisions which include attachment, social integration, opportunity for nurturing, reassurance of worth, obtaining of guidance, and a sense of reliable

alliance. Attachment is a sense that one is cared for and loved, the sense of security that is provided by intimate relationships. Social integration is obtained through sharing in group relationships. Opportunity for nurturance is obtained in relationships in which the individual has a sense of being depended on or needed. Reassurance of worth is a sense that an individual is competent, respected, or admired and is provided by work and family relationships. Obtaining guidance can furnish emotional support through access to an authoritarian or trustworthy figure. A sense of reliable alliance is provided where there is an expectation for continuing assistance.

Cobb (1976) defined social support as "information leading the subject to believe that she/he is cared for and loved, esteemed, and a member of a network of mutual obligations" (p. 300). He indicated that social support is conceived to be information belonging to one or more of the following three classes:

1. Information leading the subject to believe that he is cared for and loved is shared in intimate situations, involving trust and is referred to as emotional support.

2. Information leading the subject to believe that he is esteemed and valued reinforces his sense of personal worth and may be referred to as esteem support.

3. Information leading the subject to believe that he belongs to a network of communication and mutual obligation

allows the subject to share in group relationships where there is mutual affection. This information is shared by everyone in the network so that each member is aware that every other member knows.

Cassel (1974) discussed protective factors that buffer or cushion individuals from the physiologic or psychologic consequences of exposure to stressor situations. He suggested that the property of utmost importance common to these processes is the strength of the social supports provided by the primary groups of individuals. He claimed it would be feasible to attempt to improve and strengthen the social supports rather than reduce the exposure to stressors.

With advancing knowledge, it is perhaps not too far-reaching to imagine a preventive health service in which professionals are involved largely in the diagnostic aspects--identifying families and groups at high risk by virtue of their lack of fit with their social milieu and determining the particular nature and form of the social supports that can and should be strengthened if such people are to be protected from disease outcomes (p. 480).

Tilden (1985) stated that social support is emerging as a significant health behavior which shows promise for theory development in nursing, since nursing is concerned with the commitment to health, self-help, and the interpersonal environment of clients. She suggested that the measurement of social support has been hampered by the absence of definitional consensus.

Tilden and Weinert (1987) have examined social support in the chronically ill individual. They stated that social

support and social networks are often used interchangeably, leading to confusion in their definitions. Social support refers to "the psychosocial and tangible aid provided by the social network and received by a person. Because social support is reciprocal and mutual, it also is returned by the person to those in the network." (Tilden & Weinert, 1987, p. 614)

Social networks are the structural inter-relationships of those who provide support, such as family, friends, neighbors, co-workers, and others. Structural characteristics of social networks include dimensions such as size, density (the extent to which people in the network know each other), frequency of contact, homogeneity (the similarity of people in the network), and durability or length of relationships (Tilden & Weinert, 1987).

Quality of Life

Quality of life is a complex concept with problems in its conceptualization and definition. In order to identify quality of life domains, Campbell, Converse, and Rodgers (1976) asked random samples of Americans in the general population ($N=2,164$) to think of specific domains that described their quality of life. Participants were also asked to rate their level of satisfaction with those domains. Five broad areas emerged from the categorization of specific domains. These domains included 1) physical and material well-being, 2) relations with other

people, 3) social, community, and civic activities 4) personal development, and 5) recreation.

Objective measures of quality of life can be categorized as functional status which refers to mobility, capacity for self care and energy to engage in desired activities, and socioeconomic status, including financial security and material goods (Dimond & Jones, 1983). The subjective evaluation of quality of life is considered in terms of life satisfaction and self-esteem. Life satisfaction is related to past experiences, success, and future prospects. Self-esteem includes a sense of self love and personal worth which recognizes personal weaknesses and strengths.

In their nationwide study, Campbell et al. (1976) reported that when asked specifically about their quality of life, individuals responded in terms of life satisfaction. They suggested that life satisfaction is the most important dimension to include in quality of life measurements.

The impact of chronic illness on quality of life is an increasing concern to society and health care professionals (Burckhardt, 1984). Illness or disability is a permanent aspect of life for many people. Researchers have paid little attention to assessment of factors that influence the perception of quality of life in the chronically ill. Burckhardt (1984) further claimed that "although the goal of enhancement of quality of life is apparent in nursing's philosophical statements, it has not been measured

systematically in many of the populations nursing serves" (p. 11).

Dimond and Jones (1983) described the task of defining quality of life of an individual with a chronic illness as a difficult, if not impossible task. While the purpose and meaning of life is made up of basic needs of material and spiritual sustenance, health, and achievement of personal goals, hopes, and expectations, the onset of a chronic illness often means profound changes in the life styles of some individuals. Illness causes some change in the quality of life and life may not retain the same purpose or meaning.

Ferrons and Powers (1985) synthesized their definition of quality of life by combining the definition for quality of life developed by Dalkey and Rouke (1973) and Campbell et al. (1976). Dalkey and Rouke defined quality of life as a person's sense of well being, satisfaction or dissatisfaction with life, and happiness or unhappiness (Ferrons & Powers, 1985). Campbell et al. (1976) defined quality of life as "the satisfaction of needs." Satisfaction was defined as the perceived discrepancy between aspiration and achievement, ranging from the perception of fulfillment to that of deprivation. Need was defined as the amount of a particular reward that a person may require (Ferrons & Powers, 1985).

Ferrons and Powers (1985) examined the quality of life domains identified from studies with the general population in order to develop a tool to assess quality of life domains.

of people with chronic illness. Domains included subject's opinion of quality of life or life satisfaction, socioeconomic status, physical health, affect, perceived stress, friendships, family, marriage, achievement of life goals, satisfaction with housing and neighborhood, satisfaction with city and nation, satisfaction with self, depression, psychological defense mechanisms, and coping. Ferrons and Powers thought that life satisfaction was the most important dimension to include since it has been used extensively in quality of life research. Although overall quality of life has been measured by assessing satisfaction, they thought that the issue of individual differences in the importance of specific domains contributing to quality of life had been neglected. Subsequently, their tool, the Quality of Life Index, was constructed to measure quality of life through the subjective evaluation of satisfaction with life domains and the unique importance of each of those domains to the individual. Comparing the respondent's values with levels of satisfaction produces a more accurate reflection of quality of life.

Definitions

End-Stage Renal Disease (ESRD)--irreversible kidney disease causing chronic abnormalities in the internal environment and necessitating treatment with dialysis or transplantation for survival (Lancaster, 1983).

Hemodialysis--the removal of certain elements from the blood by virtue of difference in rates of their diffusion through a semipermeable membrane while the blood is being circulated outside the body (Miller & Keane, 1972).

In-Center Hemodialysis--a site where hemodialysis is provided in federally approved ESRD treatment facilities. The centers used for this study include facilities that have been in operation for 6 years or more. These include the three centers located in the western half of Montana--Helena, Missoula, and Great Falls.

Rural--characteristics of a rural area include low population density (less than 500 persons per square mile), distance from urban resources, the relative predominance of an unperturbed natural ecology, and the small sizes of the involved communities with fewer than 4,000 people (Rosenblatt & Moscovice, 1982). The average population density for the state of Montana is 6 persons per square mile. Therefore, for the purpose of this study, the entire state of Montana was considered rural.

Social Support--a combination of relational provisions which include attachment, social integration, opportunity for nurturing, reassurance of worth, obtaining of guidance and a sense of reliable alliance (Weiss, 1974, p. 23-24). This concept was operationalized using Weinert and Brandt's (1985) Personal Resource Questionnaire (PRQ-85). It is designed to

measure situational support and the respondent's perceived level of support.

Quality of Life--a person's sense of well being, satisfaction or dissatisfaction with life, and happiness or unhappiness (Ferrons & Powers, 1985). Quality of life was operationalized using Ferrons and Powers Quality of Life Index (QLI) which measures domain satisfaction and importance. It was developed to measure quality of life by taking into account the life domains noted by experts, the subjective evaluation of satisfaction with the domains, and the unique importance of each domain to the individual.

Assumptions

The following basic assumptions were used in the development and implementation of this research study.

1. The dialysis patients in this study honestly responded to the questions in the measurement tools in terms of their perceptions of social support and quality of life.

2. The dialysis patients in this study also responded to the demographic characteristics with accuracy and honesty.

3. The participants understood the questionnaire and answered according to their personal perceptions about their life with dialysis.

The intent of this research was not to advocate one method of treatment over another. Persons undergoing in-center hemodialysis were included in this study since it usually is

the initial treatment for people with chronic kidney failure. Using one treatment modality was an attempt to limit the scope of the study.

CHAPTER 2

REVIEW OF LITERATURE

The review of literature describes the historical, physiological, and the psychological aspects of ESRD and its treatment. The review of literature also discusses studies which have examined social support, quality of life, and demographic variables with regard to ESRD.

End Stage Renal DiseaseHistorical Perspectives

End-stage renal disease has become a major health problem within the last 40 years. Before 1940, uremic patients were seldom treated. Up until the 1960s, the uremic patient was subjected to a protein and salt-restrictive diet and relied on sedatives to help relieve progressively severe twitches which often culminated in generalized convulsions as the patient approached death (Friedman, 1978). In the last 40 years, advances in health care have made a definite difference in the longevity and quality of life of ESRD patients.

Dialysis units were established in the United States in the 1960s. By 1972 the total population with ESRD was small, less than 6,000 patients (Tyndale, 1981). With this expensive treatment, health practitioners were forced with deciding

which patients would be good candidates. The "ideal" candidate for dialysis treatment was targeted as one who was most likely to survive over time. In 1973 the U.S. Congress provided Medicare and Social Security benefits for the treatment of this catastrophic disease. As a result, patient selection for maintenance dialysis was no longer an issue. At the present time, over 150,000 patients are now on dialysis (USRDS, 1989) and over 1,800 dialysis centers serve ESRD patients (Nephrology News, 1989).

In the state of Montana for 1986, a total of 207 patients were being treated for ESRD in the four main dialysis units in the state--Billings, Great Falls, Helena, and Missoula. Half of the patients were receiving in-center hemodialysis treatments (National Kidney Foundation, 1986).

Physiological Aspects

Multiple causes exist for end-stage renal disease, but all develop into a stage in which the function of the kidney is impaired to the degree that life is threatened and the damage to the kidney is not reversible. The kidney has ceased to remove metabolic wastes and excess water from the blood (Bauers, 1983). The onset of ESRD may be insidious or very sudden. The accumulation of uremic toxins causes physiologic changes and alters the function of various other organ systems.

The uremic syndrome is characterized by chemical imbalances in the blood and manifestations of various organ

system involvement. The patient will have an elevation of urea and creatinine, as well as various electrolytes and other blood constituents, that interfere with the normal metabolic activities of the body. The uremic patient will also experience gastrointestinal involvement with nausea, vomiting, and loss of appetite. The patient will manifest central nervous system involvement that may range from tiredness and drowsiness to agitation and excitement. Headaches are common and may be quite severe. Most patients with ESRD eventually develop cardiovascular involvement with resulting high blood pressure. Two causes for high blood pressure in uremic syndrome are 1) salt and water retention which increases the intravascular fluid volume, thus increasing the workload of the heart; and 2) hyperreninemia which causes an increase in the arterial blood pressure by causing the vasculature to contract. Anemia is evident in the uremic patient because red blood cell production is depressed due to the decreased amount of erythropoietin produced by the normal kidney to stimulate red blood cell production. The patient will also experience respiratory, dermatologic, and musculoskeletal involvement, as well as psychological disturbances (Jacobberger, 1978).

Once the diagnosis of ESRD has been made, one of the variety of options for treatment of ESRD that have developed since the 1960s must be implemented to sustain life (Lancaster, 1979). These options include in-center or home

hemodialysis and peritoneal dialysis or kidney transplantation.

Choice of treatment depends on several factors. The patient's state of health and his life situation are major concerns. Cost effectiveness is also a consideration in treatment choices. Other considerations are the patient's motivation, social support system, occupation, handicaps, age, ability to travel, financial situation, and nutrition. Patients have the right to choose their treatment modality, and every attempt is made to give them their treatment choice (Coover & Conlan, 1982). Patients also have a responsibility to be an active participant in the overall plan of care.

Psychological Aspects

The stress accompanying ESRD affects every facet of the patient and family well-being. The time necessary for participation in dialysis treatments impinges on the patient's social role. Employment may be lost or must be reduced due to the necessity of the treatments coupled with the constant feeling of fatigue. The patient's dependency on a machine to sustain life and upon the family members and staff to meet his or her needs becomes overwhelming. Dietary restrictions, loss of libido, financial crisis, changes in family roles and life-style, and the threat of death are common problems. "The result of the dependency and drastic life-style change is a loss of control and alteration in the family system." (Paradisio, 1983, p. 8.)

Every aspect of physical, social, and psychological performance is touched and drastically altered by this disease process. These alterations present a multitude of challenges to nurses caring for patients with end-stage renal disease (Lancaster, 1983).

Linsay (1982) indicated that it is important to consider psychological and social as well as physical factors in the overall management of patients with ESRD. Psychological factors are not only associated with success, but also can affect survival.

Suicide is 10 to 15 times more common in dialysis patients than in the general population. An even more common cause of death in patients is withdrawal of dialysis. Uremia was listed as the cause of death in 18% of dialysis patients in the United States Dialysis Registry in 1976. Kjellstrand and Neu (1986) stated that "obviously a dialysis patient cannot die of uremia unless dialysis is stopped" (p. 11). They indicated withdrawal as a cause of death is increasing. This fact led them to conduct a study in 1983 on the controversy of terminating chronic dialysis. Their sample included 1,766 patients who started dialysis between January 1966 and July 1983. All patients were observed for a minimum of one year or until their death. Of the 704 patients that died during this time, 66 who were considered competent made the decision to stop dialysis. Twenty-six of these competent patients developed such a dislike for the dialysis procedure

that they preferred death. Another 66 patients were considered incompetent; their families and physicians together decided that stopping dialysis was best. Age and diabetes were found to be the highest risk factors for suicide.

Santiago and Chazen (1989) examined the cause of death and major contributing factors in 405 patients who died while receiving hemodialysis for ESRD between 1973 and 1985. They indicated that withdrawal from dialysis was a serious problem even though it represented a relatively small group of patients ($N=22$ or 5%) in their study. Patients who withdrew from dialysis tended to be older (mean age of 72), clinically fragile, more likely living alone or in a nursing home, and more likely to have suffered a recent major debilitating event than the rest of the dialysis population. They predicated that:

As the number of patients on dialysis suffering from serious complications increases, the potential for withdrawal will also increase. This group of patients will need increasing attention from family and members of the health care team in order to determine the best course of action in each case (p. 488).

Social Support

"The help provided by family and friends in time of distress is a powerful source of comfort and courage. Health care providers are becoming increasingly aware of social support as a factor in both health and illness." (Dimond & Jones, 1984, p. 145).

An exploratory descriptive study conducted by Dimond (1979) examined the relationship between social support and adaptation to maintenance hemodialysis in 44 subjects from a single dialysis unit. She collected data through unstructured interviews, mail questionnaires, observations, and review of medical records. Social support was measured on three dimensions: family environment, level of spouse support, and presence of a confidant. She assessed adaptation in terms of morale and changes in social functioning since the onset of dialysis. The study findings revealed a positive association between measures of social support and morale, and a negative correlation between family cohesion, presence of a confidant, and changes in social functioning. Dimond concluded that adaptation was partly a function of the social support available. She suggested further research was needed to determine the key factors that minimize the alterations in the patient's way of life in order to improve the patient's quality of life.

Availability of an adequate social support system was suggested as a significant factor in determining if an ESRD patient was dialyzed at home or in a center (Dimond, 1979). However, the findings of a study conducted by Smith, Hong, Province, and Robson (1985) did not support this hypothesis. They examined social support among 257 home and center hemodialysis patients receiving maintenance therapy and found that the presence of social support was not significant in

determining whether an ESRD patient was dialyzed at home or in-center.

A statistical view of variables predicative of adjustment in hemodialysis patients from 40 studies was conducted by Olsen (1983). Ten major variables emerged and were examined using meta-analysis. Variables found to be statistically significant were family relations, pre-dialysis functioning, and personality. Age, sex, marital status, education, IQ, time on dialysis, and health belief were not significantly predictive of adjustment.

Friend, Singletary, Mendell, and Nurse (1986) studied the relationship between participating in a social support group of similarly ill patients and longevity in ESRD patients. They followed 126 ESRD patients receiving in-patient hemodialysis for a 10-year period. They reported that patients who engaged in the group activities (controlled by its members and not dialysis staff) survived considerably longer than non-participants. The variables of religion, education, marital status, and age were not related to survival. Family history of renal disease, psychiatric illness, and levels of blood urea nitrogen (BUN) and creatinine were related to survival.

Muhlemkamp and Sayle (1986) wanted to determine how social support and self-esteem were interrelated and how this interaction influenced positive health practices in ESRD patients. The instruments used in this study were 1) the

Coopersmith (1967) self-esteem inventory (SIE), 2) the Personal Resource Questionnaire (PRQ) (Brandt & Weinert, 1985) to measure social support, and 3) Personal Lifestyle Questionnaire (Lifestyle) (Muhlemkamp & Brown, 1983) to measure positive health practices. The sample consisted of 55 men and 43 women ranging in age from 18 to 67 with a mean age of 29. The majority of the sample were single (69%); their medium income was \$10,000 to \$14,999 per year; 23% had completed college, 43% had attended college for 1-2 years, and 24% had completed high school. The study results supported the hypothesis that respondents with high self-esteem perceived their social support to be very adequate, and, more importantly, they maintained more positive health practices than did those with lower levels of self-esteem and social support.

Siegal, Calsyn, and Cuddihee (1986) studied the relationship of social support to psychological adjustment in 101 in-center hemodialysis patients. Respondents in this study were asked to rate important sources of social support; 62.4% considered their family to be the most important. The health care team was the next most important source of social support. Voluntary organizations and other leisure activities were not a major source of social support for this sample of patients. Study results indicated that a higher quality of social support--helpfulness from contacts rather than the number of contacts--resulted in a better adjustment to

dialysis and fewer psychological symptoms, such as depression and anxiety. The number of social services received by patients who have been on hemodialysis a shorter time was supported. They recommended that staff treating ESRD patients should intervene to improve the social support system of their patients as soon as possible after the diagnosis of ESRD is made.

Kutner (1987) investigated social ties, social support, and perceived health status among chronically disabled people. The sample consisted of 332 disabled persons suffering from musculoskeletal, neuromuscular, cardiac, and renal disease. The renal disease group consisted of 50 women and 81 men. The measures were available kin network, perceived support, received support, and perceived health status. Social class was assessed by Hollingshead's two-factor index of social positions providing 5 social class levels. Socioeconomic differences in patterns of received support were evident in the results. Lower socioeconomic status respondents received more help from their adult children while higher socioeconomic status respondents were more likely to receive help from non-kin, such as neighbors and friends. Perceived support from family was high for all respondents in the study. Perceived health status did not vary with the amount of perceived support but, within the disability groups, perceived health status tended to vary with the amount of help received.

Quality of Life

Many researchers have linked specific disease-related factors to quality of life, while other researchers have cautioned that this link may disappear with the introduction of intervening variables (Burckhardt, 1985). Variables such as lack of supportive relationships, lack of sufficient income, low self-esteem, lack of personal control, and increasing age may have more impact on the quality of life of chronically ill people than the disease or disability itself.

Levy and Wynbrandt (1975) interviewed a small, randomly chosen sample of 18 hemodialysis patients in order to determine their quality of life. Findings from the qualitative data showed wide variations among patients in their life adjustment to maintenance hemodialysis. Informants expressed that their life had taken a striking change as compared with the period before illness. Most had experienced severe loss of income; many had also experienced deterioration in family relationships. Emotional adaptation tended to be more successful in the patients who had flexible psychosocial support systems before their illness than those without adequate support systems. The authors concluded that emotional stresses on all patients was great. Those who were able to cope well had a sense of mastery which added an important measure of gratification to their lives. Despair and hopelessness were evident in those who coped unsuccessfully.

LaBorde and Powers (1980) compared the effects of chronic illness on the quality of life in 20 patients receiving in-center hemodialysis treatments for end-stage renal disease with 20 patients receiving treatment for severe osteoarthritis at a hospital clinic. The participants were asked to rate themselves on Cantril's self-anchoring scale on past, present, and future life satisfaction. Persons undergoing chronic hemodialysis were found to have much higher life satisfaction scores than persons with osteoarthritis. The increased sense of physical well-being reported by the dialysis group was surprising, but may have been influenced by the socializing of the dialysis patients within the center. The researchers attributed these findings to the fact that arthritis patients did not have the opportunity to experience group interaction and lacked the formal support systems available to in-center hemodialysis patients.

Comparison of research findings in studies on quality of life of patients with end-stage renal disease conducted by Evans et al. (1985) (N=859), Simmons et al. (1984) (N=458), and Hawthorne (1986) (N=101) revealed similar results. Transplant recipients reported a higher subjective and objective quality of life than patients on any form of dialysis. Campbell et al.'s Index of Well Being (1976), designed to measure the quality of life of the U.S. population, was used in all three studies.

Evans et al. (1985) analyzed the relationships between objective and subjective measures of quality of life in their study of 859 end-stage renal disease patients. Campbell et al.'s (1976) instrument was chosen in order to make quality of life comparisons between ESRD patients and the general population. Study results indicated that ESRD patients perceive only a slightly lower quality of life than that of the general population. Transplant patients' quality of life was similar to that of the general population.

Stout et al. (1987) conducted a retrospective study of 159 patients starting dialysis during 1981-84 in order to measure quality of life of high-risk and elderly dialysis patients. The role of treatment mode; age, medical, and social risk factors; and occupational status on the quality of life as perceived by the patient was assessed by means of a standardized questionnaire using Cantril's Life Satisfaction Ladder. The study population was subdivided into groups by age (less than 60 years of age and over 60 years of age) and the presence of medical and social risk factors. Males under 60 years of age with risk factors appeared least satisfied with life on several scales of assessment. The elderly groups (over 60 years of age) had a good perceived quality of life even when there were added risk factors. They recommended that risk factors should be considered when conducting quality of life assessments. These risk factors included 1) medical factors which include coexisting diseases such as cardiac and

cerebrovascular disorders and diabetes; 2) social risk factors such as isolation, unemployment, and health care compliance; and 3) age.

Demographics

The relationship between demographic variables and dialysis patients' quality of life and perceived social support has received limited study. Demographic variables addressed in this study included age, sex, marital status, education, employment, time on dialysis, and the presence of other chronic disease conditions. These variables were selected for examination in an attempt to determine risk factors that could emerge from the analysis of the demographic data obtained in this study.

Age

The annual report for the National Kidney Foundation ESRD Network Coordinating Council #2 (NKF, 1986) for the northwest region of the U.S. showed that 927 patients started dialysis in 1986. Three hundred twenty-five patients (35.1%) were over 66 years of age, 247 (26.6%) were 61-65 years of age, 190 (20.5%) were 36-50 years of age, and 140 (15.1%) were 21-35 years of age; the remaining 13 (2.7%) were less than 20 years of age. The National Institute of Health's Renal Data Systems 1989 annual report showed that, out of a total of 135,371 patients who started dialysis treatment in 1987, the largest numbers of renal patients were in the 25-54 age group (63,440)

and the next largest group was in the 54-69 years of age range (41,925).

Two studies addressed the relationship of age as it relates to social support and quality of life. Burton, Kline, Lindsay, and Heidenheim (1988) found elderly dialysis patients with stable support systems fared as well as, or possibly better than, younger patients. In comparing quality of life between groups of persons receiving a variety of treatments for ESRD, Chubon (1986) found that older persons undergoing dialysis perceived their quality of life to be better than that of younger persons.

Gender

More men are receiving hemodialysis treatment than women. National figures for 1987 showed that 73,656 males and 61,715 females started dialysis in that year (The National Institute of Health, Renal Data System, 1989). Of the 927 patients beginning treatment for ESRD in 1986 in the northwest region of the U.S., 506 were men and 421 were women (NKF, 1986). Of the 73 patients beginning treatment for ESRD in Montana for 1986, there were 45 men and 28 women (NKF, 1986).

In Levy and Wynbrandt's (1975) study, women participants rated their quality of life better than men. Their sample, consisting of 10 men and 8 women, were asked to rate their overall quality of life as good, fair, and poor. The four women who rated their quality of life as good indicated that they had a strongly supportive husband, children, and/or

friend(s). The five men who rated their quality of life as poor expressed guilt about their feelings to provide financially for their families and hopelessness concerning their future.

Marital Status

Two studies specifically discussed findings pertaining to marital status. Evans et al. (1985) indicated that marriage was less common among patients treated with in-center hemodialysis. Kutner's (1987) study of chronically disabled persons, including renal patients, found that fewer women (44%) were married than men (61%). The disabled women were more likely than disabled men to be divorced, separated, or widowed.

Education

Two studies addressed the influence of education on social support and quality of life in hemodialysis patients. Wolcott et al.'s study (1988) found that younger, better educated dialysis patients tended to have higher quality of life. A statistical review of variables predictive of adjustment in hemodialysis patients by Olsen (1983) indicated that education was the only demographic variable that showed a trend towards statistical significance for adjustment. She indicated that the medical profession has held a belief that better educated, more intelligent patients who are knowledgeable about the treatment will be more accepting of

their disease and more likely to adapt to its rigors. This belief was not supported by the data, since education was found to be a weak indicator of adjustment to dialysis. Olsen concluded that perhaps the stresses of the treatment regimen override the influence of cognitive factors.

Employment

Only one study addressed the influence of employment in relation to the study variables. Wolcott et al. (1988) found that vocationally-active subjects ($N=66$) reported better quality of current relationships and higher levels of social support satisfaction.

Time on Dialysis

Although time on dialysis was examined in studies done by Laborde and Powers (1980), Siegal et al. (1986), and Wolcott et al. (1988), there were no studies that addressed a relationship of time on dialysis with social support or quality of life.

Siegal et al. (1986) indicated that patients who had been on hemodialysis for a shorter period of time, less than two years, reported more symptoms of depression and anxiety than patients who had been on dialysis more than two years.

Other Disease Conditions

The annual report of the ESRD Network Coordinating Council for the northwest region of the U.S. for 1986 indicated that of the patients who began dialysis in 1986, 31.4% suffered from diabetes, 26.1% had renal disease other than ESRD (glomerulonephritis, nephrotic syndrome, nephrosis, pyelonephritis, and congenital anomalies); 17.2% had hypertension and 9.3% suffered from diseases of unknown etiology. The Renal Data System Report (1989) indicated hypertension was the primary disease among ESRD patients with glomerulonephritis and then diabetes as the second leading disease condition.

Patients participating in Evans et al.'s 1985 study reported an average of 1.55 disease conditions in addition to renal disease. In the study conducted by Laborde and Powers (1980), the kidney disease participants had no other disease conditions except renal failure.

CHAPTER 3

METHODS

The primary purpose of this research study was to measure the relationship between social support and the quality of life of rural ESRD patients. A second purpose was to measure and describe the influence of the following demographic variables on the social support and quality of life: age, gender, marital status, education, employment, time on dialysis, and presence of other chronic diseases.

Design

A Level II descriptive survey was selected to determine relationships between perceived level of social support and quality of life in patients receiving in-center hemodialysis treatment (Brink & Wood, 1983). Structured questionnaires were used to measure the variables. An advantage of the design is that it allows some control in measurement of the variables by the situation and the investigator. The design also dictates how the variables will be measured in testing their relationship and provides a description of the relationship between the variables rather than the variables themselves (Brink & Wood, 1983).

A weakness of the Level II survey design is the inability to manipulate the independent variable of social support. Preexisting differences in the patient's psychosocial behaviors may affect the dependent variable of the perceived quality of life. Faulty interpretation with correlational research may occur due to difficulty in interpreting the findings since behaviors and perceptions may be interrelated in complex ways (Polit & Hungler, 1983).

Sample

The sample included all in-center hemodialysis patients from three dialysis units in Montana who were willing to participate in the study. In-center hemodialysis patients were chosen for the study as an attempt to limit the sample size, and also for ease in accessibility to ESRD patients within the dialysis units for data collection. The dialysis units selected for study were those in Great Falls, Missoula, and Helena. All adult patients from these three units, regardless of age, sex, race, or any other disease conditions in addition to ESRD, were given the opportunity to participate in the study. All participants were able to give voluntary, informed consent. The patients in this study were able to read or could have someone read the questions to them; they also had no obvious mental impairment that might prevent them from completing the questionnaire.

Data Collection Procedure

Data collection was planned for a one month period in order to allow the researcher to distribute the questionnaires to each dialysis unit in the study. Following the approval of the Human Rights application by the Montana State University Human Rights Committee, hospital nursing administrators were approached for permission to conduct the study in their dialysis units.

Once hospital consents had been obtained (see Appendix A), the researcher traveled to each dialysis unit site. Within each dialysis unit, the investigator explained the purpose of the study to each in-center patient. Questionnaires were distributed to the patients who agreed to participate in the study. The participants were given an information statement to read (see Appendix B). A copy of the information statement was given to the subjects upon agreement to participate in the study. The participants were allowed to ask any questions they had once the reason for the study was explained to them. The questionnaires were given to the participants while they are receiving dialysis treatment in the center.

Upon completion of the questionnaires, the participants placed the questionnaire in a sealed envelope. The envelopes were collected by the unit supervisor, who placed them in a larger envelope which was collected by the researcher two weeks later.

Instruments

The instruments for this study were Brandt and Weinert's 1985 Personal Resource Questionnaire (PRQ-85), Part II, and Ferrons and Powers' 1985 Quality of Life Index (QLI). Both questionnaires and the demographic questions could be completed in about thirty minutes by the study participants (see Appendix B).

The Personal Resource Questionnaire (PRQ-85), Part II, developed by Brandt and Weinert in 1985, was used to measure the level of perceived social support. It is a 25-item scale based on the work of Robert Weiss. Participants respond to items using a 7-point Likert scale, e.g., 1 (strongly disagree) to 7 (strongly agree). A total PRQ score was obtained by adding the individual scores for each of the 25 items. Five PRQ items needed to be recoded in order to reflect the positive direction of the other 20 items. An example of an item on the questionnaire is, "There is someone who loves and cares about me." Reports pertaining to internal consistency for the PRQ using Cronbach's alpha vary from .85 to .90 (Weinert, 1985). Evidence of construct validity was obtained by correlating each support variable with mental health and personality variables (Beck Depression Inventory [BDI], Spielberger Self-Evaluation Questionnaire, and Eysenck Personality Inventory [EPI]). The results indicated that the measures of social support in the PRQ are indicators of a

different construct than the mental health or personality measures used in the study (Weinert, 1985).

The Quality of Life Index (QLI) by Ferrons and Powers (1985) was used to measure the quality of life of healthy individuals, as well as those who are experiencing an illness. Since 1985, four subscales have been developed for use in measuring quality of life in illness, one of which is specifically for dialysis patients. The instrument consists of two sections, one section measures satisfaction with various domains of life, and the other measures the importance of each domain to the subject. Each section consists of 35 questions; the respondents answer using a 6-point Likert scale. An example of a question from Part I (domain satisfaction) asks, "How satisfied are you with dialysis treatment?" The corresponding question from Part II (domain importance) asks, "How important is dialysis treatment to you?" The questions are answered by 1 (very dissatisfied/not important) to 6 (very satisfied/very important). Scores were determined by adjusting satisfaction responses with the importance responses. The adjustment was accomplished by recoding satisfaction scores by subtracting 3.5 from the satisfaction response for each item in order to center the scale on zero. The recoded satisfaction score was then multiplied by the importance score, item by item, in order to obtain adjusted item scores. The adjusted item scores were summed to obtain the overall adjusted score. The final

overall score was obtained by dividing the sum of items by the number of items answered in order to prevent bias due to missing scores. To eliminate negative values, 15 was added to every score to get the final score. The range possible for final overall quality of life score was 0 to 30. Reliability for the dialysis patient version using test-retest correlations were 0.80; Cronbach's alphas were 0.90 (Ferrons & Powers, 1985).

The demographic variables of age, sex, gender, marital status, education, time on dialysis, and number and type of other disease conditions in addition to ESRD were included in this study in an attempt to determine potential risk factors.

Protection of Human Rights

Montana State University's requirements for protection of human subjects were met in this study. The study design and instruments were submitted to the Human Rights Committee for approval. The patients were given an information statement explaining the purpose of the study and asked them to participate in the study. The information statement indicated that the confidentiality and anonymity of the individuals would be maintained. The information statement also stated that the study was voluntary and there would be no coercion for subjects to participate. The participants were informed that there were no right or wrong answers on the questionnaires, and they were free to finish the

questionnaire at some other time should they become fatigued. The patients were also informed that they were free to withdraw from the study at any time. They were informed that participating or not participating in the study would not affect their care within the dialysis unit (see Appendix B).

Data Analysis

Descriptive statistics with measures of central tendency were used to synthesize and summarize the demographic data from the questionnaires. Frequency distributions were used to describe the participants in relation to gender, marital status, employment, and the presence of other chronic diseases in addition to ESRD. Means and ranges were calculated to describe the participants by age, level of education, and time on dialysis.

Scores of PRQ and QLI were summed for each participant. The mean and standard deviation was then calculated for each instrument. The means were then entered into a Pearson r correlational analysis program to determine the relationship between the variables of social support and the quality of life of dialysis patients. Correlational analysis was also used to determine the relationship of the demographic variables to social support and quality of life.

CHAPTER 4

RESULTS

The purpose of this study was to investigate the relationship of social support, quality of life, and selected demographic variables among rural in-center hemodialysis patients. In-center hemodialysis patients from three dialysis units in Montana completed a questionnaire containing the Personal Resource Questionnaire (PRQ), the Quality of Life Index (QLI), and demographic items. Data from the questionnaires were entered into a PC statistical package called CRUNCH in order to perform the analysis. The findings of the study are presented in this chapter.

Sample

The sample consisted of 31 in-center hemodialysis patients from the dialysis units at the Columbus Hospital in Great Falls, St. Peter's Hospital in Helena, and St. Patrick Hospital in Missoula, Montana. Packets contained the questionnaire, an information statement (see Appendix B), and a return envelope were distributed by the researcher to the patients while they were receiving dialysis treatment in these units. The patients were asked to return their completed questionnaires in the sealed envelopes to the dialysis

supervisors. The supervisors in each unit then placed the sealed envelopes into a large envelope that was collected by the researcher two weeks later. Forty-four patients were given questionnaires in the three units; 31 patients returned completed questionnaires resulting in a 70% response rate.

Demographic Variables

The demographic variables were analyzed using descriptive statistics, including ranges, frequency distributions, means, and standard deviations. The demographic information gathered included these variables: age, gender, marital status, employment, time on in-center hemodialysis, and number and type of other disease conditions other than ESRD.

The demographic variables of age, gender, marital status, and education were a part of the background information section of the Personal Resource Questionnaire (Brandt & Weinert, 1985) and were included in this study as a means of identifying potential risk factors. The variables of time on dialysis and number and type of other disease conditions in addition to ESRD were added based on the literature review.

The patients ranged in age from 29 to 84 years of age with 15 (48%) under the age of 60, and 14 (45%) over the age of 60. Two respondents (5%) in the study did not state their age on the questionnaire. The mean age of the participants responding to that item was 54.7 years of age (see Table 1).

Table 1. Distribution of adult in-center hemodialysis patients grouped by age (N=31)

Age	Frequency	Percent
29-35	4	13
36-45	4	13
46-55	5	16
56-65	4	13
66-75	6	19.5
76-85	6	19.5
No Answer	2	6
Totals	31	100

The sample consisted of 19 men (61%) and 11 women (36%). One respondent did not complete the gender item on the questionnaire.

Thirty of the thirty-one participants responded to the marital status item on the questionnaire. Fifteen (48%) of the thirty respondents were married; seven (22%) were divorced; two (6.5%) were separated; four (13%) were widowed; and two (6.5%) were never married.

The distribution of participants by education revealed that 3 (10%) had not completed high school; 15 (48%) had completed high school; 7 (23%) had some college courses after high school; and 5 (16%) had college degrees. Datum was missing on one patient. The mean for this group of participants was 12 years of formal education.

Data analysis of the employment question revealed that 3 participants (10%) were working full-time; 3 (10%) were working part-time; 6 (19%) were unemployed and seeking employment; and 16 (52%) were retired. One participant was a full-time homemaker and one was receiving a social security disability.

The question about length of time on in-center hemodialysis revealed that 18 respondents had been on in-center hemodialysis less than 2 years; 13 had been on in-center hemodialysis over 2 years. Two respondents did not complete this questionnaire item. The mean time on in-center hemodialysis was 26.5 months (see Table 2).

Table 2. Distribution of adult in-center hemodialysis patients by time on dialysis (N=31)

<u>Time on Dialysis</u>	<u>Frequency</u>	<u>Percent</u>
2-12 months	11	36
13-24 months	5	15
25-36 months	6	20
37-48 months	4	13
Over 5 years	3	10
No Answer	2	6
Total	31	100

The last two demographic variables measured were the number of other disease conditions in addition to ESRD that the participants exhibited and the type of disease conditions.

The mean for the number of additional disease conditions along with ESRD was 1.9. Nine participants had one other disease; 15 reported 2 additional diseases; and the remainder had more than 3 additional disease conditions (see Table 3).

Table 3. Distribution of adult in-center hemodialysis patients by number of other disease conditions in addition to ESRD ($\bar{M}=1.9$)

Number of Diseases	Frequency	Percent
1	9	29
2	15	49
3	4	13
4	1	3
5	1	3
No Answer	1	3
Total	31	100

The major disease conditions that the participants reported in this study included hypertension, diabetes, and heart disease (see Table 4). The other disease conditions reported included arthritis, back problems, thyroid disease, gout, ulcers, arteriosclerosis, colon, and liver disease. One participant did not respond to the item.

Table 4. Distribution of adult in-center hemodialysis patients by type of other disease conditions in addition to ESRD

<u>Other Disease Conditions</u>	<u>Frequency</u>
Hypertension	18
Diabetes	10
Heart Disease	10
Arteriosclerosis	1
Arthritis	7
Back Problems	5
Lung Disease	0
Other Diseases	7
No Answer	1

Social Support

The Personal Resource Questionnaire (PRQ) by Brandt and Weinert (1985) was used to measure social support (see Appendix B). Possible scores ranged from 25 to 175. The more positive the score, the more social support was perceived by the participants. The participants in the study responded to all 25 items on the PRQ section of the questionnaire. Scores obtained from the participants responding to this study ranged from 61 to 164. The mean score was 131, and the standard deviation was 26.11.

Quality of Life

The dialysis version of the Quality of Life Index (QLI) by Ferrons and Powers (1985) was used to measure quality of life of the participants in the study. The two-part instrument was originally designed for use with healthy individuals and was adapted for dialysis patients by adding questions that dealt with their satisfaction with and importance of dialysis treatments (see Appendix B). The participants answered the 35 items in both parts using a 6-point Likert scale. Possible scores ranged from 0 to 30. The scores obtained from the participants in this study ranged from 12 to 28. The mean score was 19.6 with a standard deviation of 4.84.

There were three QLI questions to which many of the participants did not respond or, if they did respond, they gave low scores. The question that was most frequently unanswered in Part 1 was, "(If you are a transplant candidate) How satisfied are you with efforts being made to increase your potential for having a successful kidney transplant?" The corresponding question in Part 2 asked "(If you are a transplant candidate) How important is a successful kidney transplant to you?" Of the 31 participants who completed the questionnaire, 17 failed to respond to this question, indicating that these patients were probably not transplant candidates. This finding was probably due to the age of this

group, since ESRD patients over 65 years of age are not generally considered for kidney transplants.

The second question that many participants did not respond to on the QLI asked "How satisfied are you with your sex life?" in Part 1. The corresponding question in Part 2 asked "How important is your sex life to you?" Of the 31 study participants, 10 failed to respond to this question and another 10 gave low scores from 1-3, giving this item a negative value in the total score.

The third QLI question to which study participants failed to respond or gave low scores asked "How satisfied are you with your personal faith in God?" in Part 1. Part 2 asked "How important is your personal faith in God?" Six of the participants in this study failed to answer this question while nine gave scores of 1-3, which, when adjusted, were negative values toward the overall score.

Research Questions

A computer program, Pearson Product Moment Correlation, was used to answer the research questions. Table 5 depicts the correlation matrix of social support, quality of life, and the demographic variables. The first research question asked whether a relationship existed between social support and quality of life among dialysis patients in rural in-center hemodialysis facilities. A significant positive relationship ($r=.58$, $p<.001$) was found between the variables of social

support and quality of life. This result indicates that some form of social support for in-center hemodialysis patients influenced their quality of life or how satisfied they are with their life with dialysis.

Table 5. Pearson r Correlation Matrix

Variables	1	2	3	4	5	6	7	8	9
1. Social Support	1.00	.58***	-.02	.02	-.10	-.10	-.08	.14	.20
2. Quality of Life		1.00	.16	-.23	-.23	-.08	-.21	.12	-.10
3. Age			1.00	.07	.22	.27	.55**	.08	.25
4. Gender				1.00	.36*	.61***	.42*	.24	.26
5. Marital Status					1.00	.45*	.70***	.01	.43
6. Education						1.00	.40*	.24	.51**
7. Employment							1.00	.07	.52**
8. Time on Dialysis								1.00	.27
9. Number of Other Diseases									1.00

All correlations have 29^o of freedom. The P values are 2-tailed values.

*=p<.05

**=p<.01

***=p<.001

The second research question asked whether relationships existed between the demographic variables of age, gender, marital status, education, employment, time on dialysis, presence of other chronic disease, and social support. There

were no significant relationships with any of the demographic variables and social support (see Table 5).

The third research question asked "What relationships exist between the demographic variables of age, gender, marital status, education, employment, time on dialysis, presence of other chronic disease, and quality of life?" There were no significant relationships demonstrated between any demographic variables and quality of life scores (see Table 5).

Some significant relationships occurred between the demographic variables (see Table 5). A significant relationship in a positive direction ($r=.55$, $p<.01$) occurred between the demographic variables of age and employment, indicating that the older dialysis patient was more likely to be unemployed. A significant relationship ($r=.61$, $p<.001$) was found between the variables of gender and education. Since the dichotomous variable was coded using the higher number for men, this finding indicates that a greater number of years of education were associated with being male. Another significant positive relationship was found between the variable of gender and employment ($r=.42$, $p<.05$), indicating being a male in this study was associated with the higher unemployment or being retired.

A significant positive correlation ($r=.36$, $p<.05$) was found between variables of gender and marital status, inferring that men (possessing the higher value) were more

likely to be unmarried (widowed, divorced, or separated were grouped together to be the higher value). A significant positive correlation also existed between the variables of marital status and education ($r=.45$, $p<.05$), indicating that the unmarried participants in this study were more likely to have more education. Marital status was also positively correlated with employment ($r=.70$, $p<.001$), indicating the unmarried respondents in the study were more likely to be unemployed or retired. The significant positive correlation between marital status and number of other disease conditions in addition to ESRD ($r=.43$, $p<.05$) indicated that the unmarried participants had more diseases along with ESRD than married participants in the group (see Table 5).

Significant positive relationships occurred between the variables of education and employment ($r=.40$, $p<.05$) and education and number of other disease conditions ($r=.51$, $p<.01$). These results indicated that the participants with more years of education were more likely to be unemployed or retired and that the participants with more education were associated with more other disease conditions in addition to ESRD.

The last positive correlation occurred between the variables of employment and number of other disease conditions in addition to ESRD ($r=.52$, $p<.01$). This indicated that an increasing number of other disease conditions were associated with unemployment and retirement.

A patient profile resulting from the analysis of the demographic variables in this study indicated that the majority of ESRD patients in the sample were older, unmarried, unemployed, educated men who had two other disease conditions in addition to ESRD, and had been on in-center hemodialysis for less than two years. Since the relationship between perceived social support and quality of life for the entire sample was of moderate size and highly significant, these findings suggest that the unmarried male participants perceived their social support to be equivalent to that of the married participants. However, the demographic variable of marital status was not significantly related to either the perceived level of social support or quality of life for this group of participants. Comparison of social support scores revealed that married participants had a mean social support score of 140 while unmarried participants had a mean score of 123. The mean social support score for women was 129; men had a mean social support score of 127.

Comparison of the quality of life scores had similar but less dramatic results. Married participants had a mean quality of life score of 20, while the unmarried participants had a mean score of 18.7. Women also reported higher quality of life scores, with a mean of 20, while men had a mean of 18.9. The difference in mean social support scores between married and unmarried participants indicated that unmarried participants perceive less social support, whether it be men

or women, and the unmarried can be identified as a group at risk.

CHAPTER 5

DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

Review of the literature pertaining to the psychological aspects of ESRD revealed that patients on dialysis have many stresses which affect every aspect of their overall well-being. One aspect of their well-being, social support, is becoming a significant variable in the overall management of health care. In addition, quality of life has also become a significant variable in the management of patient care, especially in the areas of medical ethics, financial and reimbursement mechanisms, and new technology. However, no studies were found which specifically examined the relationship of these two variables to each other. The purpose of this study was to examine the relationship between the variables of social support, quality of life, and selected demographic variables in rural in-center hemodialysis patients. This chapter summarizes the findings and also discusses the implications for nursing and recommendations for future research.

Discussion

The questionnaires for this study, which contained the PRQ, QLI, and the demographic questionnaire, were distributed

by the researcher to in-center hemodialysis patients while they were receiving dialysis treatment in the units in Great Falls, Helena, and Missoula. Forty-four patients agreed to participate in the study and accepted the questionnaires; 31 returned the completed questionnaires, resulting in a 70% response rate by the participants. Polit and Hungler (1983) indicated that there is a positive effect on the rate of questionnaires returned with the personal contact of the researcher and the participants during data collection. In addition, the fact that the researcher is a dialysis nurse and was able to answer some of the participants' questions about dialysis treatment may have influenced the high response rate.

Three research questions were addressed in this study. The finding for the first research question, "What is the relationship between social support and quality of life among dialysis patients in rural in-center hemodialysis facilities?" was a highly significant correlation between the level of social support and quality of life. Some form of social support for in-center hemodialysis patients helps them attain a higher quality of life as they undergo dialysis therapy. Based on findings from other studies by Burckhart, Siegel, et al. and Labarde and Powers, this relationship was not surprising. Burckhart (1985) indicated that a lack of supportive relationships may have an impact on the quality of life of chronically ill people. Siegel, Calsyn, and Cuddihee (1986) examined the relationship of social support to

psychological adaptation and determined that the family of in-center hemodialysis patients was the most important source of social support, with the health care team being the next most important source of support. Labarde and Powers (1980) found that hemodialysis patients had higher life satisfaction scores than patients who were suffering with osteoarthritis. The increased sense of well-being may have been influenced by the socializing of the dialysis patients while receiving in-center treatment.

The second research question asked about relationships existing between demographic variables and social support. No significant relationships were found between social support and any of the demographic variables. There were also no significant relationships between the measure of quality of life scores and demographic variables, the relationship examined in the third research question.

Some significant relationships were found between the demographic characteristics of the patients responding to this study. These relationships are explored in more depth in the following paragraphs.

Age

The participants in this study ranged in age from 29 years of age to 84 years, with a mean age of 54 years. While there was no correlation with the variable of age with either social support or quality of life scores, the average age of this group did support the findings from other national and

regional reports on age of hemodialysis patients. The age of the patients in this group closely matched regional figures, with the larger percentage of patients being over 51 years of age (52%). The findings of this study did not support those of Chubon (1986), who found that older persons perceived their quality of life to be better than that of younger persons, and Burton, et al. (1988), who found that elderly dialysis patients had more stable support systems.

Gender

Similarity exists between the gender of the participants in this and with those in national and regional figures. All information reports that there were more men on dialysis than women. In this study, 61% of the participants were men, while 35% were women.

A positive correlation was found in this study between the variables of gender and education, indicating that more years of education was associated with being male. A similar relationship was found between the variables of gender and employment, indicating that, in this study, being a male was associated with being unemployed. An examination of the descriptive statistics pertaining to gender revealed women reported slightly higher social support and quality of life mean scores than men. The findings of this study do lend some support to those of Levy and Wynbrandt (1975), who found that women had a higher quality of life than men.

Marital Status

Results from this study indicated that about half of the study participants were married, while the rest were either divorced, separated, widowed, or single. Kutner's (1987) study indicated that disabled women with a chronic illness were more likely to be divorced, separated, or widowed. In this study, there was a significant relationship between the variables of marital status and gender, indicating that the men are more likely to be unmarried. However, examination of the descriptive statistics pertaining to gender and marital status revealed a difference of only one. Eight of the men participants were unmarried (five divorced, one separated, and two never married), while seven of the women participants were unmarried (two divorced, one separated, and four widowed). Further examination of the descriptive statistics found that married participants had somewhat higher social support mean scores and slightly higher quality of life mean scores.

This study's findings indicated that approximately one-half of the participants were without a spouse and that these unmarried participants perceive less social support in their relationships. A chief risk identified in this study were the unmarried ESRD patients which increases the need for dialysis staff to attempt to intervene in their behalf. Since the relationship between social support and quality of life is significantly related, the results infer that the dialysis team may be a part of the social support system for the

participants of this study. Labarde and Powers (1980) attributed the higher quality of life scores of dialysis patients in their study, which compared quality of life of dialysis and osteoarthritis patients, to the fact that dialysis patients have the opportunity to experience group interaction within the dialysis unit. This group is composed of the dialysis staff and other patients in the unit who comprise a formal support system for the patients.

Education

Since no relationship was found between level of education and quality of life, the study findings do not support those of Wolcott, et al. (1988), who found that younger, better educated dialysis patients tends to have a higher quality of life. Significant relationships were found between education and other demographic variables of gender, marital status, and number of other disease conditions. These findings indicated that more years of education were associated with being of male gender, being unmarried, being unemployed, and having more additional disease conditions.

Employment

The results of this research indicated participants over 51 years of age were most likely retired or not working, as a significant correlation was found between employment and age. An additional significant correlation was found between employment and number of other disease conditions in addition

to ESRD, indicating that the presence of a greater number of other disease conditions was associated with unemployment and retirement. Since there was no correlation of the employment variable with social support in this study, this study's findings did not support those of Wolcott, et al. (1988), who found that vocationally active subjects had reported better quality of current relationships and higher levels of social support satisfaction.

Time on Dialysis

The participants in this study reported a range of 2 months to 13 years on in-center hemodialysis. More than half of the group had been on dialysis for less than two years. The variable of time on dialysis was the only variable that had no correlation with any other variables in this study. The literature review indicated time on dialysis had been looked at by Siegel, et al. (1986), who found that ESRD patients on hemodialysis a short time, less than two years, reported more symptoms of depression and anxiety than patients who had been on dialysis for more than two years.

Other Disease Conditions

The participants of this study reported having from one to five other disease conditions present in addition to ESRD. The majority of the participants indicated they had two other disease conditions present along with ESRD. The mean of 1.9 other disease conditions reported in this study corresponds

to findings of Evans, et al. (1985), who reported that their study participants had an average of 1.55 disease conditions in addition to renal disease.

The most frequently encountered disease condition reported was hypertension. The second most commonly reported disease was diabetes. The problems reported by this sample correspond with national and regional reports which indicated that hypertension and diabetes were the greatest causes of kidney failure.

Some participants in this study failed to answer questions on the Quality of Life Index which dealt with their transplant status and sex life. Of the 31 participants who completed the questionnaire, 17 failed to respond to the question regarding transplant candidates. In the past, some transplant centers set the upper age limit at 55 to 60 years as acceptance criteria for transplantation. Many centers are now becoming more willing to transplant older patients in good physiologic condition. Sixteen of the participants in this study were over the age of 55, and over one-half of the participants exhibited two or more additional chronic disease conditions, thus making them poor transplant candidates.

One-third of the participants failed to respond to the question regarding the satisfaction and importance of the patient's sex life, and another one-third of the participants rated this item with low scores. Fortner-Frazier (1981) has reported that ESRD itself causes decreased libido in male and

female patients and causes impotence in males and infertility in females. Some participants may also have been reluctant to give out such personal information.

Implications for Nursing

The findings of this study emphasize that assessment of the role of social support for the dialysis patient should be a priority in the provision of nursing care for dialysis patients. The ability of dialysis patients to cope with their illness is a primary function of the family environment. The availability of support for patients must be assessed to determine the manner in which they receive support, whether it be tangible, emotional, or information support that is provided by family members. The patient's perception of the social support, whether objective or subjective, must also be investigated. Assessment of the family's understanding of the illness, the family's ability to provide support and help, the kind of support that is needed and available, and the perception of this support by the patient and the family is important. An understanding of the family context in which the dialysis patient lives may also give some basic understanding of the patient's social support system.

Siegel, et al. (1986) indicated that the family was considered to be the most important source of social support for the dialysis patients in their study. They indicated that the health care team was the second most important source of

social support for the dialysis patient. Nurses and health care providers must be aware of the importance of their presence and actions as they become an important source of social support for the patients, which will ultimately affect the patient's quality of life status.

Friends, spouse, and other social support systems all influence self-esteem and self-concept, whether it be a healthy individual or an individual with a chronic illness. When any of these are lost in a short period of time, the person may experience profound depression, unresolved grieving, and giving up. The support provided by the family and health care professionals could be a critical factor in helping to reestablish earlier coping strengths. Nurses and other health care providers must assess the patient's physical, emotional, and social status in order to gain important information with which to build a plan of care, but to also provide support by their presence and confident manner. Grief resolution may be needed to prevent the accumulated losses from becoming overwhelming and causing hopelessness. Effective and sustained communication between the patient and his family and between the family and health care providers is essential for the functioning of the dialysis patient in order to achieve effective support and independence in dealing with the illness.

The nature of the helping relationship established by the nurse and other health care givers will influence the

patient's perception of quality of life. Miller (1983) has described some nursing strategies that are helpful for nurses in establishing a supportive relationship with the dialysis patient. The helping relationship should be characterized by caring, concern, unconditional acceptance, empathy, and respect. The nurse must be responsive to the patient's unique abilities and give recognition for the knowledge and life experiences of each patient. The nurse's responsiveness will enhance the patient's feeling of self-worth. This communicates the nurse's regard of the patient as a whole person, not just the present health problem. A nurse can share a sense of joy with the patient in that he or she is able to spend time and self with patients while gaining understanding about the lives of patients with similar problems.

The nurse in the dialysis unit is the prime person responsible for recognition of and intervention for patients dealing with the psychological aspects of patients' everyday living with ESRD. A psychiatric nurse or master's prepared nurse is in a position to recognize and provide for intervention in crisis situations. The nurse can serve as a resource person or information giver, or can take an active role in establishing liaison with other helping resources. The nurse must be equipped to cope with the lowered self-concept and denial of the person on dialysis. The use of nursing process involves development of a therapeutic

interpersonal relationship with the client to facilitate assessment of factors associated with client anxiety, as well as to intervene to reduce anxiety. Knowledge of the stages of personality growth can help the nurse to understand possible reasons for client problems and suggest possible intervention strategies (Leddy & Pepper, 1985). The therapeutic nature of the nurse-patient relationship has been described as the human relationship that exists between "an individual who is sick, or in need of health services, and a nurse especially educated to recognize and to respond to the need for help" (Hildegard Peplau in Leddy & Pepper, 1985, p. 136).

Another area for providing social support for dialysis patients is through support group socialization. Activities planned with patients, family, and friends to provide the social and emotional support help the patient regain a sense of worth and competence that are necessary to deal with the losses ESRD patients face. Friend, et al. (1986) reported that patients who engaged in group activities survived considerably longer than non-participants. Group socialization is a frequently used therapy in nursing and other disciplines, but is not so readily available for the dialysis patient and family. Dialysis patients and/or their family could receive significant benefit from a support group experience. Whether group work with dialysis patients is pursued along education or psychological needs, more of it is

needed for the dialysis patient population. Support groups can reduce feelings of isolation and seclusion by offering an environment of acceptance and camaraderie. Support groups can be used as a major mechanism for achieving a sense of security and belonging when patients with a common problem are brought together for a common purpose, particularly for the patient without a family support system.

Miller (1983) indicated that hope is an intrinsic component of life and that the basis of hope is faith. Nursing has a responsibility to inspire hope through sensitivity and an understanding of the patient's plight. An individual's hope can be fostered by the utilization of the internal strengths and resources of another. Nurses can radiate hope and demonstrate faith and confidence in patients. "The expectation for living life fully is conveyed in an open, loving, helping nurse-patient relationship" (p. 292).

Miller (1983) has also indicated that hope can be invigorated by a belief in accomplishing goals. Nurses may need to help patients set goals. Goals that are helpful in inspiring hope are goals that consider (1) physical strides for the patient, (2) work to be accomplished, (3) responsibilities to discharge, and (4) love relationships to renew or sustain. Accomplishing goals can provide hope for the patients, but for some individuals an established action plan to accomplish goals is founded in a belief in God.

Results from this research indicated a low response rate and low scores of many who did respond to a question on the Quality of Life Index which asked about the satisfaction with and importance of the dialysis patient's personal faith in God. There is little information in the literature that addresses the spirituality of ESRD patients or why this question has such limited value to the study participants. A belief in God could be an avenue of pursuit in the provision of social support for dialysis patients as a means of providing hope and comfort for them as they attempt to deal with the anxieties that result from ESRD.

Lapp (1974) stated "We [nurses] make a living by what we get, but we make a life by what we give" (p.43). Lapp has also indicated that nurses need to be aware of patients' spiritual needs. Patients may need to be encouraged to use religious practices that provide hope, such as reading scripture or requesting chaplain visits. Patients may be hesitant about using religious practices openly due to a fear of being ridiculed by professionals whose decisions are founded on scientific rather than theological principles. An environment must be created where the patient feels comfortable expressing a hope and faith in God. Miller (1983) stated that "arriving at inner peace with the human experience is the ultimate result of turning over the despair to God" (p. 297). When all in life is grim and beyond the individual's influence, hopelessness may be prevented by

turning to God. Nursing can support the patient's hope and faith in God as a means of providing social support in an attempt to bring about a higher quality of life for ESRD patients.

Recommendations for Further Study

The findings from this study indicate that the perceived level of social support in rural in-center hemodialysis patients was associated with the quality of life. Therefore, social support and quality of life as a focus of concern for nursing is needed in future studies. Recommendations for future research include the following:

1. Since this is the first known study to directly measure social support and quality of life, this study should be replicated with a larger sample size. It also should be replicated with samples in more densely populated urban settings.

2. Measurement of social support in future studies should include an examination of social networks in an effort to determine where hemodialysis patients receive their support.

3. A replication of this study is needed with a larger sample to determine whether length of time on dialysis has an effect on perception of social support and social support networks.

4. Future studies are needed to examine the differences between hemodialysis and continuous ambulatory peritoneal dialysis patients with regard to social support and quality of life.

5. Studies are needed to measure the influence and assistance of social support by family members of an ESRD patient as compared to the influence of nursing involvement with an ESRD patient and for the impact of group support experiences on quality of life scores.

6. Qualitative exploration is needed to determine why participants failed to respond or gave low scores to the question on the QLI pertaining to a personal faith in God.

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APPENDICES

APPENDIX A

HOSPITAL CONSENTS

HOSPITAL CONSENT



Columbus
Hospital

Established in 1892 by Sisters of Providence

500 15TH AVENUE SOUTH · P.O. BOX 5013
GREAT FALLS, MONTANA 59403 (406) 727-3333

January 24, 1990

Karleen Anderson
5815 Glass Drive
Helena, MT 59601

Ms. Anderson:

This document will serve as a written consent form for the Columbus Hospital Dialysis Unit's participation in your Master's Research proposal. I have reviewed the research tool and consider it clear and concise. I consider the data collection method to be quite acceptable.

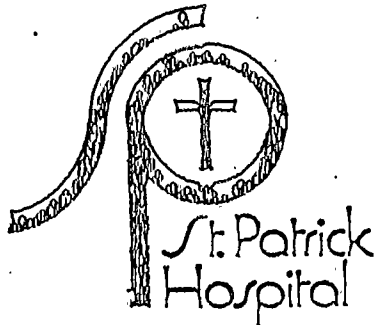
The Columbus Hospital Dialysis Unit would expect a summary of the research findings as agreed upon per phone call.

Thank you,

Anthony Peterschick, RN, BSN
Renal Administrator
Columbus Hospital Dialysis Unit

AP/dw
cc

HOSPITAL CONSENT



February 19, 1990

Karleen Anderson
5815 Glass Drive
Helena, MT 59601

Dear Ms. Anderson:

We have reviewed your research project to study the quality of life and social support among in-center hemodialysis patients in Montana. Approval to conduct your research at St. Patrick Hospital has been formalized. Please communicate directly with Marsha Hartsell, Manager of the Dialysis Unit, to arrange your visit.

We look forward to sharing the results of your study as a means of staff development to enhance the quality of patient care.

Sincerely,

A handwritten signature in cursive script that reads 'Jeannine Peretti'.

Jeannine Peretti, R.N.
Acting Vice-President/Nursing Service

/av

HOSPITAL CONSENT

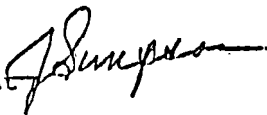


(406) 442-2480 • 2475 Broadway, Helena, Montana

M E M O

DATE: February 3, 1990

TO: Karleen Anderson

FROM: Jean Simpson, Vice President 

SUBJECT: Research Proposal

Your request to conduct your research with distribution of questionnaires to dialysis patients at St. Peter's Community Hospital is approved with the following requirements:

1. That you obtain the Dialysis Medical Director's approval;
2. That the patients are clearly advised of the voluntary nature of the survey;
3. That the patients' identities are not revealed in the thesis; and,
4. That it be made very clear to the patients that this is not a St. Peter's Hospital survey but rather a study conducted by an MSU student as a research project for a Master's thesis.

JS/swg

cc: Nancy Pierce, Manager, Dialysis
Dwight Hiesterman, M.D., Medical Director, Dialysis

APPENDIX B

STUDY QUESTIONNAIRES

INFORMATION STATEMENT

February, 1990

TITLE OF STUDY: The Relationship of Social Support and Quality of Life among Rural Hemodialysis Patients in Montana

I am working toward my Master's Degree in Nursing from Montana State University. As a registered nurse working with dialysis patients for over ten years, I am interested in the support systems provided by family and friends of dialysis patients and the relationship of that support on a person's perceived quality of life. Hopefully, the results from this study will help nursing to provide improved care for dialysis patients and their families. Studies have been done in the U.S. with regards to the effects of social support for dialysis patients. Studies have also been done rating the quality of life among dialysis and transplant patients, but there is very little information that compares social support and quality of life of dialysis patients. Therefore, I am asking for your help in this study.

Your participation will involve the completion of a written two-part questionnaire. This will take about 30-40 minutes of your time and could be done during your dialysis treatment. There are no right or wrong answers on the questionnaires.

Your assistance in this study would be greatly appreciated. You are free to not answer certain questions and withdraw from the study at any time. You are free to finish the questionnaires at some other time for your convenience. Your participation in this study is purely voluntary. Your care within the dialysis unit will not be effected in any way by your participating or not participating in this study.

Any risk from this study to you would be minimal. You may feel some discomfort answering questions about your life with dialysis. Should you decide that this discomfort is significant, a list of therapists who are available for counseling can be obtained from your unit social worker or the researcher. While participating in this study will not benefit you, results from this study could help medical personal to provide better care for dialysis patients.

Please do not put your name on the enclosed questionnaire. Information that is obtained from this questionnaire will be reported as group data and will not identify you personally in any way. Completion and return of this questionnaire to me indicates that you have consented to participate in the study. Please place the completed questionnaire in the envelope provided to be mailed back to me or collected by your units supervisor.

If you have any further questions, you can write me at 5815 Glass Drive, Helena, MT. 59601, or call me at 458-5200.

Sincerely,

Karleen Anderson R.N.

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

Patricia Brandt & Clarann Weinert

Below are some statements with which some people agree and others disagree. Please read each statement and **CIRCLE** the response most appropriate for you. There is no right or wrong answer.

- 1 = STRONGLY DISAGREE
 2 = DISAGREE
 3 = SOMEWHAT DISAGREE
 4 = NEUTRAL
 5 = SOMEWHAT AGREE
 6 = AGREE
 7 = STRONGLY AGREE

STATEMENTS

-
- a. There is someone I feel close to who makes me feel secure 1 2 3 4 5 6 7
- b. I belong to a group in which I feel important 1 2 3 4 5 6 7
- c. People let me know that I do well at my work (job, homemaking) 1 2 3 4 5 6 7
- d. I can't count on my relatives and friends to help me with problems 1 2 3 4 5 6 7
- e. I have enough contact with the person who makes me feel special 1 2 3 4 5 6 7
- f. I spend time with others who have the same interests that I do 1 2 3 4 5 6 7
- g. There is little opportunity in my life to be giving and caring to another person 1 2 3 4 5 6 7
- h. Others let me know that they enjoy working with me (job, committees, projects) 1 2 3 4 5 6 7
- i. There are people who are available if I needed help over an extended period of time 1 2 3 4 5 6 7
- j. There is no one to talk to about how I am feeling 1 2 3 4 5 6 7
- k. Among my group of friends we do favors for each other 1 2 3 4 5 6 7

- 1 = STRONGLY DISAGREE
 2 = DISAGREE
 3 = SOMEWHAT DISAGREE
 4 = NEUTRAL
 5 = SOMEWHAT AGREE
 6 = AGREE
 7 = STRONGLY AGREE

STATEMENTS

- l. I have the opportunity to encourage others
 to develop their interests and skills 1 2 3 4 5 6 7
- m. My family lets me know that I am important
 for keeping the family running 1 2 3 4 5 6 7
- n. I have relatives or friends that will help me
 out even if I can't pay them back 1 2 3 4 5 6 7
- o. When I am upset there is someone I can be
 with who lets me be myself 1 2 3 4 5 6 7
- p. I feel no one has the same problems as I 1 2 3 4 5 6 7
- q. I enjoy doing little "extra" things that make
 another person's life more pleasant 1 2 3 4 5 6 7
- r. I know that others appreciate me as a
 person 1 2 3 4 5 6 7
- s. There is someone who loves and cares
 about me 1 2 3 4 5 6 7
- t. I have people to share social events and
 fun activities with 1 2 3 4 5 6 7
- u. I am responsible for helping provide for
 another person's needs 1 2 3 4 5 6 7
- v. If I need advice there is someone who
 would assist me to work out a plan for
 dealing with the situation 1 2 3 4 5 6 7
- w. I have a sense of being needed by another
 person 1 2 3 4 5 6 7
- x. People think that I'm not as good a friend
 as I should be 1 2 3 4 5 6 7
- y. If I got sick, there is someone to give me
 advice about caring for myself 1 2 3 4 5 6 7

QUALITY OF LIFE INDEX (DIALYSIS) - PART 1*
(Domain Satisfaction)

People differ in how they look at their lives. The things that are satisfying to one person may not be satisfying to someone else.

For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. If none of the answers fit exactly, pick the answer that comes closest to how satisfied you are. Please mark your answer by circling the number.

If some questions do not apply to you, please leave them blank. For example, one question asks about your job. If you are unemployed, leave the question blank. Please try to answer all the questions that apply to you.

There are no right or wrong answers.

1 = VERY DISSATISFIED
2 = MODERATELY DISSATISFIED
3 = SLIGHTLY DISSATISFIED
4 = SLIGHTLY SATISFIED
5 = MODERATELY SATISFIED
6 = VERY SATISFIED

- | | | | | | | | |
|----|---|---|---|---|---|---|---|
| 1. | How satisfied are you with dialysis treatment? | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. | How satisfied are you with the health care you are receiving? | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. | How satisfied are you with your physical independence (ability to do things for yourself, get around)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. | (If a transplant candidate) How satisfied are you with the efforts being made to increase your potential for having a successful kidney transplant? | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. | How satisfied are you with your potential for getting off dialysis (for example, through a successful transplant or a medical discovery)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. | How satisfied are you with your potential to live a long time? | 1 | 2 | 3 | 4 | 5 | 6 |

8.	How satisfied are you with your family's health?	1	2	3	4	5	6
9.	How satisfied are you with your children?	1	2	3	4	5	6
10.	How satisfied are you with your family's happiness?	1	2	3	4	5	6
11.	How satisfied are you with your relationship with your spouse/significant other?	1	2	3	4	5	6
12.	How satisfied are you with your sex life?	1	2	3	4	5	6
13.	How satisfied are you with your friends?	1	2	3	4	5	6
14.	How satisfied are you with the emotion support you get from others?	1	2	3	4	5	6
15.	How satisfied are you with your ability to meet family responsibilities (things you have to do for your family)?	1	2	3	4	5	6
16.	How satisfied are you with your usefulness to others?	1	2	3	4	5	6
17.	How satisfied are you with the amount of stress or worries in your life?	1	2	3	4	5	6
18.	How satisfied are you with your home (furniture, house or apartment)?	1	2	3	4	5	6
19.	How satisfied are you with your neighborhood?	1	2	3	4	5	6
20.	How satisfied are you with your standard of living?	1	2	3	4	5	6
21.	How satisfied are you with the overall conditions in the United States?	1	2	3	4	5	6
22.	(If employed) How satisfied are you with your job?	1	2	3	4	5	6
23.	(If unemployed, retired, or disabled) How satisfied are you with not having a job?	1	2	3	4	5	6
24.	How satisfied are you with your education?	1	2	3	4	5	6
25.	How satisfied are you with your financial independence?	1	2	3	4	5	6
26.	How satisfied are you with your leisure time activities?	1	2	3	4	5	6

27.	How satisfied are you with your ability to travel on vacations?	1	2	3	4	5	6
28.	How satisfied are you with your potential for a happy old age/retirement?	1	2	3	4	5	6
29.	How satisfied are you with your peace of mind?	1	2	3	4	5	6
30.	How satisfied are you with your personal faith in God?	1	2	3	4	5	6
31.	How satisfied are you with your achievement of personal goals?	1	2	3	4	5	6
32.	How satisfied are you with your happiness in general?	1	2	3	4	5	6
33.	How satisfied are you with your life in general?	1	2	3	4	5	6
34.	How satisfied are you with your personal appearance?	1	2	3	4	5	6
35.	How satisfied are you with yourself in general?	1	2	3	4	5	6

QUALITY OF LIFE INDEX (DIALYSIS) - PART 2*
(Domain Importance)

People differ in how they look at their lives. What is important to one person may not be important to another.

For each of the following, please choose the answer that best describes how important that area of your life is to you. If none of the answers fit exactly, pick the answer that comes closest to how you feel. Please mark your answer by circling the number.

If some questions do not apply to you, please leave them blank. For example, one question asks about your job. If you are unemployed, leave the question blank. Please try to answer all the questions that apply to you.

There are no right or wrong answers.

1 = VERY UNIMPORTANT
2 = MODERATELY UNIMPORTANT
3 = SLIGHTLY UNIMPORTANT
4 = SLIGHTLY IMPORTANT
5 = MODERATELY IMPORTANT
6 = VERY IMPORTANT

- | | | | | | | | |
|----|---|---|---|---|---|---|---|
| 1. | How important is dialysis treatment to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. | How important is your health to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. | How important is health care to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. | How important is your physical independence (ability to do things for yourself, get around) to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. | (If you are a transplant candidate)
How important is a successful kidney transplant to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. | How important is it to you to get off dialysis (for example, through a successful transplant or a medical discovery)? | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. | How important is living a long time to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. | How important is your family's health to you? | 1 | 2 | 3 | 4 | 5 | 6 |

9.	How important are your children to you?	1	2	3	4	5	6
10.	How important is your family's happiness to you?	1	2	3	4	5	6
11.	How important is your relationship with your spouse/significant other to you?	1	2	3	4	5	6
12.	How important is your sex life to you?	1	2	3	4	5	6
13.	How important are your friends to you?	1	2	3	4	5	6
14.	How important is emotional support to you?	1	2	3	4	5	6
15.	How important is meeting family responsibilities to you (things you have to do for your family)?	1	2	3	4	5	6
16.	How important is being useful to others to you?	1	2	3	4	5	6
17.	How important is it to you to have a reasonable amount of stress or worries?	1	2	3	4	5	6
18.	How important is your home to you (furniture, house or apartment)?	1	2	3	4	5	6
19.	How important is your neighborhood to you?	1	2	3	4	5	6
20.	How important is a good standard of living to you?	1	2	3	4	5	6
21.	How important are the overall conditions of the United States to you?	1	2	3	4	5	6
22.	(If employed) How important is your job (or working) to you?	1	2	3	4	5	6
23.	(If unemployed, retired, or disabled) How important would it be to you to have a job?	1	2	3	4	5	6
24.	How important is your education to you?	1	2	3	4	5	6
25.	How important is your financial independence to you?	1	2	3	4	5	6
26.	How important are leisure time activities to you?	1	2	3	4	5	6
27.	How important is the ability to travel on vacations to you?	1	2	3	4	5	6
28.	How important is having a happy old age/retirement to you?	1	2	3	4	5	6

- | | | | | | | | |
|-----|--|---|---|---|---|---|---|
| 29. | How important is peace of mind to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. | How important is your personal faith in God to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. | How important is achieving your personal goals to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 32. | How important is happiness to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 33. | How important is it to you to be satisfied with life? | 1 | 2 | 3 | 4 | 5 | 6 |
| 34. | How important is your personal appearance to you? | 1 | 2 | 3 | 4 | 5 | 6 |
| 35. | How important are you to yourself? | 1 | 2 | 3 | 4 | 5 | 6 |

BACKGROUND INFORMATION

1. In what year were you born? _____

2. Your gender (circle number of your answer)?

- 1 Woman
- 2 Man

3. What is your present marital status?

- 1 Married
- 2 Divorced
- 3 Separated
- 4 Widowed
- 5 Never Married
- 6 Common-law
- 7 Living Together

4. How many years of school have you completed?

_____ years of school

5. What is your employment status?

- 1 Working Full-Time
- 2 Working Part-Time
- 3 Unemployed, looking for work
- 4 Unemployed, not looking for work
- 5 Retired
- 6 Full-Time Homemaker

6. How long have you been on in-center hemodialysis?

_____ years _____ months

7. What other chronic disease conditions do you have in addition to End-Stage Renal Disease?

- 1 Hypertension
 - 2 Diabetes
 - 3 Heart Disease
 - 4 Arteriosclerosis
 - 5 Arthritis
 - 6 Back Problems
 - 7 Lung Disease
 - 8 Other (please state)
-

APPENDIX C

PERMISSION FOR USE OF QUESTIONNAIRES

PERMISSION FOR USE OF QUESTIONNAIRE



Montana State University
Sherrick Hall
Bozeman, Montana 59717-0005

College of Nursing

February 6, 1990


Karleen Anderson, R.N.
5815 Glass Drive
Helena, MT 59601

Dear Karleen,

Thank you for your letter. I'm so glad that you are progressing with your study, and that you are using the PRQ-85. You certainly have my permission to use the instrument and demographics sheet. We have done some format revision on the PRQ-85 to make it easier for respondents to follow. I am sending you a new packet of our information so that you will be totally current.

Good luck in your endeavors.

Sincerely,


Clarann Weinert, S.C., Ph.D., R.N.
Associate Professor

PERMISSION FOR USE OF QUESTIONNAIRE



THE
UNIVERSITY
OF
ILLINOIS
COLLEGE
OF NURSING

University of Illinois at Chicago
Department of Medical-Surgical Nursing
845 South Damen Avenue, 7th Floor
Box 6998, Chicago, Illinois 60680
(312) 996-7900

May 13, 1987

Kathleen Anderson, B.S.N., R.N.
512 Stadler Road
Helena, Montana 59601

Dear Ms. Anderson:

Thank you for your interest in the Quality of Life Index (QLI). I have enclosed the dialysis version of the QLI and the computer program for calculating scores. I have also included a list of the weighted items that are used for each of four subscales: health and functioning, socioeconomic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate subscale scores and overall scores.

In return of our permission to use the QLI, I would appreciate it if you would send me the raw data from the QLI and sociodemographic information for psychometric purposes.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research project.

Sincerely,

Carol Estwing Ferrans, PhD, RN
Assistant Professor

CEF:ln

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