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The Social Support of Spouses of Patients on Hemodialysis

by

Christine Lisa Mudge

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

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of the

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by

Christine Lisa Mudge

"I count myself in nothing else so happy as in a soul remembering my good friends." (Shakespeare, Richard III)

Dedication

This paper is dedicated to my friends for their love, support, and encouragement.

> Who is more indefatigable in toil when there is occasion for toil than a friend? Who is readier to rejoice in one's good fortune? Whose praise is sweeter? From whose lips does one learn the truth with less pain? What fortress, what bulwarks, what arms are more steadfast than loyal hearts? (Dio Chrysostom, First Discourse on Kingship)

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Thank you.

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Chapter 1

Introduction

Although chronic illness is a condition that dramatically affects the individual, its impact on the person's family also can be profound (Bruhn, 1977; Czaczkes & Kaplan-DeNour, 1978; Lawrence & Lawrence, 1979). The slow progressive "downward trajectory" of chronic illness can produce a sense of grief and psychological stress in both the individual and the family that may further compromise the condition of the patient and the health status and sense of well-being of family members (Golodetz, Evans, Heinritz, & Gibson, 1969; Holmes, 1978; Klein, Dean, & Bogdonoff, 1967; Strauss & Glaser, 1975).

One example of chronic illness that affects the family system is loss of kidney function or end stage renal disease (ESRD) (Hampers, Schupak, Lourie, & Lazarus, 1973; Strauss & Glaser, 1975; Streltzer, Finkelstein, Feigenbaum, Kitsen, & Cohen, 1976). When renal failure does occur, hemodialysis is the initial therapy most commonly implemented (Devins, Binik, Hollomby, Barre, & Guttmann, 1981; Nolph, 1981). Based on the 1984 report of the United States Health Care Financing Administration, Medical Information System, there are approximately 80,000 patients utilizing hemodialysis as a treatment modality for ESRD. This is more than twice the number in 1979 and can be attributed to an increase in Federal funds for treatment (Burton & Hirschman, 1979). More than 90% of these patients dialyze in-center (Nolph, 1981) and approximately 12,500 reside in California (Krakauer, Grauman, McMullan, & Creede, 1984). Men comprise 56% of those undergoing hemodialysis and women, 44%. Thirty-two percent of patients are between the ages of 24 and 44; 42% are between the ages of 45 and 64. Approximately 70% are white and 24% are black. Since approximately 12%

of the United States' population is Black, this percentage reflects a proportionally higher incidence of ESRD in the Black population. Mortality statistics indicate that 10% of dialysis patients die annually (Burton & Hirschman, 1979).

Hemodialysis is a process of blood purification whereby toxic substances are removed from the blood into a dialysis solution by means of a semipermeable membrane. It usually is initiated when remaining renal function drops between 5 and 10% to prevent severe symptoms and complications (Devins et al., 1981; Nolph, 1981). Treatment consists of 12 to 15 hours of therapy per week in three daily 4-to-5 hour sessions. There are strict dietary and fluid restrictions as well. The procedure demands anticoagulation of the blood to prevent clotting the artificial kidney and the disruption of body fluid composition to ensure the effective removal of waste products.

These physiological changes, together with the removal of salt, often cause unpleasant side effects during dialysis, such as cramps, nausea, vomiting, and sudden drops in blood pressure (Nolph, 1981). Unfortunately, despite the advances of modern technology, the artificial kidney and dialysis have not completely duplicated the complex functioning of the human kidney. Dialysis, for instance, does not remove some toxic, higher density molecules. Nor does it produce errythropoieten, which assists the bone marrow in red blood cell formation and the activation of vitamin D. Because dialysis does not replace these substances or remove others, patients frequently suffer from anemia, bone disease, and a variety of other complications that can lead to death, itself (Gutch & Stoner, 1975; Nolph, 1981).

Of the psychological changes in patients undergoing hemodialysis for

ESRD, the most frequently reported complaint is depression (Czaczkes & Kaplan-DeNour, 1978; Kaplan-DeNour, 1980; Sheridan, 1977). Other psychological and physiological changes include fatigue, denial, helplessness, suicidal tendencies, passive non-compliance, sleep disturbances, anorexia, anxiety and phobias in response to treatment, loss of libido, and impaired sexual function (Abrams, 1971; Blodgett, 1981; Devins et al., 1981; Hampers et al., 1973). A variety of patient-identified stresses evolve from these complications, including the constant threat of death, feelings of dependency upon a machine, personal and economic burdens, reduction in personal freedom and time, and dietary restrictions (Devins et al., 1981; Strauss & Glaser, 1975).

ESRD is a chronic, stressful, and pervasive life event for which there is no cure. Its course is unpredictable and all encompassing; even in the best of situations, treatment is extremely demanding. It is not surprising, therefore, that the chronicity of the illness and its treatment can produce profound psychological and physiological changes in the patient. These changes can have an equally severe impact on the patient's family. General systems theory provides a framework for conceptualizing this relationship between patient and family, and the ability of both to adjust to ESRD and hemodialysis (Chowanec & Binik, 1982). The requirements of a system are that its members be in a stable relationship and interact with one another over time (Buckley, 1967). The family is an example of such a system, and it can be assumed that what affects one family member affects others in the family as well (Satir, 1967).

How well the patient adapts to the stress of ESRD and hemodialysis contributes to the well-being of the family and spouse. The stress of home dialysis on the spouse of the patient can manifest itself in a

variety of adverse effects (Chowanec & Binik, 1982; Shambaugh & Kanter, 1969; Sheridan, 1977). The additional work, added responsibility, and continual tension in the home environment can be so severe that psychiatric intervention is required (Smith, McDonald, Curtis, & Dewardener, 1969). Even after the passage of time, spouses of patients on hemodialysis have reported continuing feelings of depression, frustration, insecurity, increased anger and marital strain, and more headaches (Atcherman, 1981; Holcomb & McDonald, 1973; Shambaugh, Hampers, Bailey, Snyder, & Merrill, 1967). Whether the spouse is able to adjust to the illness and its treatment can affect the nature of the marital relationship, itself (Streltzer et al., 1976).

Spouses of patients utilizing in-center dialysis have reported many of the same psychological stresses as those attending home dialysis patients; and the few studies that have compared home and in-center dialysis have found both groups to be depressed, although home dialysis seems particularly disruptive of family life because of the increased stress on the spouse (McGee, 1981). The spouses of in-center patients also have been found to adjust to their situation through denial and fantasy formation and by becoming excessively close to the patient (Shambaugh et al., 1967). Whether dialysis is in-center or in the home, there are psychological consequences for the spouse that include feelings of depression, anger, frustration, hostility, insecurity, and anxiety (Chowanec & Binik, 1982; Finkelstein, Finkelstein, & Steele, 1976; Shambaugh & Kanter, 1969; Shambaugh et al., 1967; Steele, Finkelstein, & Finkelstein, 1976). Marital discord, sexual dysfunction, and social apprehension have been indicated as well (Speidel, Koch, Balck, & Kniess, 1979).

It is unclear whether reactions to ESRD and dialysis are the same

in every case for both patient and spouse (Hagberg & Malmguist, 1974). Although patients have been found to be depressed more often, the severity of that depression and degree of marital discord, for instance, have been greater in spouses (Finkelstein et al., 1976; Smith et al., 1969; Steele et al., 1976).

Regardless of the particular reactions by patient and spouse, each strongly affects the other in their mutual adjustment to hemodialysis. The emotional support of the spouse, especially, has been shown to be highly significant in the patient's response (Abrams, 1971; Blodgett, 1982; Chowanec & Binik, 1982; Dimond, 1979; Greenburg, Weltz, Spitz, & Bizzozero, 1975; Olsen, 1983). Spouses have been considered to be assistants in the care of the patient in ESRD and expected to promote the patient's adherence to the regimen of care, participate in home dialysis, and work for the general rehabilitation of the patient (Kaplan-DeNour, 1980). It is the family, and the spouse in particular, that is the main source of support for the chronically ill member (Crossman, London, & Barry, 1981; Czaczkes & Kaplan-DeNour, 1978; Greenberg et al., 1975; Simmons, Klein, & Simmons, 1977).

Although the literature recognizes that the familial or social support of the spouse is crucial in dealing with illness in the family (Cobb, 1976; Dimond, 1979; Fuller & Karlson, 1981; O'Brian, 1980, Shanas, 1979; Sheridan, 1977; Winkes, 1983), there is less said about support of the spouse of the ill family member (Kaplan-DeNour, 1980). A few studies do indicate that self-help groups provide a source of social support for the spouse and patient in adapting to hemodialysis (Brinker & Lichtenstein, 1981; Foster & McKegney, 1978; Shambaugh & Kanter, 1969; Shambaugh et al., 1967). But what effect social support has on enhancing a sense of well-

being in the spouse is less clear.

By identifying the perceived sources of social support of spouses of patients on hemodialysis and determining how this support affects their sense of well-being, it should be possible to moderate their stress. Nursing can then direct its energies toward developing and maintaining that support.

Purpose

The purposes of this study are to identify the perceived sources of social support of spouses of patients on chronic in-center hemodialysis and to describe how these sources of social support influence the spouses' sense of well-being.

Chapter 2

Theoretical Framework

Systems theory and social support provide a theoretical framework for a discussion of the impact of chronic illness on the family. As conceptualized by Buckley (1967) and von Bertalanffy (1968), a system is a means of structuring and organizing reality. A system has a continuous boundary, which maintains an interrelated assembly of parts. At any particular moment in time, these parts may be related directly or indirectly, be simple and consistent or complex and changing, intermittent or continual, mutual or unidirectional, casual or intense. The structure of a system at a particular time is determined by its interrelation of parts at that moment. There is, simultaneously, both an ongoing continuity within the system and change over time.

The family and its individual members are considered to exist in an open system, that is, they have the ability to relate to their environment and to one another (Hazzard, 1971). The characteristics of an open family system have been defined by Miller (1980) as including wholeness, being nonsummative, and equifinality. Wholeness and nonsummative are primary characteristics of systems theory and refer to the fact that the whole is greater than, and different from, the sum of its parts. Equifinality indicates that the pattern of family interaction may be initiated at a variety of starting points with the same results and that different results can occur from the same interaction. Essentially, an open family system means that what affects one family member affects all others in the family as well (Satir, 1967).

A primary function of the family is to utilize these characteristics to meet its goals, which are differentiated and attained through various

subsystems. For there to be effective family functioning, the boundaries of these subsystems must be clear. Only if they are, can the family members who belong to them carry out their functions without interference and still maintain contact with others in the family (Minuchen, 1974).

One example of a family subsystem is the spousal subsystem. It is the core of the family and has specific tasks vital to family functioning. Skills necessary to accomplish these tasks include mutual accommodation and complementarity, the function of which is to provide a pattern of support for family members and the family as a whole (Minuchen, 1974). When this function is disrupted by the impact of chronic illness such as ESRD on the adult family member of the spousal subsystem, however, the whole system is affected and family goals must be reorganized.

Social support. Because social support is threatened by chronic illness, it provides another theoretical framework for a discussion of the impact of chronic illness on the family. Although it has been assumed that what affects one family member affects others in the family, the marital relationship between spouses has particular significance on the equilibrium of the family and is a primary source of social support (Klein et al., 1967; Satir, 1967).

In health related research, social support has been considered to be a psychosocial variable that moderates stress and enhances one's well-being (Cassel, 1975; Cobb, 1976; Dean & Lin, 1977; Kaplan, Cassel, & Gore, 1977; Norbeck, 1981). Conceptually, however, there has been less agreement regarding how social support actually is defined.

Dimond and Jones (1983) have summarized the literature on social support and perceived it to fall into four definitional categories: social support as relational provision, information, structure, and

interaction. For Weiss (1974), social support is a combination of six categories of relational provisions: attachment, social integration, opportunity for nurturance, reassurance of worth, sense of reliable alliance, and obtaining guidance. Attachment is provided by close relationships, in which the participants have a sense of security and place. If such attachment is lacking in a given relationship, the participants feel lonely and restless. Individuals also may become lonely and isolated if there is not social integration provided by social networks of shared concerns. Social integration also offers a basis for companionship and socializing. Opportunity for nurturance is provided by adult/child relationships in which the responsibility for children permits a meaning to life and reason for living that otherwise might be absent. Reassurance of worth derives from relationships that confirm an individual's competence in social roles. Reliable alliance is provided by family ties and, when lacking, can cause an individual to feel abandoned and vulnerable. Obtaining guidance is provided by someone trusted to offer help and emotional support, particularly in time of need. Weiss concluded his definition of social support by stating that a deficit in any of these categories that define the term may create a condition of "restless distress."

Cobb (1976) perceived social support to be information, the second of the categories presented by Dimond and Jones (1983). It is "information leading the subject to believe that he is cared for and loved, esteemed and a member of mutual obligation (p. 300). Cobb has argued that social support does not consist of material assistance but of less tangible giving. Social support as structure is presented by such authors as Mitchel (1969) and Walker, MacBride, and Vachon (1977), who identified support as a set of linkages among a defined set of individuals that permits

an understanding of the behavior of the persons involved. There are four categories to this structure: size, the number of people in the social network; density, how well the individuals know and contact each other; homogeneity of the membership, the extent to which the network shares common demographic characteristics, values, and lifestyles; and dispersion of membership, the ease in which the network interacts. Social support as interaction can be summarized by three dimensions: content, the meaning individuals give to their relationship; directedness, the amount of mutual sharing; and intensity, the strength of personal bonding.

In their categorization of social support, Dimond and Jones (1983) emphasized the definitional diversity of the term and proposed that all conceptual definitions of social support in the literature involved four basic areas. The first is "communication of positive affect," which is a sense of warmth and caring that encourages self-esteem and affirms behaviors. "Social integration" is a sense of belonging to a supportive group and having an opportunity to exchange and share experiences. "Instrumental behavior," which is not in total agreement with all definitions, is the provision of material aid as a component of social support. "Reciprocity" is a continual supportive transaction that is mutually satisfying. It is apparent from this overview that social support is a necessary component of an individual's sense of well-being and contributes to one's ability to withstand stress.

Kahn (1979) has conceptualized social support as the "interpersonal transactions that include one or more of the following: the expression of a positive affect of one person toward another; the affirmation or endorsement of another's behavior, perceptions, or expressed view; the giving of symbolic or material aid to another" (p. 85). This definition

of social support agrees with the broad categories presented by Dimond and Jones (1983) and is used as the operative definition of social support in the present study.

Kahn has described the three components of supportive transactions in some detail. Affective transactions are identified as expressions of liking, admiration, respect, and love. Affirmative transactions are those that acknowledge an appropriate act or statement from another person or the expression of agreement. Direct aid or assistance are those personal transactions that provide social support, such as advice, information, time, or financial aid.

The mode in which social support is provided is by what Kahn defined as a "convoy." A convoy consists of the interrelationship of an individual to a group of individuals. There is an emphasis on the giving and receiving of social support in relation to the focal person, and the "set of persons on whom he or she relies for support and those who rely on him or her for support" (p. 94). This convoy is initiated by seeking out other individuals with whom there is a significant interchange of social support. The implication is that this interchange within the convoy is dynamic and variable, depending on the problem or specific transaction. Job change, relocation, death, and divorce were cited as examples of particular transitions or changes in the convoy.

The formal properties of the convoy can be measured through the utilization of network analysis theory. The convoy consists of two subsets: properties of the convoy as a whole, and properties of the separate dyadic links within the convoy. The properties as a whole include size, internal and external connectedness, homogeneity and stability, and symmetry in giving and receiving. Separate properties include frequency of contact

magnitude, which refers to the importance of the transaction; initiative, by either the focal person or others; range of life domains, for example, the neighborhood or family; type, which refers to affirmation, affect, or aid; symmetry, the balance between support giving or receiving, or both; duration, the time since the initiation of the relationship; and capacity, the maximum potential support for specific instances.

Kahn and Antonucci (1981) have utilized the concentric circles diagram to demonstrate the changes in an individual convoy over time. With a change in the convoy, itself, as with a chronically ill spouse, the actual or perceived source of social support may be altered.

These theories offer a foundation by which the social support of spouses of patients on chronic hemodialysis may be examined. Norbeck (1981) and Dimond and Jones (1984) have discussed the implications of social support for clinical nursing, theory, and research. Nursing needs to identify the properties of the individual, perceived and available support, and to promote the development of support or maintain or supplement existing support through a network of relationships.

Effective psychosocial assessment of available or perceived support of spouses of patients in ESRD may allow the nurse to evaluate the situation more appropriately and intervene in the prevention of health risks involved in living with a chronically ill mate.

Literature Review

The psychological problems of a chronic illness that confront patients and their families are multiple and varied. They include prevention and management of the crisis, symptom control, prescribed regimens, social isolation, adjustment to the condition, and financial considerations (Strauss & Glaser, 1975). Together, they comprise a major life change event, the effects of which can not only change the attitudes of the sick member but also those of all the members of the family unit (Bruhn, 1977). Coping with chronic illness requires medical, financial, and familial resources as well as considerable interactional skills. If any of these are lacking, an effective response to the disease may fail (Strauss & Glaser, 1975). Often, the changes occurred by chronic illness are abrupt, and family role changes and task reassignments must occur as quickly. This disequalibrium and the attempt to adapt to rapid change is extremely stress provoking and can cause the family of a chronically ill member to become sick, themselves (Bruhn, 1977; Holmes, 1978).

Impact of chronic illness on the family. Klein et al. (1967) have explored the nature and extent of spousal involvement in the chronic illness of a husband or wife. The implicit hypothesis in this longitudinal study was that chronic illness has an impact on the family that requires readjustments in functioning. The sample consisted of 121 chronically ill patients and 73 spouses (46 men and 27 women) in a university clinic. To obtain data, a semistructured interview was used as well as three questionnaires: a psychophysiologic distress index, a role tension index, and an activities questionnaire.

Results indicated that chronic illness did have an impact on the spouse. When symptoms of the illness increased in severity, 67% of the

spouses had a corresponding increase in symptomatic levels, e.g., nervousness and feelings of fatigue or tiredness. There also was a 56% increase in role tension reported by the spouses. The most frequently scored responses were "feelings of being jumpy," "gets angry easily," and "easily depressed, sad or blue." There also was a positive correlation between role tension and symptom status ($p < .001$) and amount of outside employment between patient and spouse ($p < .001$). These findings support the notion that illness does exert a significant impact on well family members, especially spouses.

To demonstrate the impact of chronic illness on the family, Golodetz et al. (1969) conducted an exploratory study of family members who cared for the chronically ill at home. The purpose of the investigation was to draw a portrait of the family member's role and to set the groundwork for further research in the area. Patients were selected from an urban city core of medically indigent adults. Fifty-nine households were chosen, consisting of a variety of ethnic and cultural backgrounds. The family members, or "responsors" as they were termed by the authors, were primarily spouses, 89% of whom were women, with an age range of 40 to 80 years. Data were collected through observation by the home-care team during their clinical activities.

Results indicated that the responsors were affected by the illness process. This was demonstrated primarily by the poor health status of the responsors, themselves. Of the total sample, 31 had a significant illness, 18 had a symptomatic chronic illness that required regular care, and 5 had current previous episodes of psychosis. Other indicators of the impact of chronic illness on family members were their lack of outside activities, sense of isolation, and preoccupation with care giving.

The researchers concluded that chronic illness did adversely affect the family member caring for the chronically ill. Because the family is unable to make the necessary role changes and adjustments, it frequently breaks down in response to chronic illness. Well members, too, may sympathetically get sick in response to the one who is chronically ill. With time, as the situation worsens, their condition deteriorates as well (Bruhn, 1977; Pless, Roghmann, & Haggerty, 1972).

ESRD as a chronic illness. ESRD and hemodialysis can have a particularly profound effect on the patient and family. Landsman (1979) has characterized the patient with ESRD on hemodialysis by the prolonged duration of the condition and the uncertainty of its prognosis. There is an extensive literature on the patient on chronic hemodialysis that has been directed toward the stresses of the condition, how the patient copes with them, and the required medical regimen (Abrams, 1970; Blodgett, 1981; Dimond, 1980; Harris, Hyman, & Woog, 1982; Olsen, 1983; Parker, 1980; Wright, Sand, & Livingston, 1966).

A variety of complex physiological and psychological problems can derive from the condition and its treatment, including real or threatened loss, conflict between dependence and independence, changes in coping strategies, shifts in family roles and responsibilities, and the threat of impending death (Czaczkes & Kaplan-DeNour, 1978). Twenty-nine stressors were described by Baldree, Murphy, & Powers (1982) in their study of dialysis patients. Its purpose was three-fold: to design and test an instrument for patients to evaluate the incidence and degree of stress associated with dialysis, determine commonly used coping strategies, and explore the relationship between coping and stress. Their sample consisted of 35 patients who had been dialyzed at least 6 months. Nineteen were women

and 16 were men; 19 were black, 13 white, and 3 Hispanic; their mean age was 42.2 years. Twenty-five were unemployed and 60% were single. Content validity of the stress instrument was empirically supported by previous research and unanimous acceptance by six nurse experts, who characterized the stress of hemodialysis as either psychological or physiological. A small pilot study confirmed the appropriateness of the characterization. Instrument reliability was established by test-retest with 13 patients; Spearman's rank ordering by repeated ratings indicated instrument reliability to be $\underline{r} = .71$ ($\underline{p} < .01$). Coping strategies were measured by the Jalowiec and Power's instrument, which has a five-point Likert-type format consisting of 40 affective and problem oriented coping skills. Content validity of the instrument was empirically supported; using Spearman's rank ordering, reliability was estimated to be $\underline{r} = .79$ ($\underline{p} < .001$).

Results indicated that fluid restriction was the most commonly reported stressor, followed by muscle cramps, fatigue, job uncertainty, and food and activity restrictions. Approximately one-half of the patients reported a decrease in social life and changes in family responsibilities. The least reported stressors were shifts in family role with the spouse and impairment in the ability to procreate. The most commonly reported coping strategy was to maintain some control of the situation and hope that it improved; blaming someone else was reported least often. The family of the dialysis patient may have been reported less often either as a source of stress or a means of coping because over half of the sample was single and so may not have had reason to experience changes in family roles.

The psychological stressors of patient adjustment to hemodialysis have been catalogued by Blodgett (1981) in a comprehensive review of the research and theoretical literature. He identified common problems such

as depression, phobia and anxiety in response to treatment, suicidal behavior, passive non-compliance with the medical regimen, sleep disturbances, anorexia, and dependence/independence conflicts. This last problem was found to be characteristic of patients on chronic hemodialysis. Dependence upon the equipment and regimen of care precluded any rehabilitation, and independence from them jeopardized the patient's health status. This double bind was identified as a major source of stress for the dialysis patient and is to be resolved not so much by a change in the medical regimen as with those who care for the patient, e.g., health care workers, employment relationships, and the family, in particular.

Devins et al. (1981) also have identified hemodialysis as stressful for the patient. The purpose of their study was to test the reformulated learned helplessness theory of depression and to explore the psychological impact of limited control in ESRD. The sample consisted of 45 patients, 15 dialyzed in-center by staff, 15 self-care in-center, and 15 on home dialysis; 25 of these patients were post transplant. Three interviews, consisting of questions related to demographics and medical history, and psychometric tests for depression, self-esteem, and locus of control were conducted. There also were separate ratings by hospital staff, family, and the patients, themselves. Sixteen dependent variables of helplessness and depression were retracted into six factors, and a multiple regression correlation strategy used to evaluate them. A correlation then was done to compare helplessness theory to two hypotheses: patients' perceived control over eight non-treatment life dimensions (work, social relations, recreation, material need satisfaction, psychological need satisfaction, community and civic activities, physical well-being, diet) and patients' perception of dialysis.

Although results failed to support the reformulated learned helplessness theory of depression, they did indicate that the mode of dialysis delivery differed significantly ($p < .01$) in relation to perceived control. Hospital based staff delivery patients experienced less control ($M = 4.4$) than did either the hospital self-care patients ($M = 5.9$) or home dialysis patients ($M = 6.2$) as indicated by a 95% confidence interval. Perceived external locus of control and uncontrollability (i.e., low levels of control over the eight non-treatment dimensions) also were associated with depression.

Similar results were found by Goldstein and Reznikoff (1971), who conducted a study of 22 male patients on hemodialysis for 4 months or more and a control group of 24 male patients recovering from minor medical conditions (e.g., pneumonia, hernia). The groups were matched for age, sex, socioeconomic level, and hospitalization. It was hypothesized that the dialysis patient copes with the responsibilities and anxieties of treatment by adopting an external locus of control, which results in behavior that is no longer perceived as life sustaining, thereby avoiding the threatened area of responsibility. It also was hypothesized that a patient from a lower socioeconomic level would show a greater degree of externality.

A number of psychological tests were administered to both groups, including the internalization/externalization scale and the two-factor index of social position. Other tests were not identified, nor were the reliability and validity of the instruments that were mentioned discussed. Results indicated that the hemodialysis group demonstrated greater external locus of control than the control group. The second hypothesis was confirmed only for the control group, demonstrating that low socioeconomic

level was associated with high external locus of control. Goldstein and Reznikoff concluded that the hemodialysis patient did not regain a sense of mastery as treatment progressed but perceived behavior as having no effect upon the condition. They suggested that such a lack of control may precipitate a depressed state that could be directly attributed to the possibility of suicide. Abrams, Moore, and Westervelt (1971) also have reported suicide to be a risk for dialysis patients and attributed it to the multiple psychological stresses of the patient's condition.

A major psychological problem reported by dialysis patients has been depression (Czaczkes & Kaplan-DeNour, 1978). It is precipitated by a variety of factors, including impaired physical function, a change in social or financial status, loss of membership in social groups, continual threat of injury, frustrated instinctual drives such as hunger and thirst, and an inability to plan for the future (Sheridan, 1977).

Families of dialysis patients. There has been relatively little written about the stress of the family and spouses of patients on hemodialysis, even though they have been shown to be greatly affected by the patient's ability to adjust to treatment and provide much of the support (Greenberg et al., 1975; Hampers et al., 1973; Winkes, 1983). Reported stressors on the family have included financial insecurity, dependency needs, inability to adjust, marital discord, and sexual dysfunction (Chowanec & Binik, 1982; Czaczkes & Kaplan-DeNour, 1978; Finkelstein et al., 1976; Steele et al., 1976). It is because the stress of hemodialysis does have an effect on the family of the patient that much of the literature has reviewed dialysis in the home.

Holcomb and MacDonald (1973) sought to investigate the nature and frequency of problems related to home dialysis. The social and family

functioning of 23 home dialysis patients and their spouses (14 men and 9 women) were studied. Patients were between 20 and 40 years of age and had been dialyzed for at least 6 months; their spouses were between 23 and 40 years old. The Heimler Scale of Social Function (an instrument for which no indication of validity or reliability was given) was used to measure major areas of daily living, including work, personal interests, finances, friendship, family, and sex. Test results indicated that the patient group experienced feelings of depression and frustration sufficiently strong that one third of them wished that they were dead. Similar feelings, although not so strongly felt, were expressed by spouses, whose depresssion was associated with feelings of insecurity and a lack of appreciation for their efforts in caring for the patient, as well as diminished sexual activity. Holcomb and MacDonald concluded that home dialysis was stressful and depressed both patient and spouse.

Atcherman (1981) also investigated the demands of hemodialysis on the patient and spouse. Thirty-five spouses were interviewed, using McCabe's interview schedule (for which no reliability or validity was presented), to determine their stress-related feelings and experiences during a period of home dialysis training and after using dialysis in the home for 3 months. Eighty percent of the sample were wives and 20% husbands; 63% were less than 45 years of age. Sixteen variables were analyzed according to age, length of disease, and hours of employment outside the home. Findings indicated that levels of stress were highest during the training period but had decreased by the time of the second interview 3 months later. Some variables still remained high even then, and included needle insertion, dialysis sessions, the possibility of mechanical problems, ability to adjust, marital strain, becoming angry easily, and increased

headaches. Those spouses younger than 45 years reported higher levels of concern than those who were older. Spouses of patients who had ESRD for less than 2 years reported higher levels of concern at both the initial and later interview sessions, as did spouses who were employed or not. Whether more or less stressed by home dialysis according to the variables studied, Atcherman concluded that home dialysis was a stressful event for the spouse of the patient.

Steltzer et al. (1976) in their sample of 16 married couples agreed that home dialysis is disadvantageous to spouses, who reported having less free time and mobility and increased responsibility. The presence of the dialysis machine served to remind them constantly of their situation. The impact of home dialysis on spouses was sufficient enough for the authors to conclude that they were less affected by the disease than the change in the marital relationship it affected. They recommended, as a result, that training programs for home dialysis given special attention to the spouses of patients in ESRD.

Smith et al. (1969) also concluded that the burden of home dialysis fell more heavily on the spouses of hemodialysis patients in describing a small number of spouses, 60% of whom identified psychological problems (primarily fatigue) and 25% of whom were recommended for psychiatric treatment. Complaints derived from the added work at home, increased responsibility, and continual tension. In an anecdotal report, Kaplan-DeNour (1970) attempted to start patients on home dialysis, assuming that it would be less stressful for the patient than in-center dialysis. There was patient resistance, however, due to the objective aspects of dialysis, attitude of the health care team, patient personality, attitude of the spouse, and the financial situation. The psychological complications for both patient

and spouse that developed after the initiation of home dialysis resulted in increased levels of stress and hostility.

When in-center dialysis is compared to home dialysis, many of the responses by spouses are the same. Maurin & Schenkel (1976) conducted an exploratory study to describe the intrafamily interactions of hemodialysis patients. Their sample consisted of 20 family units, 18 of which were married, 1 single, and 1 divorced. Seventeen of the participants were men and three were women; the mean age was 46.7 years. Eighteen were dialyzed in-center and two at home. Each family was interviewed using the Wells and Rubiner Conjoint Family Diagnostic Interview to obtain data on various aspects of family life. To quantify the information from the interview, the interviewer completed the Family Index of Tension. Results indicated that dialysis required role adjustments in all the families, especially with household tasks and social relationships. As the dialysis became an increasing focus of family life, families tended to become more socially and communally withdrawn. Spousal needs were met less often, as well, both by the family and spouse.

McGee (1981) has demonstrated that home dialysis is an added stress for the spouse of the patient and compromised the quality of family life. Fifty structured interviews were mailed to spouses of patients on hemodialysis or administered in person. Twenty-two of the patients were dialyzed in the hospital and 28 at home. The independent variable was location of dialysis; the dependent variables were satisfaction with the location, resentment of dialysis, pre- and post-dialysis marital happiness, and patient dependence on the spouse and others. Several hypotheses were proposed that related to adjustment of the family to dialysis in the hospital and at home. Spouses of home dialysis patients were expected to be less satisfied with

dialysis in the home, resent it more strongly, report lower levels of family functioning and marital happiness, perceive the patients to be more dependent, and report more negative behavioral changes in their children.

Results indicated that only two of the hypotheses were accepted at the .05 level of significance. Satisfaction with the location of dialysis was higher for hospital dialysis spouses than for home dialysis spouses, who found patients to be more dependent upon them. Although not significant, there was a trend that older female spouses in larger, happy marriages with fewer children made the best adjustment to dialysis. Regardless, McGee concluded that home dialysis was stressful for the spouse.

Steele et al. (1976), in a study of 17 patients dialyzing in-center and their spouses, sought to determine the relationship of dialysis-provoked depression to sexual functioning and marital discord. Ten of the patients were men and seven were women; their mean age was 46 years. Evaluation of marital status and sexual functioning was assessed by means of a self-administered questionnaire developed by the researchers. Psychological status was determined by the KDS-1 questionnaire. A high prevalence of sexual problems was reported, which the patients related to their level of depression and the spouses to the level of marital discord. The investigators considered marital discord to be high, even though it was rated as low by the patients and their spouses, conjecturing that the disease and its treatment surplanted any marital problems. It was concluded that, although the relationship among depression, sexual dysfunction, and marital discord was elusive, dialysis did increase sexual dysfunction for both patients and spouses.

A similar conclusion was reached by Finkelstein et al. (1976), who evaluated patterns of marital interaction and conflict in 17 in-center

and home dialysis patients by means of a standardized psychiatric evaluation form. Results indicated that the stress of dialysis on a marriage frequently did cause marital discord and sexual dysfunction.

Shambaugh et al. (1967) evaluated the emotional impact of hemodialysis on the spouse of the patient in ESRD both in-center and at home to determine the emotional disturbance of the spouse and, secondarily, their coping behaviors. The sample consisted of nine spouses who were trained in home dialysis, three who employed private duty nurses to operate the machine at home, and six who were married to patients utilizing in-center dialysis. These 18 spouses, 13 of whom were women, were interviewed one to three times over a 1-year period by a psychiatrist. At the same time, weekly meetings were conducted, although it was not indicated how they were managed or what tools were utilized. All three groups were represented in the meetings, but only nine spouses attended regularly.

It was found that spouses were stressed by multiple losses and frustrations, to which they responded with feelings of deprivation and hostility. Some developed regressive behaviors, serious depression, avoidance/denial reactions, and excessive closeness, which the authors defined as an infantile closeness that sometimes was excessive enough that the spouse had difficulty in leaving the patient's side. Spouses of patients on in-center dialysis, with one exception, demonstrated excessive closeness. They also had avoidance/denial reactions, the most common cause of which were the psychological regression and possible death of the patient. It is apparent from this study, and others, that dialysis, whether in-center or at home, can have a significant psychological and physiological impact on both patients in ESRD and their families and spouses.

Social support. The demands of hemodialysis may be such that they

require a reorganization and readjustment for the patient and family. How well this adjustment is made is, in large part, dependent on the spouse. Social support is one means of assisting in this adaptation to chronic illness (Cobb, 1970; Kaplan et al., 1977; Shanas, 1979; Shambaugh & Kanter, 1969; Winkes, 1983). Social support is a variable that has been shown to increase coping ability, moderate the effects of stress in life change events, and enhance health by reducing symptoms of illness and promoting one's sense of well-being (Cobb, 1976; Diamond, 1979; Kaplan et al., 1977; Nuckolls, Cassel, & Kaplan, 1972; Weiss, 1974).

The concept of social support, itself, has been variously defined, depending upon the author's perception of how individuals help and care for one another. Conceptually, Cobb (1976) has defined social support as "information leading the subject to believe that he is cared for and loved, esteemed, and a member of mutual obligation" (p. 300). Weiss (1974) perceived social support to be reflected in a combination of six categories of relational provisions: attachment, social integration, opportunity for nurturance, reassurance of worth, sense of reliable alliance, and the obtaining of guidance. Kahn (1979) described social support as the "interpersonal transactions that include one or more of the following: the expression of a positive affect of one person toward another; the affirmation or endorsement of another person's behavior, perceptions or expressed views; the giving of symbolic or material aid to another" (p. 85).

Although research related to social support has flourished in the literature, its conceptualization has been diffuse (Mitchell & Trikett, 1980; Roberts, 1984). A number of studies, for instance, have considered the relationship of social support to life change events (Cobb, 1976; Kaplan et al., 1973). Such studies include social support as it

relates to parents grieving over the death of an infant (Helmath & Steinitz, 1978), divorced family members (Kitson, Noir, & Masson, 1982), mothers with abused children (Salzinger, Kaplan, & Artemyeff, 1983), and the health care practices of married and single individuals (Hubbard, Muhlenkamp, & Brown, 1984).

Two studies of social support and life change events are considered to be classics in the literature and are reviewed more closely. The first, by Nuckolls, Cassel, and Kaplan (1972), explored the degree to which psychosocial assets are protective and how they relate to the detrimental effects of life crisis on the complications of pregnancy. A convenience sample of 340 white prima gravidas who had registered for obstetrical care before their 24th week of pregnancy was evaluated. The women all were less than 29 years of age; only 170 provided complete data after delivery. Three instruments were used to obtain data: a questionnaire to measure psychosocial assets, a schedule of recent experiences, and post-delivery medical records. Social support was identified by means of psychosocial assets, which were measured by a questionnaire designed to identify the subjects' feelings or perceptions concerning herself, her pregnancy, and her overall life situation, including relationships with her husband, extended family, and community. Life crisis was measured by a life change score calculated from the Holmes and Rahe Schedule of Recent Experience. It provided a summed score of life changes that occurred 2 years before the pregnancy and a second score for changes that occurred during the pregnancy. The questionnaire was mailed to the women during their 32nd week of pregnancy; the first questionnaire had been administered when the women registered for their obstetric care. The reliability and validity of the instruments were not presented.

On the basis of specific criteria developed for the study, each pregnancy was categorized as either "complicated" or "normal," a division that was accepted when it became apparent that there were no identifiable cluster patterns of complications in pregnancy. Chi-square tests indicated that there was no correlation between age, social class, educational level, and duration of pregnancy or between those subjects who completed the study and those who did not. Nor were there any significant differences between the two groups for the major independent variables. To test to what degree multiple life changes might be modified by psychosocial assets, a contingency table was formulated. It revealed that, when confronted with increasing life changes, women with high psychosocial assets had only one-third the complication rate of women whose assets were low. The authors concluded that, even though low psychosocial assets did not cause clinical disequilibrium in the face of life crisis, it did enhance susceptibility to environmental insult. The importance of this research is that it demonstrates that psychosocial assets do moderate the stress of life crisis.

A second classic study of social support and life change events is by Gore (1978), who conducted a descriptive longitudinal study to identify whether social support altered individual health status during a stressful life event such as job loss. The sample consisted of 54 rural and 46 urban men with a mean age of 49 years who had been terminated from their blue-collar jobs after at least 20 years seniority. There also was a control group of 74 men who were continually employed in comparable jobs during the same time period. All the men were interviewed at specific intervals in their homes by a public health nurse over a 2-year period.

Three variables were measured: stress, health, and social support. Stress was considered to be job change and economic deprivation.

Depression and self-blame were the dependent health variables and were measured by a 26-item index that inquired about anxiety, tension, self-esteem, and sadness. Illness symptoms also were measured by the number of physical complaints presented over a 2-week period from a list of 13 possible symptoms. Cholesterol levels were drawn at each visit. Social support, an intervening variable, was measured by a 13-item index that evaluated perceptions of whether wife, parents, and relatives were supportive or not. The reliability and validity of these instruments were not discussed.

Initial results indicated that social support did not decrease stress, and an analysis was conducted, therefore, to examine the pattern of health-related responses for supported and unsupported men over time. The sample was stratified into three groups, with specific criteria related to the level of social support and employment of each man. This resulted in consistent differences in the dependent variables by the degree of support and indicated to the author that social support did moderate the severity of psychological and health-related responses to unemployment. Perceived economic deprivation, for instance, was significantly associated with depression in the unsupported men ($\underline{r}$ = .58, $\underline{p} < .05$). Social support was shown to moderate the perception of economic deprivation and depression and, to a lesser degree, job termination. Supported men also reported lower levels of illness symptoms than did re-employed men. It was concluded that loss of a job when there is not a sense of self-worth maintained by a supportive relationship contributes to negative health responses. The implication of this study is that social support does moderate life crisis and may prevent altered health states and so enhance well-being. Without this buffering effect, there may be an exacerbation of life stress.

The conclusion that social support facilitates a positive response to stressful life events is one shared by other studies that have focused on social support as a moderator in health-illness situations, for example, as buffering depression in the disruption of social networks (Elmores, 1984), its relationship to medication dosage in patients with intrinsic asthma (de Aruja, Van Arsdel, Holmes, & Dudley, 1973), its effectiveness in an advocate in recovery from tuberculosis (Roth & Eddy, 1967), in the family for the elderly ill during visiting patterns (Shanas, 1979), and how it is perceived in the promotion of healthy life styles (Hubbard et al., 1984).

Two studies on the impact of health and illness on the family are particularly important and reviewed in detail. Fuller and Karlson (1981) conducted a correlational study to determine the extent adult sons and daughters perceived their parents as dependent and the effect that perception had with respect to personal autonomy, well-being, and other variables influencing the relationship. The theoretical basis for the study was that, if these middle-aged adults perceived their parents to be a source of stress, their well-being could be adversely affected, both physically and psychologically. Two hypotheses were proposed: that parental dependency was negatively related to the children's perceptions of autonomy and that this perception of autonomy and social support was positively related to well-being. Questionnaires were mailed to 150 adults; 44 were returned from 26 daughters and 18 sons, 80% of whom were married. Forty-one of the daughters were mothers, themselves, and three of the sons were fathers. Variables included personal autonomy, perceived parental dependency, social support, and well-being. Personal autonomy was measured by a 13-item personal autonomy scale developed by Gorden

that consisted of statements such as "generally make plans on my own." Responses were scored from 0 to 4, the higher numbers indicating greater autonomy. Although the authors indicated that the scale had face validity, no other evidence of validity or reliability was presented.

Perceived parental dependency was measured by a 4-item dependency scale developed for the study. Four questions addressed whether the parents were physically, mentally, financially, and generally dependent, and scored responses from 0 to 4, reflecting a range from no perceived dependency to total dependency. Social support was measured by a 2-part questionnaire on the children's perception of support from the social environment. The first part was a 9-item family cohesion subscale of the Family Environment Scale, which was used to identify whether family members did help and support one another. Responses were summed, with a possible score from 0 to 9. Test-retest reliability was .86, with an internal consistency coefficient of .78; no evidence of validity was reported. The second part was a 12-item modified version of an emotional support scale that had been developed by one of the authors to identify childrens' perceptions of emotional support from health care professionals. Items included referred to such inferents as "listen to you" and "reassure you." It had a coefficient alpha of .88, which was considered to be satisfactory.

Well-being was measured in three dimensions: physical, psychological, and social. Physical well-being was determined by a 5-item questionnaire on the health status of the individual. Items included perceptions of health status at present and 1 year earlier, number of visits to a physician for personal illness, number of prescriptions or over-the-counter medications currently being taken, and how the responsibility of caring for their parents affected health status. The reliability and validity

of this instrument was not indicated.

Psychological well-being was measured by a 48-item checklist of the Multiple Affect Adjective Checklist that measured anxiety, depression, and hostility. The reliability of this checklist was considered to be the same as the scale from which it was taken. Internal consistency coefficients in normal subjects ranged from .74 to .81 for anxiety, .91 to .92 for depression, and .80 to .90 for hostility. The anxiety and depression scales showed high validity in patients and normal subjects; the hostility scale had high validity only in normal subjexts. Subjects were asked to think about their responses in caring for their parents and to check the words that best described their feelings; scores ranged from 0 to 10 for anxiety, 0 to 24 for depression, and 0 to 14 for hostility. Social well-being was measured by two subscales of the Sickness Impact Profile: social interaction (20 items) and leisure and recreation (8 items). Validity coefficients for the tool ranged from .49 to .61; the test-retest reliability was .88, and the individual subscale reliability coefficients from .62 to .90. Scoring ranged from 0 to 100; however, this standard was changed in order to better assess for changes in well-being that resulted from caring responsibilities.

An open-ended questionnaire completed the data collection and permitted the subjects to indicate why they felt that they could be depended upon and what services were available to them in caring for their parents. A correlational analysis between variables was conducted, and results indicated that subjects who perceived parental dependency as low rated their own personal autonomy, social support, and sense of well-being as high. Children of elderly parents who perceived high parental dependency rated their personal autonomy as low. The first hypothesis, therefore, was

supported. There was no relationship, however, between personal autonomy and the physical component of well-being, although there was a significant relationship between personal autonomy and well-being anxiety, $r(42) = -.39$ and well-being depression, $r(42) = -.30$. Also significantly related to well-being was family cohesiveness: anxiety, $r(42) = -.45$, $p < .01$; depression, $r(42) = -.48$, $p < .01$; hostility, $r(42) = -.36$, $p < .05$.

A hierarchical multiple regression design was used to test the interaction of personal autonomy and social support, and each dimension of well-being was analyzed twice, first with family cohesiveness as a measure of social support and then with professional emotional support. In each analysis, personal autonomy and social support were entered in the same order, with the interaction between personal autonomy and social support measured last. Results demonstrated that family cohesiveness as a measure of social support was the strongest variable for each dimension of well-being. Social support mediated by family cohesiveness did help the family cope with the responsibilities of caring for an aged or ill parent.

A second important study on the impact of health and illness on the family was conducted by Fengler and Goodrich (1979). Their exploratory study examined the special needs of wives whose husbands were chronically ill or disabled, their hypothesis being that wives were equally as needy as their husbands. The sample of 34 was chosen from a volunteer workshop evaluation study of older handicapped men who had been randomly assigned to the workshop project as a control group and followed over a 6-month period. The husbands ranged in age from 65 to 85 years, with a mean age of 73; their wives were aged 59 to 81 years, with a mean of 67. Approximately 80% of the men suffered from cardiac disabilities, which affected their mobility and ability to communicate (asphasia).

Data were collected by means of a semi-structured interview administered by senior nursing students utilizing the Life Satisfaction Scale, A and B. The reliability and validity of the instrument was not discussed but cited in a reference. An average score for each participant was calculated and ranked. Results indicated significant correlations between the high-scoring husbands and high-scoring wives, as well as between the low-scoring husbands and wives. After further investigation, five coping supports were identified and categorized, including health and income, role overload, intimacy and companionship, isolation, and social support. All of the categories, except social support, indicated similarities between the high and low groups. In the social support category, the high group tended to have a greater amount of social support than the low group. Families in the high group found social support to be both expressive and instrumental in nature and freely and frequently expressed. When compared to a national survey that had used the Life Satisfaction Scale, the individuals in this study had lower mean scores than even the low income or very old elderly in the national sample.

The researchers concluded that, since the life satisfaction scores of husband and wife significantly correlated and social support reflected more in the high group, the patient-husband could be indirectly benefited if the wife could be helped in establishing a form of social support. The significance of this study is that it is one of the few to correlate positively high life satisfaction with social support in the presence of chronic illness.

In summary, these studies on social support imply that advanced age or illness can be a source of stress within the family system that is manifested in physical symptoms that can threaten the well-being of healthy

family members. One effective coping pattern in responding to this stress in the family is social support, which suggests that nursing should provide and enhance social support for family members, especially spouses. Such support would improve well-being and so reduce the threat to the health status of the family and spouse.

Social support and hemodialysis. As useful as social support has been demonstrated to be in facilitating the well-being of the family and its individual members, relatively little has been written on the social support of the hemodialysis patient or the patient's family. There have been some studies, however. MacElveen (1972) investigated the adaptive outcomes of patients on home dialysis and found that the components of social support (trust, common goals, means consensus, and mutuality of respect) were positively related to adherence to the medical regimen, activity, and morale. A study by DeNour and Czaczkes (1976) on the influence of personality on adjustment to dialysis indicated that an outlet for releasing feelings about the dialysis, for instance, a social worker or psychiatrist, was important in the adjustment of the patient. Foster and McKegney (1978) and Abrams et al. (1971) have conducted studies on suicide and survival rates of patients on dialysis and concluded that family support did enhance the survival rate among patients. Olsen (1983), in a statistical review of variables that predict patient adjustment to hemodialysis, confirmed that family functioning and support were positive predictors of adjustment. In the absence of such familial support, self-help groups were found to be invaluable. Compliance has been another variable shown to be positively associated with social support (O'Brian, 1980b; Pentecost, Zwerenz, & Manuel, 1976).

A recent study by Hilbert (1985) sought to determine whether higher

levels of social support positively correlated with higher levels of compliance. The sample consisted of 26 dialysis patients (17 women and 9 men) who had been in treatment for an average of 4.5 years. Subjects ranged in age from 22 to 72 years, with a mean age of 46.9. Fifty-eight percent were married, 15% had not married, and the remainder were divorced, separated, or widowed. Social support was measured by two subscales: an 8-item directive guidance factor that dealt with providing information and directions to the patients, and a 4-item affection factor that dealt with physical and verbal expressions of caring that had been developed from the Inventory of Socially Supportive Behaviors. Reliability of the subscales was .867 and .835, respectively. There was felt to be sufficient content validity in that the behaviors described in each factor were consistent with the psychological support categories of guidance and intimate interaction. Compliance was measured on a self-reporting Likert scale in relation to diet, fluid intake, and medication over an average period of 3 months. Physiological compliance were weight gain, serum potassium, and phosphorus. All subjects completed a demographic questionnaire, the social support questionnaire, and the compliance rating scale; physiological measures were taken from the patients' medical records.

Results indicated that dietary and fluid compliance were significantly correlated ($p < .002$), as were medication and fluid compliance ($p < .05$) for self-reporting and physiological compliance. A total compliance score, therefore, was used as the only measure of compliance. Fifty-eight percent identified their spouse as the most important person for social support, and the same percentage of the sample were married. Other family members or a same-sex friend were named by others in the sample. Pearson's correlation was used to determine the relationship between social support

and compliance. Total scores for social support, the two factors in relation to the total score for compliance, were correlated to be .415 (p =.017) and -.129 (p =.266), respectively.

It was concluded that the hypothesis was supported but only for the directive guidance factor. When demographic and illness variables were analysed, they were found to be insignificant. Only length of time on dialysis showed a significant negative relationship ($p<.05$) between total compliance and those patients who had been on dialysis for 5 years or longer. This study supports others that concluded that social support does have an impact on patient compliance to hemodialysis and that, more specifically, such support from a person who is important to the patient is influential in promoting compliance.

To more clearly demonstrate the impact of social support on the patient, Dimond (1979), in a descriptive study, investigated the relationship between social support and adaptation to chronic hemodialysis. The sample consisted of 36 patients (22 men and 14 women), one half of whom had been dialyzed at home, the other half in-center for 5 to 66 months, with a mean of 32 months. They ranged in age from 22 to 77 years, mean 46 years; 27 were married, 5 single, and 4 widowed.

The purpose of the study was to examine the relationship between three sources of social support (spouse, family, and confidant) and adaptation to chronic hemodialysis as measured by morale and changes in social functioning. Social support was measured using the indicators of family support, spouse support, and the presence or absence of a confidant. Two subscales of the Family Environment Scale developed by Moos and Insel were used to determine supportive interpersonal relationships among family members. The family cohesion subscale consisted of nine items measuring

helpfulness and supportive behavior in family members; the family expressiveness subscale was nine items that measured encouragement and open expression of feelings within the family. Test-retest reliability for expressiveness was .73 and for cohesiveness, .86. Validity was not discussed.

Spousal support was measured by a 10-item 5-point scale developed for the study. Items related to spouse encouragement, sensitivity, availability, and involvement in patient care. Reliability was estimated at .70, with an item-total correlation from .64 to .90; coefficient alpha was .93. Validity for the scale was not indicated. Scores could range from 10 to 50, with the higher scores reflecting greater spousal support. To measure the presence or absence of a confidant, subjects were asked to respond either "yes" or "no" to whether there was anyone in particular with whom they talked or confided about themselves or their problems. Adaptation was measured using two indicators: morale and change in social functioning since the onset of dialysis. Morale was measured by the MacElveen 17-item 5-point behavior-morale scale. Items reflected posture, body attitude, facial expression, speech, verbalization, and general attitude. A single score was generated by summing individual scores on each item; they ranged from 17 to 85, with the higher scores indicating higher morale. Total item correlation was from .45 to .79, with an alpha coefficient of .95. Reliability was estimated, based on the analysis of internal consistency. Changes in social functioning were measured by three subscales of the Sickness Impact Profile: household management, leisure and recreation, and social interaction. Test-retest reliability of the instrument was .88, with .62 to .90 on the subscales; validity was established at .49 to .61. A percentage score was generated for each subscale and for the total scale; the higher this percentage, the greater the change in social

functioning. Medical status was measured by the number of medical complications that were secondary to ESRD. Data were collected by four methods. Each patient was interviewed for demographic data and the presence or absence of a confidant. Morale level was assessed at the same time by the principal investigator, although exactly how this was done was not indicated, and spousal support assessed by a specially trained nurse. A review of the patients' medical records by the principal investigator provided the approximate number of medical problems over a 6-month period. Results were determined by Pearson's correlation.

It was found that each social support scale was positively and significantly related to morale (family cohesion .44, $p < .01$; spousal support .44, $p < .01$; confidant .31, $p < .05$). Family expressiveness related most significantly, .55, $p < .01$. Family cohesion and availability of a confidant showed a significant negative correlation with changes in social functioning (-.54 and -.40, respectively, $p < .01$), which indicated that greater cohesiveness and confidant availability were associated with fewer changes in social functioning since dialysis began. Family expressiveness and presence of a confidant also were significantly related to a number of medical problems (-.33 and -.41, respectively, $p < .01$), which indicated that increased family expressiveness, presence of a confidant, and higher morale were associated with fewer medical problems, and that more changes in social functioning were associated with more problems.

Dimond concluded that family cohesiveness was indicated to be a primary source of support for dialysis patients. Specific aspects of social support contribute to adaptation, and further research is needed to operationally define and measure these multiple dimensions of social support. This relationship between spouse support and morale of the

dialysis patient is consistent with previous studies (MacElveen, 1972) and demonstrates that social support does affect patient adaptation to dialysis.

A study by Maurin and Schenkel (1976) also confirms that the level of family support influences the patient's physical well-being and experienced emotional conflicts. Its purpose was to explore and describe the intra-family interactions of hemodialysis patients. All family units had a significant other living with them; 18 were married, 1 divorced, and 1 single; the mean length of time married was 21.9 years. Seventeen of the subjects were men, and 3 were women; 18 were dialyzed in-center and 2 in home training programs. Their mean age was 46.7 years. All the families were interviewed using the Wells and Rubiner Conjoint Family Diagnostic Interview, which measures various aspects of family life, including performance, finance, and assignment of responsibilities. To quantify this information, the interviewer completed the Family Index of Tension, which identified 15 variables of family/patient interaction, e.g., affect regarding patient problem, family members' ability to satisfy patient needs, degree of involvement with others, and perception of role enactment.

Although results indicated that the majority (18) of families felt a positive sympathy for the patient, all families reported that the situation required readjustment, primarily in the areas of household tasks and social relationships. There was a suspicion that some tension existed between spouses, which the researchers recommended be confirmed by individual interviews with each spouse that then could be compared. Seventeen families reported that their social world had narrowed due to a lack of energy on the part of the patient, although both patient and spouse did tend to be involved with one another. In five situations, the patient was perceived by the spouse to perform poorly; most patients, on the

other hand, regarded their spouse as "good" or "very good" in their willingness to help. Although the number was not specified, spouses expressed the feeling that they had to put aside their own needs so as not to burden the sick member. In that sense, the dialysis patient exercised considerable control in the family. There was little overt communication between members and even less with the children of the family. Families were socially withdrawn and, instead, lived a patient-centered existence. The conclusion of the study was that the family was the primary source of the social support that was so important in the dialysis patient's adjustment to treatment. Although there was considerable family support for the patient in ESRD, the patient was not always able to provide that support, particularly to the spouse, in turn.

Social support of the family and spouse. Although the literature indicates that the social support of the family and spouse moderates the stress of the hemodialysis patient, there is less presented on the support of the spouses of patients in ESRD. One study that does mention the emotional impact of hemodialysis on the spouse is Shambaugh et al. (1967), who reported that group discussions provided a source of support and adjustment for many spouses. This theme was considered more extensively in a later study by Shambaugh and Kanter (1969) in an investigation of group meetings on the spouses of patients on hemodialysis.

The sample consisted of 12 spouses and the parents of an adolescent boy; nine were women and 5 were men. Three patients dialyzed at home and 10 in-center. Six of the spouses met consistently for 8 months at 1 hour, 15 minute meetings. These sessions were taped and transcribed, and all but four of the participants were interviewed from 6 months to 1.5 years later. Upon initiation of the series, spouses were told that the meetings

were to be investigative and supportive of machine operation. The acutal outcome of the meetings, however, was to help the spouses find a common ground between denial and despair. Behaviors were observed and a number of stresses observed, including the severe medical complications of the dialysis patients, their possible death, and regressive behaviors. Spouses were observed to respond to these stresses with intense feelings of deprivation, excessive psychological closeness, and strong hostility, which often lead to attendant feelings of guilt. Spouses who operated the dialysis machines had fantasies of destroying their partners and responded to their feelings of anxiety, depression, and guilt with a variety of defenses, particularly denial. Renal transplantation was imagined to be a solution to the stress of dialysis. During the course of the meetings, spouses eventually were able to separate themselves psychologically from their partners and grieve in the recognition that the relationship had changed as a result of dialysis. The conclusion of the study was that small on-going group discussions can provide a mechanism for the social support of spouses of patients on hemodialysis.

In summary, this literature review has identified the nature of chronic illness, specifically ESRD and its treatment, and the impact that hemodialysis has on the family and spouse of the patient. Although the relationship of social support to various life change events and health/illness situations has been researched extensively in the literature, there is a lack of research evidence that demonstrates how spouses of patients in ESRD on hemodialysis perceive social support and how that support affects their sense of well-being. Anecdotally, it has been shown that social support does promote the adaptation of the family and spouse to ESRD (Brinker & Lichtenstein, 1981; Paradiso, 1983; Winkes, 1981).

Chapter 3

Methodology

This study addresses the following research questions:

1. What are the perceived sources of social support of spouses of patients undergoing in-center hemodialysis?

2. What is the relationship of the spouses' perceived social support to their sense of well-being?

3. What is the relationship between the dependent variables of social support and well-being to the demographic characteristics of the spouse, spousal illness, and length of time married?

4. What is the relationship between social support and well-being to the patient's presence during the interview with the spouse?

5. What is the relationship between social support and well-being to the number of years the patient has been on hemodialysis?

6. How do the spouses of hemodialysis patients perceive their situation in living with a chronically ill mate?

7. What are the emotional reactions of spouses living with a mate on hemodialysis?

8. What strategies do the spouses of patients on hemodialysis use to support themselves?

9. How do the spouses of patients on hemodialysis define social support?

10. Would spouses of hemodialysis patients utilize a resource person if one were available?

11. Would spouses of hemodialysis patients participate in a spouse-only social support group if one were available?

Definition of Terms

Chronic illness. "All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care" (Strauss & Glaser, 1975, p. 1). Chronic illness is to be determined by whether the patient is in ESRD and has utilized hemodialysis for 1 year or more.

Social support. "Interpersonal transactions that include one or more of the following: the expression of a positive affect of one person toward another; the affirmation or endorsement of another person's behavior, perceptions or expressed view; the giving of symbolic or material aid to another" (Kahn, 1979, p. 85). Social support is measured by the Norbeck Social Support Questionnaire (NSSQ), which evaluates the individual's perception of the value of the functional characteristics of social support, affect, affirmation, and aid; and the network or structural characteristics of social support, which include stability, availability, and duration of listed network members.

Well-being. Well-being is a bipolar measure of mental health that can be classified on a continuum between positive and negative states, the components of which are psychological distress, which comprises anxiety, depression, and loss of behavioral/emotional control; and psychological well-being, which is comprised of general positive affect and emotional ties (Ware, Johnston, Davis-Avery, & Brook, 1979). Well-being is evaluated by the Mental Health Index component of the Rand Health Insurance Study, General Well-Being Questionnaire (cited in Ware et al.,

1979).

Spouse. A spouse is defined as one who has been legally married to a patient on hemodialysis for at least 1 year.

Patient. A patient is one who is in ESRD and has utilized in-center hemodialysis as a treatment modality for a minimum of 1 year.

Spousal illness. Spousal illness is any medical problem identified by the spouse.

Employed. Employed is defined as one who receives pay for work outside the home.

Design

This naturalistic study has both quantitative and qualitative components. A descriptive survey design was used to determine the spouses' perceived sources of social support and the influence of that support on their sense of well-being. An exploratory descriptive design was used to identify how the spouses defined social support and to examine how social support influenced their sense of well-being.

Sample

The sample consisted of 23 adults ranging in age from 35 to 82 years, with a mean of 60. Nine were men and 14 were women. Thirteen were identified as white, 7 as black, and 3 as "other" (2 Hispanic and 1 Filipino). Couples have been married from 11 to 55 years, with a mean of 35. Educational level ranged from 5th grade to a completed master's, with a mean of 12th grade. Patients have been on dialysis from 1 to 14 years, with a mean of 5. (see Table 1).

Instruments

Four instruments were used in the collection of data, three questionnaires and an unstructured interview.

Norbeck Social Support Questionnaire (NSSQ). The NSSQ is a self-reporting questionnaire that takes approximately 10 minutes to complete. It is based on Kahn's (1979) conceptualization of social support, which is directed at how much affect, affirmation, and aid is derived from a set of network members at any point in time. The Norbeck instrument has three components: total function, which measures affect, affirmation, and aid; total network, which includes the number in the network and the availability and duration of the relationships; and total loss, which measures the number of categories of persons lost and the amount of provided support lost (Norbeck, Lindsey, & Carrieri, 1981). Test-retest reliability for the NSSQ was established through a study of each functional and network property item on a group of graduate nursing students (range .85 to .95). Using inter-correlations, internal consistency also was evaluated for all items. Correlations were high and ranged from .89 to .98, except for aid items, which ranged from .69 to .80, and loss items, which ranged from .54 to .68. To determine the response bias in establishing validity, a short form of the Marlow-Crowne Test of Social Desirability was administered concurrently with the NSSQ. The NSSQ was not significantly related to this socially desirable measure (range .01 to .17), which suggests that the NSSQ is free of a socially desirable response bias (Norbeck et al., 1981).

Construct validity was determined by questionnaire packets mailed to 500 randomly selected staff employees at a large medical center (Norbeck, Lindsey, & Carrieri, 1983). One hundred thirty-six were returned, representing the responses of 47 men and 89 women, 42% of whom were married and the mean age of which was 35.8 years. A correlation was done between the NSSQ and the Functional Interpersonal Relations Orientation

(FIRO-B) developed by Schultz (1978). The FIRO-B consists of six 9-item subscales that measure the "expressed" and "wanted" components of each of three interpersonal needs: inclusion, affection, and control. The test-retest and reproducibility of the subscales are high (.76 and .94, respectively). There are statistically significant correlations between this instrument and the NSSQ for the constructs of need for inclusion and affect. Correlation between the NSSQ and the construct of need for control was not significant, which indicates that the interpersonal needs of inclusion and affection are related to available social support and that need for control is not (Norbeck et al., 1983).

Concurrent validity of the NSSQ has been tested with the Personal Resource Questionnaire (PRQ) developed by Brandt and Weinet (1981) and based on Weiss's conceptual model. It has two parts: an examination of an individual's resources and a measurement of five relational dimensions. The second part has high levels of internal consistency and lower levels of predictive validity. Both instruments were administered to 55 female graduate students, 87.3 of whom were white, with a mean age of 32.9 years. There was a significant, but low, correlation between the network properties of the NSSQ and the PRQ and a medium correlation between the functional components of the two instruments (Norbeck et al., 1983).

Predictive validty was examined to determine whether social support buffered the psychological effect of life stress. The same graduate students were administered two tests: the Life Experiences Survey, which measures life stress and has a test-retest reliability of .56 to .88 and validity that significantly correlates with other stress-related measures; and the Profile of Mood Status, a 65-item scale that measures anxiety, anger, depression, vigor, fatigue, and confusion, and has a test-

retest reliability of .65 to .74 and an internal consistency of .90. When subscales of the NSSQ were analyzed on a hierarchical multiple regression, results demonstrated that negative mood had a strong relationship to life stress (Norbeck et al., 1983).

In a follow-up study, the NSSQ was examined for sensitivity and stability over time. The instrument was mailed to 75 entering graduate students, of whom 44 responded (all were women, with a mean age of 30.9 years), and again 7 months later. For each NSSQ subscale and composite variable, paired t-tests were calculated. Results indicated a moderate-to-high correlation between first and second testing for subscales and variables, ranging from .58 to .78. As predicted, only network composition changed and not the actual number of persons listed in the network (Norbeck et al., 1983).

Mental Health Index (MHI). The MHI is a self-reporting questionnaire that takes approximately 10 minutes to complete. It measures mental health based on a continuum that represents the assessment of positive and negative states (Ware et al., 1979). Its two scales, Psychological Distress and Psychological Well-Being, are divided into subscales, distress being defined by the constructs of Anxiety, Depression, and Loss of Behavioral/Emotional Control; and well-being by General Positive Affect and Emotional Ties. An overall score comprised of both scales, and one item evaluating Life Satisfaction, are identified as the Mental Health Index (MHI). The MHI measures general well-being in the present study (see Figure 1).

The focus of the MHI is the psychological symptoms of mood and anxiety disorders, although there is an attempt to assess disorders related to loss of control. The instrument has 47 questions, 13 of which measure

anxiety, 19 depression and positive well-being, 3 self-control, 3 emotional ties, and 1 life satisfaction. Thirty-eight of these questions elicit information "during the past month." Another eight questions estimate socially desirable response sets, which are based on a diverse sample of beliefs and behaviors, and endorse or negate items regardless of content on MHI scores.

Each subscale includes such items as the following:

Anxiety: "How much of the time during the past month did you feel relaxed and free of tension?" "How much of the time during the past month have you felt calm and peaceful?"

Depression and Positive Well-Being: "During the past month how much of the time have you generally enjoyed the things you do?" "During the past month how often did you feel that you had nothing to look forward to?"

Self-Control: "During the past month have you been in firm control of your behavior, thoughts, emotions, feelings?" "During the past month have you any reason to wonder if you were losing your mind or losing control over the way you act, talk, think, feel, or of your memory?"

Emotional Ties: "How much of the time have you felt lonely during the past month?" "During the past month how much of the time have you felt loved and wanted?"

Life Satisfaction: "How happy, satisfied, or pleased have you been with your personal life during the past month?"

Socially Desirable Response Set: "In choosing your friends how important to you are things like their race, their religion, or their political beliefs?" "How often have there been times in your life when you felt you acted like a coward?"

There are 11 different types of response scales, excluding those for socially desirable items. The most frequently used scale, used in 19 of the 38 items, consists of six choices, ranging from "all of the time" to "none of the time." Most of the items associated with this response scale seek to determine "how much of the time" specific symptoms are experienced. For 10 of the items, the scale includes six choices, ranging from "always" to "never." The remaining nine items are associated with a specifically tailored response scale.

The MHI is a highly reliable and valid tool for the the examination of well-being. In testing a sample of more than 1000 individuals, internal consistency reliability on the overall MHI score has been demonstrated to be .90 and test-retest reliability .77 at 1 to 4 weeks and .5 at 1 month. Construct validity is .5, and correlations between the MHI subscales and a number of other validity variables (e.g., stress at home and work) are significant (range .16 to .41), with reliability estimates for construct-specific scales and the MHI exceeding .5. Because of this strong association of subscales, the overall MHI score was developed. Scoring high on the MHI demonstrates the achievement of self-control, high levels of positive well-being, and the absence of extreme symptoms of anxiety and depression during the previous month. Likewise, low scores refer to a mix of frequent symptoms of depression/anxiety and the loss of control over behavior, thoughts, and feelings. Extreme scores on the MHI can be interpreted directly; however, most respondents in the general population are within extremes (range 62 to 226), making it more difficult to score.

In this mid-range there is a trade-off between the simple MHI score and the information likely to be gained from the construct-specific scores.

Scoring and interpretation of each specific construct on the MHI, consequently, has been done separately because the most predictive scales differed, depending on the category of the variable. For example, anxiety has been identified as the most predictive of stress-related variables, depression of financial problems, and positive well-being of work enjoyment. MHI groups can be correctly understood only when the construct-specific scales are scored and interpreted separately. Any one of these scales has the potential to significantly alter the overall MHI score.

Demographic questionnaire. A demographic questionnaire was developed for the present study that includes questions related to the subjects sex, age, ethnicity, marital status, length of time married, religion, educational level, occupation, and current illnesses (see Appendix A). There also are three questions on the patients' occupation and educational level and six on the patients' renal disease, e.g., onset of disease, initiation of dialysis, other patient illnesses, prior chronic ambulatory peritoneal dialysis or kidney transplant. The instrument was not test for reliability or validity.

Interview. Data regarding the influence of social support on the well-being of spouses whose mates were on chronic hemodialysis were collected (see Appendix B). The focus of the interview questions included the following: a definition of social support, sources of social support, feasibility of independence, altered feelings of helplessness/hopelessness, feelings of depression or isolation, financial constraints or capabilities, alteration in mental or physical status, responses of other family members, assistance in the activities of daily living, alteration in one's basic belief system. The interview concluded with specific questions on whether the subject would attend a support group for husbands

and wives of patients on chronic hemodialysis, were one available, and whether the subject would utilize a resource person.

Procedure

A convenience sample was selected from three dialysis units according to the following procedure: The head nurse of each dialysis unit was contacted by phone and permission obtained to utilize the unit. Each head nurse, in turn, obtained verbal consent from the medical director of the facility prior to initiation of the study. A list of married patients then was obtained from each head nurse and, in one unit, from the social worker. Listed spouses who met the criteria of the study were called to confirm an interview at a mutually agreed upon time. A follow-up call was made to verify the appointment. In two of the units, patients were given a brief description of the study prior to their spouses being called.

Over a 12-month period, 23 interviews were conducted by the investigator in the homes of the subjects, each lasting from 3 to 5 hours and recorded by notes taken during the interview. Eighteen were held with the subject alone, and 5 with the patient or other family member present. A written consent form was obtained from each subject that indicated the potential risks of the study, its independence from any therapeutic interventions, the time involved, and the maintenance of confidentiality. It also was indicated that participation was voluntary and that the subjects were free to withdraw at any time (see Appendix C). These aspects were reinforced verbally, as well. The phone number of the investigator was provided in the event that the subjects had any questions or comments; none did, however. Administration of the instruments consistently was the same: demographic, MHI, NSSQ, and interview. All subjects offered additional information about themselves and their spouses while completing

the questionnaires. (There is a variation in sample size because one subject did not answer a question on one of the questionnaires.) Only instructional information concerning the completion of the instruments was provided, with the exception of Question 10 on the MHI, which states "In general would you say your morals have been beyond reproach?" Many of the subjects did not understand the word "reproach," which was defined for them as meaning "Your morals are the best they can be."

Chapter 4

Results

The findings presented in this chapter are arranged according to the questions proposed and divided into two sections: the quantitative results of the study, which are presented under Questions 1 through 5, and the qualitative results, which are presented under Questions 6 through 11.

What are the perceived sources of social support of spouses of patients undergoing in-center hemodialysis? Mean percent scores for each NSSQ network category for every subject were determined from responses on that questionnaire (see Table 2). The spouses' perceived source of social support was derived primarily from the Family or Relatives category of the NSSQ. The mean percent for this category was 61.12% (range 39.83% to 82.40%), which is considerably higher than that for any of the other social support categories (range 0 to 11.69%). The implication is that approximately 61% of the total sample identified their main perceived source of social support to be family or relatives, as determined by the number listed in each support category. The second most significant perceived source of social support was identified as the Friends category, with a mean of 11.69%. The Spouse or Partner category ranked third and had a mean of 8.51%.

The variable of functional support indicates the quality of a relationship and is defined by the subscales of Affect, Affirmation, and Aid. Average functional support for each relationship category was computed to determine the quality of the spouses' perceived social support. Those subjects who listed their spouse or partner as supportive (n = 17) also ranked them as highest in quality of support. The average functional

support score for the category of Spouse or Partner was 20.7 out of a possible score of 30, with a range of 17.28 to 24.12 (see Table 3). While 22 subjects identified Family or Relatives as the greatest proportion listed in the network for social support, the average functional support score for that category was rated 17.4 out of a possible score of 30, with a range of 14.2 to 20.6. This is less than that for Spouse or Partner and indicates that those subjects who listed their spouses as supportive found them to be more supportive than those individuals listed in other relationship categories. Twelve subjects identified the Friends category as supportive, the mean score of which was 18.75, with a range of 15.54 to 22.51. Mentioned by only two subjects each, the mean scores for Health Care Providers and Minister, Priest, Rabbi were the next highest, with scores of 18.50 and 18.25, respectively. Neighbors were listed by seven subjects; the mean score was 15. For Work/School Associates, identified by four subjects, the mean also was 15.

What is the relationship of the spouses' perceived social support to their sense of well-being? The Pearson correlation coefficient was used to determine the relationship of social support to well-being; more specifically, a correlation matrix demonstrated that the seven subscales of the NSSQ were correlated with the MHI (see Table 4). There was a significant negative correlation between Affirmation, Aid, and Total Functional Support on the NSSQ with Anxiety, Depression, and Psychological Distress as measured by the MHI (r = -.375 to -.442, $p < .05$). When affirmation, aid, or total functional support are reduced, symptom levels of anxiety, depression, and psychological distress increase. There also was a significant negative correlation of Aid with Loss of Behavioral/Emotional Control (r = -.372, $p < .05$), which demonstrates that when aid

is decreased, there is a corresponding increase in loss of control.

Psychological Well-Being was positively correlated with the social support subscales of Affect (r = .426, p<.05), Affirmation (r = .488, p<.01), Aid (r = .435, p<.05), Total Functional Support (r = .464, p< .01), Total Network Properties (r = .352, p<.05), and Number in Network (r = .357, p<.05), which suggests that psychological well-being is increased as social support is strengthened. This notion is enforced by the fact that General Positive Affect positively correlated with all social support subscales except Total Loss (r = .419 to .531, p<.05). There were no significant correlations between well-being variables and the social support subscale of Total Loss or between social support subscales and Emotional Ties and Life Satisfaction. The overall MHI score, which represents general well-being from both positive and negative perspectives, was significantly and positively correlated to four social support subscales: Affect (r = .386, p<.05), Affirmation (r = .450, p< .05), Aid (r = .447, p<.05), and Total Functional Support (r = .439, p< .05). The correlation between well-being and social support was supported as well by the moderately negative correlation between Psychological Distress and the subscales of Affirmation (r = -.400, p<.05), Aid (r = -.442, p<.05), and Total Functional Support (r = -.391, p<.05) and between Depression and these same subscales (r = -.407, p<.05; r = -.424, p<.05; r = -.379, p<.05, respectively). Psychological distress and depression increase as there is a lessening of aid, affirmation, and total functional support.

What is the relationship between the dependent variables of social support and well-being to the demographic characteristics of the spouse, spousal illness, and length of time married? A comparison of group means

utilizing separate variance t tests was conducted on the categorical variables of Spousal Employment, Spousal Illness, Race, and Sex; the Pearson correlation coefficient was conducted on the continuous quantitative variables of Age and Length of Time Married. For the variables of Spousal Employment, Spousal Illness, and Race, there were no significant comparisons of group means on either the MHI or NSSQ (see Tables 5 through 10).

Although there was not a significant comparison of group means for the variable of Sex with the social support variables of the NSSQ (see Table 11), there was one with the MHI. As presented in Table 12, the women in the sample demonstrated significantly higher levels of Anxiety ($p = .0002$), Loss of Behavioral/Emotional Control ($p = .003$), and Psychological Distress ($p = .002$) than did the men, who also showed significantly higher levels of Life Satisfaction ($p = .03$) and Psychological Well-Being ($p = .03$). Scores on the overall MHI confirmed that, for this group living under the same circumstances, the men had a better sense of general well-being than did the women ($p = .003$).

As shown in Tables 13 and 14, there were no significant correlations of Age with the NSSQ, although this variable did significantly and negatively correlate with the Emotional Ties subscale of the MHI ($r = -.467$, $p = .02$), which suggests that older spouses have fewer emotional ties. This is consistent with the notion that one's support system, itself, ages and eventually dies, as does the individual. Length of Time Married (see Tables 15 and 16) was significantly and negatively correlated with the social support subscale of Total Functional Support ($r = -.423$, $p = .03$), which consists of Affect ($r = -.379$, $p = .04$), Affirmation ($r = -.445$, $p = .02$), and Aid ($r = -.355$, $p = .05$). This is confirmed by Total Network Properties ($r = -.369$, $p = .05$) and Number in Network ($r = -.394$,

p = .04) scores. The longer the spouse was married, the less support, the less positive affect, the less affirmation, and the less aid from others. If social support does diminish with increased length of time married, it is not certain why there was no significant correlation between Length of Time Married and well-being.

What is the relationship between social support and well-being to the patient's presence during the interview with the spouse? The variable Patient Present during the Interview was defined as whether the patient was present or absent during any part of the interview with the spouse. Eighteen patients were not present and five were. When group means for this variable were compared with the NSSQ, only the Total Loss subscale was significant (p = .05), which suggests that those spouses with a patient absent demonstrated a greater sense of loss than those for whom the patient was present (see Table 17). When group means for the same variable were compared to the MHI, significantly higher levels of Anxiety (p = .04), Depression (p = .04), Loss of Behavioral/Emotional Control (p = .004), and Psychological Distress (p = .04) were demonstrated for those spouses whose mates were absent (see Table 18). Those spouses who requested their presence during the interview, on the other hand, demonstrated higher levels of General Positive Affect (p = .04), Emotional Ties (p = .0001), Life Satisfaction (p = .0007), and Psychological Well-Being (p = .009). These results suggest that those spouses who interviewed with the patient present have a better sense of well-being than those who did not; this was confirmed by the Mental Health Index (p = .01).

What is the relationship between social support and well-being to the number of years the patient has been on hemodialysis? There was no significant correlation between Number of Years the Patient has been on

Hemodialysis and the social support subscales of the NSSQ (see Table 19). There were significant correlations with well-being, as demonstrated by the subscales of General Positive Affect (r = .560, p = .004), Emotional Ties (r = .398, p = .04), Life Satisfaction (r = .427, p = .03), and Psychological Well-Being (r = .547, p = .005), and no significant negative correlations with Psychological Distress and its subscales (see Table 20). A major finding of the study was the significant positive correlation of the variable with the overall Mental Health Index (r = .426, p = .03). It suggests that the longer the patient is on hemodialysis, the greater the spouse's sense of well-being, although it is not possible to indicate at what point or to what extent this sense of well-being improves. The qualitative results of the study are presented in the following set of questions:

How do the spouses of hemodialysis patients perceive their situation in living with a chronically ill mate? Three persistent and overlapping themes can be identified in the spouses' perception of living with a mate on hemodialysis: isolation, changes in patient behavior, and increased responsibilities. They can be characterized in the following narratives: One active 82-year-old woman who continues to work described her social isolation and its interrelation to the other themes; her husband had been on dialysis for 3 years.

> It's difficult to get out; he's sick all the time; it's always something. He's not the same; either his behavior is different or he can't do anything anymore. He's not responsible enough; I do everything for him, all his care--everything. There isn't time for anything else; he is the center of everything. Our family, kids, are busy with their own lives, so I do it all. I do everything.

> I'd like to get out more, but I can't leave him for a minute. If someone came in, I'd go; otherwise, I can't leave him; he's too irresponsible.

Behavioral change, ranging from increased fatigue to more erratic manifestations, was another theme mentioned by all the spouses. A 62-year-old woman described her husband as "not the same; he's so irresponsible. I have to watch him all the time--more and more. Sometimes I wonder if his mental function is OK. He's less alert and so irresponsible. Our friends come around less, too; it's inconvenient for them, what with the food and my husband's behavior." Another spouse described his situation.

> My wife is so moody, more moody all the time. I can't predict her behavior; she's less responsive and her attention span is shorter. I have to direct her, almost her every move; it wears on me. I focus on her every day. There have been some horrible times I wasn't prepared for. I can't get out and away from it either, and my friends don't come by as much as they used to. Everything has been bad since dialysis. I have to bathe her, dress her, cook, clean--everything. Dialysis isn't a cure, and I was led to believe it was and when you realize it isn't, it's a shock. Nobody told us all the problems that come with renal failure and dialysis.

A woman described her husband as "so much worse since dialysis; he's had a nervous breakdown and just isn't himself. I don't know what to do; he's so depressed; he never goes out, so I don't either. He cries alot and knows something is wrong but doesn't know what. He's on three nerve pills every day, but it doesn't help. Sometimes, he's like a wild man, just thrashing around." An even more extreme example was related by one woman,

whose husband's eating behavior had become increasingly bizzare; frequently, she found him in their backyard, eating dirt.

A final theme identified by all the spouses was the increased responsibilities in caring for a mate on hemodialysis, especially in response to the fatigue that was a consequence of treatment. One man explained his situation: "My wife is very tired; she can't do much for herself anymore, so I do everything--I work and clean, take care of her. I drive her to dialysis and pick her up. I don't have time to do anything else but work and take care of her. It's hard but that's how it is; the way it is is the way it is. There isn't much I can do about it."

All the spouses were aware of the behavioral changes in their mates on hemodialysis and experienced increased responsibilities as a result. There were those who felt socially isolated because of the need to care for the patient, and a majority expressed a strong desire to get out of the house. Few, however, thought that their friends had pulled away since the onset of treatment, and fewer still considered their families to have become more distant.

What are the emotional reactions of spouses living with a mate on hemodialysis? Three themes emerged in the emotional reaction of spouses living with a mate on hemodialysis: depression, guilt, and anger. These feelings were not mutually exclusive and often merged. The most common was depression, which usually was precipitated by changes in the patients' status, feelings of lonliness and isolation, and fears about one's own health. A 41-year-old black woman whose husband had been on dialysis for 2 years expressed many of those feelings:

> My blood pressure is up; I'm so stressed; depending on how he is depends on how I am. My voice is lost and my hair falls out with

> the stress. Sometimes, I can't take it; I just explode; it's not me. I lie to my husband just to cope. He's changed so much he's not the same; he's just like a wild man sometimes. I'm moody myself, I wish I wasn't. I'm anxious alot, too; I feel guilty that I've messed up so many people's lives. Even though my family is around, I feel so depressed and alone. I'm always blue, always depressed about money. We're on a fixed income, it's so hard; we've got kids at home to feed. It's hard to get out, even if just to go to the store, so I'm home alot. I feel guilty if I go. I got no strength; I hurt for him. No happiness here, only sadness, and it's getting worse. [Tears]

Spouses of patients who had been on dialysis for a longer period of time said that depression was worse in the beginning, an observation that is confirmed by the quantitative analysis. The longer the patient has been on hemodialysis, the greater the spouse's sense of well-being. Many still complained of ongoing depression and related their own well-being to the condition of their spouse. One can recognize such an attitude in the following example by a 57-year-old white male, whose wife had been on dialysis for 9 years: "When my wife is down, I'm down, no matter what. Initially, when my family withdrew, it hurt and I was depressed occasionally, but its indirect relationship to how my wife was feeling was harder. My depression correlates with how my wife is feeling physically or mentally. We're tied to each other; what affects her gets to me. I want to be near her every moment I am able." Many spouses also expressed a desire to have a place "to let it all go" and so to unburden themselves of the depression, guilt, and anger they felt.

Guilt, a second common reaction to the spouse on hemodialysis, was

related to the increased attention required in caring for the patinet. Many felt too guilty to leave the patient alone even to run short errands, such as a trip to the grocery store. Such a feeling already has been exemplified but can better be illustrated in the following reaction by a 72-year-old woman whose husband had been on dialysis for 2 years:

> We don't, or rather can't, really go anywhere or do anything, so nothing really matters. He's too tired from dialysis, and I feel too guilty leaving him alone. I worry too much and it's not worth it. I wish he had more energy but I guess it's to be expected; it's just hard to accept. I'd like to get out more, but I can't leave him; he's not responsible enough to be alone; someone would have to be with him all the time. Sometimes, I take him but it's so difficult, so we just stay home alot. I feel too guilty to go and I just worry while I'm gone, but it's depressing, too.

Anger was verbalized less often by spouses of patients on hemodialysis, although there were expressions of hostility at the situation. This feeling was conveyed by a 79-year-old man whose wife had been on dialysis for 2 years.

> Her vomiting and itching drive me crazy. I yell at her to stop, especially when we are eating. I can't take it; it makes me feel dizzy and then I worry about my own health. I can't afford to be sick; I need to be here with her. It's so hard to be responsible all the time; I can't ever just go; I have to be home with her. You know, I have a bucket in every room so she can vomit; it reduces my clean-up time. I hate it all. We even sleep in separate rooms, but I still hear her vomit at night. It's so depressing; I can't stand it and I know it will never end.

The following narrative by a 59-year-old black woman summarizes the anger felt by many of the spouses:

> I get overwhelmed alot and feel angry. It lasts for awhile, then I turn it against myself. I smoke and eat alot and then get depressed; I withdraw and get real depressed if I don't do what he asks. I feel guilty if I don't. I'm angry and overwhelmed. I don't deal well with him or the situation. I wish he'd get better or die. I know that's awful but that is how I feel sometimes. I get so bitchy; I just have to go; he's too demanding and I can't take it.

These expressions of depression, guilt, and anger were the most common emotional reactions of spouses living with a mate on hemodialysis. Of the three, depression was experienced most often and was verbalized by 20 of the 23 subjects. Primarily, it resulted from a change in the patient's health status, fears concerning one's own health, and the lack of independence that resulted in caring for the patient.

What strategies do the spouses of patients on hemodialysis use to support themselves? Belief in the power of prayer and in a personal God were the primary means whereby the spouses of patients on hemodialysis supported themselves. Nineteen subjects identified this support to be the one significant aspect of their lives that gave them strength to confront the daily demands of caring for their mate. This is a particularly important source of support in that none of the subjects mentioned it on the NSSQ. Many in the sample felt that their families, just by being available and listening to them, offered support. Fewer mentioned organizations and work as sources of support, and fewer still identified their pets as a source of comfort. In every case, the spouses of patients on hemodialysis found that permitting themselves a reprieve from their

situation, whether simply by talking to someone or going to work, allowed them the sense of being able to cope again.

The following three narratives are examples of these strategies for self-support:

> I go to work to relax. I have my girls and a few friends that listen to me, but work is the best because it is ongoing and consistent and I can think about the problems of somebody else. I also believe in God and the power of prayer, and when I'm real down I pray and it really helps; it works. Sometimes,too, I just go out and walk a-round. I have to or I'll snap.
>
> I have someone come in twice a week and help with housework; that lets me care for my wife more. I have friends I could call and they'd come, too, but for this I don't like to do that. Mostly, I'm on my own. I call on God; I have a strong faith and I believe in the power. It's always there and it always helps. My dog--my dog is just a great comfort to me, too; she helps me to relax.
>
> Through the Lord and Bible and through the people I come in contact with--they all help me in their own way. My family, especially my kids, they help me out and it reduces my work around the house. I work full-time but I wish I could be with my wife more. I cope better mostly when my wife is OK. When she's not, all that's left is prayer and I believe in it.

It is apparent from these narratives that a strong faith in God and in the power of prayer were important strategies in coping with the patient on hemodialysis.

<u>How do the spouses of patients on hemodialysis define social support</u>? Spouses define social support in one of three ways: someone to talk to,

someone who is available, and financial stability. These aspects of support are not mutually exclusive; many subjects included more than one; and in every case financial support was cited, at least one other source of social support was mentioned as well. Social support perceived as someone to talk to was characterized by the following statements: "someone who is honest with me," "someone who gives me moral support with mutual trust," "somebody around that I can talk to and they'll just listen to me," "someone around I can talk to who agrees with me and my thoughts," "someone being there, not necessarily in person but available to me, that I can talk to and just relieve my tension; I don't want someone here to clean and work, I want someone I can talk to, who's available."

Social support perceived as someone who is available was exemplified in such comments as: "having someone around in case of an emergency who can act quickly," "someone to pick up stuff for me," "someone to help around the house," "someone to take over and give me some time for myself." More sustained remarks included: "doing--it's in the doing for someone; being there is good, but it's the doing that counts; somebody who will do for you, not just talk," "a person to be around when I need them for some purpose; emotional is as important as other ways," "somebody to give me a ride, go to dinner with, take my husband to dialysis, or just visit with me."

Financial stability was identified less often as a source of social support, although it did consistently emerge as a companion to the other themes of support. It was characterized in such statements as "having somebody there and enough money to get by on," "somebody who can really help you and enough money to be comfortable." Each of these forms of social support find verification in Kahn's (1979) conceptualization of

social support as the expression of a positive affect, affirmation of another's behavior, and the giving of material or symbolic aid.

Would spouses of hemodialysis patients utilize a resource person if one were available? Nineteen of the 23 spouses in the total sample indicated that they would have utilized a resource person at the initiation of dialysis and during the first year of treatment if one had been available. The role of this resource person was identified by the spouses as one of information giving, both formally and informally. By the end of the first year of dialysis, three spouses felt that they would not utilize such a person if they had received sufficient information during the first year. Seventeen stated, however, that an ongoing relationship with such a person would be very helpful, particularly during a crisis or change in the medical regimen.

The information that the resource person was expected to provide was identified consistently by those spouses who would utilize such a person. There would be information on normal renal function, as compared to renal failure; dialysis and other treatment options; the influence of other disease processes; and dialysis and the medical regimen, including diet. Many spouses stated that having someone available just to confirm normal or abnormal patient behaviors would be extremely beneficial in reducing their stress and anxiety. Two spouses voluntarily indicated that a nurse would be most appropriate as a resource person with whom they would feel most comfortable. One woman expressed the desire to have such a person be available for both her and her husband, as their concerns were not always the same. Only three spouses stated that they had no need for a resource person, either during the patient's dialysis or in the future.

Would spouses of hemodialysis patients participate in a spouse-only

social support group if one were available? Sixteen spouses (11 women and 5 men) indicated that they would participate in a spouse-only social support group, although one woman did indicate that, because she did not drive, she could attend only if transportation were provided. Three additional spouses volunteerly suggested that a social support group for their adult children would be just as helpful as one for themselves. They thought that by helping the children to cope they, themselves, would be assisted in coping as well. One woman mentioned that, although her husband also would benefit from such a group, it would be better if, initially at first, both spouse and patient had their own groups to attend. Of those who did support such a group, the majority felt that it should meet every month and be facilitated either by a nurse or social worker. Of the seven spouses who would not participate in a support group, five (3 men and 2 women) had the patient present during the interview. This is consistant with the quantitative data, which demonstrate that those spouses who interviewed with the patient present showed a greater sense of positive well-being.

Chapter 5

Discussion

The purposes of this study were to identify the perceived sources of social support of spouses of patients on chronic in-center hemodialysis and to describe how those sources of support influence the spouses' sense of well-being. Primarily, the study sought to determine perceived sources of social support and the relationship of that support to the spouses' sense of well-being.

The major sources of social support identified on the NSSQ were Family or Relatives, Friends, and Spouse or Partner, respectively. Although listed as third in importance as a source of support, Spouse or Partner also was identified as providing the greatest source of functional support. If not as commonly sought as a source of support, the spouse or partner provided more support or support perceived to be of a higher quality when it was given. This characterization of support is evident in the interviews as well. The majority of spouses indicated that, although their spouses had been the major source of support prior to the initiation of dialysis, the treatment so affected the behavior of the patient and so increased the responsibilities of the spouse that the patient no longer was perceived as able to provide the same level of support. Given the deterioration of the spousal relationship due to the ESRD of one of its members, it is not surprising that support in coping with the spouse would come, not from that person, but from family and friends. It is more difficult to ascertain why, then, the functional support of the spouse was identified to be so high on the NSSQ. It may be that the spouses perceived their husbands or wives on dialysis as the nominal source of support because of their role. Too, it may be that spouses

felt more obliged to identify the support of the patient on the NSSQ, since that datum was recorded on the instrument, than in the interview, where it was transmitted orally.

Nineteen of the 23 spouses interviewed identified their personal religious belief to be a source of support. Faith in God and the power of prayer were regarded as the most important source of support in their daily lives. Religious belief is not a category of social support on the NSSQ, although it may be represented by Minister, Priest, Rabbi, which is listed. Only five spouses identified that category as supportive, however, and it may be that a distinction was perceived to exist between personal faith and its public mediators.

One of the most significant conclusions of the study is that social support and well-being were significantly and positively correlated. When social support was perceived to be high, the spouses' sense of well-being was high as well. Conversely, a lessening of social support lowered a sense of well-being. One explanation as to why some of the correlations between these two variables are relatively high may be that social support and well-being, although important concepts in themselves, overlap and share a common domain. For example, the Affect subscale demonstrated an expected moderately positive correlation between the two variables ($\underline{r}$ = .488, $\underline{p} < .01$).

The corresponding increase and decrease of Total Functional Support and well-being is also supported by the two scales of the MHI, Psychological Well-Being and Psychological Distress. The significance of this correspondence is that the spouses's sense of well-being is mediated by the quality of their social support network and not simply the number of individuals in it. Although Total Network Properties and Number in

Network significantly and positively correlated with Psychological Well-Being, this correlation was not demonstrated on the MHI score, which showed a significant positive correlation for Total Functional Support (Affect, Affirmation, and Aid). This is further support of the notion that it is not the number in the network but its quality that determines well-being. Life Satisfaction, a third scale of the MHI, did not correspond with the NSSQ. Final confirmation that social support and well-being are positively correlated is from studies on other populations (e.g., Cobb, 1976) that have demonstrated that social support enhances the ability to cope, moderates the effects of stress in life-change events, and promotes health by reducing the symptoms of illness.

Aside from the primary purposes of the study, there are other findings derived from the quantitative and qualitative data. Length of time the patient had been on dialysis significantly and positively correlated with the overall Mental Health Index. The longer the patient had been on dialysis, the greater the spouse's sense of well-being. This is consistent with the interviews, where the majority of spouses identified the first 2 years of dialysis as the most difficult but indicated that their social support increased after the patient had been on dialysis "for awhile." There was no significant correlation between the number of years the patient had been on dialysis and the social support subscales of the NSSQ.

Even though the spouse's sense of well-being increased with the length of time the patient had been on dialysis, the perception of social support decreased with the length of time married. If social support and well-being are correlated, one must ask why this is so. It may be that as family and friends diminish over time, so does the social support

that they provided; on the other hand, the adjustment to dialysis, both to its mechanics and to its inevitable duration, may enhance the perception of well-being over that same period of time, especially when compared to the initiation of treatment. Even though the spouses' social support may have lessened, knowing that the patient on dialysis is stable may reduce initial fears and uncertainty and so increase the sense of well-being.

The literature has demonstrated that the effects of ESRD and hemodialysis on the family of the patient are profound (e.g., Chowanec & Binik, 1982; Czaczkes & Kaplan-DeNour, 1978; Golodetz et al., 1969; Strauss & Glaser, 1975). The qualitative results of this study find support in the literature in two major areas: perceptions of the spouse in living with a patient on dialysis and the emotional reactions of the spouse to such a situation. Spouses perceived their situation as one of increased isolation and responsibilities and of changes in patient behavior that necessitated the direction of all the spouses' energies and activity to the care of that person (cf. Maurin & Schenkel, 1976; Smith et al., 1969). The principal emotional reactions of the spouses to their situation were depression, guilt, and anger. These emotions, too, have been identified in the literature, especially depression (cf. Atcherman, 1981; Chowanec & Binik, 1982; Holcomb & MacDonald, 1973; Shambaugh & Kanter, 1969). Excessive closeness of the spouse to the patient, also identified in the literature (Shambaugh & Kanter, 1969), was demonstrated by only two subjects in the present study. Sexual dysfunction and marital discord have been presented as difficulties in living with a patient on dialysis (cf. Finkelstein et al., 1976; Steele et al., 1976) but were not explored in the present study.

The importance of social support in moderating the effects of stress, especially in the spouses of patients on dialysis, has been demonstrated in the anecdotal literature, as well (cf. Paradiso, 1983; Shambaugh & Kanter, 1969; Winkes, 1983). The research literature does not speak to the social support of spouses of patients on hemodialysis, however. This study has indicated that such support is necessary and that a social support group may be useful in providing a mechanism to enhance the spouses' sense of well-being. Spouses of patients on dialysis indicated that they would attend such a group and utilize a resource person, especially during the first 2 years of dialysis.

Limitations

There are limitations to the descriptive design of the study. As described by Brink and Wood (1978) and Gortner (1982), a descriptive survey design is useful in determining the relationship among variables. Its advantages include usefulness in obtaining subjective information about opinions, beliefs, and values; and an ability to allow research to be conducted in a natural setting. There are disadvantages to the design, as well, including the lack of control over extraneous variables and threats to internal validity, such as interviewer and environmental effects and response sets. An exploratory descriptive design is useful when there is an insufficient knowledge base because it provides the flexibility to explore all aspects of the problem. Its main disadvantage includes reduced control over extraneous variables, potential selectivity and subjectivity in the collection and analysis of data, reduced reliablility and validity due to high flexibility, and unstructured data collection.

A weakness of this study is that five spouses interviewed with the patient present. Although this variable was not significantly correlated

with the NSSQ, it was with the MHI. Increased Anxiety, Depression, Loss of Behavioral/Emotional Control, and Psychological Distress were all elevated in spouses who interviewed without the patient. In contrast, General Positive Affect, Emotional Ties, Life Satisfaction, Psychological Well-Being, and the overall Mental Health Index were all elevated in spouses who interviewed with the patient present. Although the sample size was small, these results are significant in that they may have altered both the quantitative and qualitative data by affecting the spouses' response. Other study limitations include the lack of data on the spouses' marital satisfaction before dialysis and the fact that data were collected at a set point in time. The wide age span of the sample may make generalization to a particular age population difficult, even though there were no significant correlations between age and social support and well-being.

Implications

A majority of spouses identified the first year of hemodialysis as the most difficult and as a time when they would have most readily utilized additional support had it been available. This may be true because spouses perceived the patient as providing the highest quality of support, even though primary support came from family and relatives. When this support is affected by the onset of illness, the spouse may not receive the support necessary to maintain a healthy sense of well-being, particularly during the initiation and first year of dialysis. This contention is supported by the fact that spouses have a higher sense of well-being after the patient has been on dialysis for approximately 1 year.

It is at the initiation of dialysis and during this first year that nursing could assist the spouses of patients on hemodialysis in their adjustment to the patient's condition and increase their well-being by

means of this social support. There are three ways this could be done. Social support groups have been shown to assist patients on dialysis (Dimond, 1979; Paradiso, 1983; Winkes, 1983). It could assist the spouses of patients on hemodialysis as well. When asked whether they would attend such a group, a majority of the spouses indicated that they would. A resource person who would be available to answer questions and provide information is another means of reducing or eliminating the stress of adjusting to dialysis. A majority of spouses stated that they would utilize such a person, particularly during the first year of dialysis. A third means of providing social support to the spouses of patients on hemodialysis is primary care, whereby a nurse is assigned to a single patient. It might even be feasible to extend that role to providing resources to the spouse of the patient.

The wives of patients on hemodialysis demonstrated significantly higher degrees of Anxiety, Loss of Behavioral/Emotional Control, and Psychological Distress than did the husbands, who had greater Psychological Well-Being, General Positive Affect, Life Satisfaction, and overall Mental Health Index scores. Because the women in the sample who live with a chronically-ill spouse had a lower sense of well-being overall than the men, the means of social support should be directed primarily to them. One way of doing so is by supporting the spouses' belief in God and the power of prayer. A majority of spouses identified this to be a principal means of coping with their situation; its encouragement, either individually or with others, would be one means of offering social support to the spouses of patients on hemodialysis.

Future Research

This study examined the relationship of social support and well-being

of spouses of patients on in-center hemodialysis at a set point in time. Areas for future research include a longitudinal study to investigate the nature of social support to well-being before and after the initiation of dialysis. This would permit a clearer understanding of how these variables change and where nursing might best intervene. Another area for research would be the particular effectiveness of a social support group, resource person, and primary care in enhancing the well-being of spouses. Research should investigate, as well, at what point spouses perceived an improved sense of social support and well-being so as to determine when nursing can most effectively provide that support. The literature has demonstrated that social support does promote the adaptation to life-change events, of which ESRD and hemodialysis are examples (Cobb, 1976; Strauss & Glaser, 1975). If the spouse can be supported in this life-change event, then as family theory indicates, both the spouse as well as the patient and family should benefit.

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Appendix A

Background Sheet

I. D. Number: _____

Interviewer: _____ Date: _____

Interviewee: _____

Address: _____ Phone: _____

_____

Sex: Male Female Your age: _____ Your husband/wife age: _____

Are you legally married? Yes No If yes, how long? _____

Do you and your husband/wife live together? Yes No

Religion: _____ Do you attend a weekly worship? Yes No

Highest grade you completed: _____ Your husband/wife completed: _____

What is your occupation? _____

What is your husband/wife occupation? _____

Are you working now? Yes No How many hours per week? _____

Is your husband/wife working now? Yes No How many hours per week? ____

When was your husband/wife diagnosed with kidney disease? _____

When did your husband/wife start on dialysis? _____

Has your husband/wife ever dialyzed at home? Yes No When? _____

Has your husband/wife ever had a kidney transplant? Yes No When? _____

Has your husband/wife ever been on CAPD? Yes No When? _____

Does your husband/wife have any other illnesses? _____

_____

Do you have any illnesses? _____

Appendix B

Unstructured Interview Guide

1. What does support mean to you?

2. Can you tell me about the things, organizations, or people that give you the most support?

3. In what way does this support you?

4. What other kinds of support do you have?

5. In what way(s) are these supports available to you?

6. In what way(s) are these supports not available to you?

7. Suppose you were in some kind of crisis, what would you need from your supports?

8. How would these needs be met by your supports?

9. What kinds of support do you need in your everyday life?

10. Where do you get this support?

11. How have your supports changed since your husband/wife went on dialysis?

12. How do you feel about these changes?

13. If there are gaps in the support you receive, what do you feel would be most helpful in filling them?

14. Do you feel you are the major source of support for your spouse?

15. Do you feel your spouse is your major source of support?

16. Have there been any changes in your activities since dialysis?

17. If so, what kind of changes?

18. What are your feelings about dialysis?

19. How did your family and friends respond to your spouse's dialysis?

20. Do you feel that a group of husbands and wives of patients on hemodialysis meeting together would benefit you?

21. Would you attend such a group?

22. Would you utilize a resource person if one were available?

23. What would you see as the function of such a person?

Appendix C

Consent to Participate in Research

Christine Mudge is a registered nurse and a graduate student at the University of California, San Francisco. She is studying the actual and perceived sources of social support and states of well-being of spouses of clients on chronic hemodialysis. Since I am a husband/wife of a client on hemodialysis, she has invited my participation.

If I agree she will interview me for one hour and have me fill out two questionnaires taking approximately 30 minutes. This will either be in my home or in a private room at the dialysis center. The interview will be taped if I agree. All tapes will be destroyed or erased at the end of this study.

My name will be given a code number to identify the information that I give. The list of matching names and code numbers will be locked separately so that my confidentiality will be protected to the extent possible. Only Christine Mudge or her advisor, Virginia Carrieri, R.N., D.N.S., will have access to the information I have given. My name or any other information that might identify me personally will not be used in any publication resulting from this study.

The potential risk to me in participating in this study is that some of the questions in the questionnaires or interview may make me feel uncomfortable. If this should happen, I can refuse to answer any questions or stop the interview at any time.

Although this study will result in no direct benefit to me or my husband/wife, the knowledge gained may affect future decisions on the development of a self-help social support group for spouses of clients on in-center hemodialysis.

If I have any questions at this time I can talk to Ms. Mudge. If there are any questions later, I can call Ms. Mudge at (415) 527-2428. If I have any problems or objections I may call the committee that is connected with the protection of research participants. Their phone number is (415) 666-1814.

My participation in this research project is voluntary. I am free to refuse to be in the study or withdraw from the study at any time. My refusal to participate will not jeopardize my husband's/wife's health care in any way.

I have been given a copy of this form to keep. If I wish to participate, I will sign this form.

_____ _____

Date Name

Table 1

Demographic Data

Characteristic	n	M	Range
Sex			
Male	9	-	-
Female	14	-	-
Race			
Caucasian	13	-	-
Black	7	-	-
Other	3	-	-
Religion			
Protestant	17	-	-
Catholic	5	-	-
Jew	1	-	-
Employment			
Employed	11	-	-
Retired	12	-	-
Spousal illness[a]			
Hypertension	7	-	-
Arthritis	5	-	-
"Heart trouble"/angina	2	-	-
Ulcers	2	-	-
Obesity	2	-	-
Gout	1	-	-

(table continues)

Characteristic	n	M	Range
Recovered alcoholic	1	-	-
Weak back	1	-	-
Peripheral vascular disease	1	-	-
Asthma	1	-	-
Decreased hearing	1	-	-
Hyperglycemia	1	-	-
Age (years)	-	60	35-82
Education (years)	-	12	5-19
Length of time married	-	35	11-55
Length of time on hemodialysis	-	5	1-14

Note. N = 23. M = mean.

[a] n = 11.

Table 2

Mean Percent of Total Network Number Listed for Each Relationship Category

Source of support category	M%	SD
Spouse or partner	8.51	7.67
Family or relatives	61.13	21.30
Friends	11.70	13.33
Work/school associates	4.41	11.54
Neighbors	7.20	12.11
Health care providers	1.16	3.97
Counselor or therapist	0.36	1.74
Minister, priest, rabbi	1.20	4.71
Other	0.00	0.00

Note. N = 723 responses; M% = mean percent; SD = standard deviation.

Table 3

Average Functional Support for Each Source of Support Category

Source of support category	n	M	SD
Spouse or partner	17	20.71	3.42
Family or relatives	22	17.41	3.22
Friends	12	18.76	3.77
Work/school associates	4	15.19	7.15
Neighbors	7	15.41	4.69
Health care providers	2	18.50	6.36
Counselor or therapist	1	13.00	0.00
Minister, priest, rabbi	2	18.25	0.35
Other	0	00.00	0.00

Note. N = 67 responses; M = mean; SD = standard deviation

Table 4

Correlation Matrix of the Norbeck Social Support Questionnaire and the Mental Health Index

	Well-Being Variables[a]								
Support Variables	ANX	DEP	LBEC	GPA	ET	LS	PD[b]	PWB[c]	MHI[d]
Affect	-.340	-.289	-.236	.488**	.171	.177	-.306	.426	.386*
Affirmation	-.385*	-.407*	-.298	.531***	.280	.234	-.400*	.488**	.450*
Aid	-.375*	-.424*	-.372*	.481**	.288	.114	-.442*	.435*	.447*
Total functional support	-.381*	-.379*	-.302	.521***	.245	.172	-.391*	.464**	.439*
Total network properties	-.254	-.234	-.148	.419*	.094	.126	-.235	.352*	.303
Total loss	.066	.106	.086	.038	.025	.119	.140	.035	-.032
Number in network	-.273	-.248	-.161	.433*	.097	.095	-.260	.357*	.315

[a]Well-being variables are abbreviated as follows: ANX = anxiety, DEP = depression, LBEC = loss of behavioral/emotional control, GPA = general positive affect, ET = emotional ties, LS = life satisfaction. [b]PD = psychological distress (which is measured by ANX, DEP, and LBEC). [c]PWB = psychological well-being (which is measured by GPA and ET). [d]MHI = mental health index (which is measured by PD, PWB, and LS).

*$p < .05$, one-tailed. **$p < .01$, one-tailed. ***$p < .001$, one-tailed.

Table 5

Comparison of Group Means of Spousal Employment with the Norbeck Social Support Questionnaire

Support Category	p value	M	SD
Affect	.46		
Retired[a]		66.83	49.03
Employed[b]		82.46	50.45
Affirmation	.55		
Retired		56.50	44.22
Employed		67.46	41.91
Aid	.65		
Retired		51.67	39.94
Employed		60.36	50.03
Total functional support	.50		
Retired		172.50	129.39
Employed		210.27	135.28
Total network properties	.39		
Retired		93.75	59.36
Employed		113.64	50.22
Total loss	.72		
Retired		2.33	5.31
Employed		1.64	3.91
Number in network	.36		
Retired		9.67	6.32
Employed		12.00	5.68

(table continues)

Note. M = mean; SD = standard deviation.

[a]n = 12. [b]n = 11.

p < .05.

Table 6

Comparison of Group Means of Spousal Employment with the Mental Health Index

Well-Being Category	*p* value	*M*	*SD*
Anxiety	.10		
Retired[a]		21.09	7.02
Employed[b]		27.55	10.37
Depression	.21		
Retired		8.09	2.63
Employed		9.91	3.86
Loss of behavioral/emotional control	.16		
Retired		17.73	5.75
Employed		22.73	9.67
General positive affect	.71		
Retired		39.27	8.33
Employed		37.64	11.45
Emotional ties	.63		
Retired		8.46	2.84
Employed		9.09	3.21
Life satisfaction	.13		
Retired		4.27	1.10
Employed		3.36	1.57
Psychological well-being	.62		
Retired		56.00	11.66
Employed		53.00	15.77

(table continues)

Well-Being Category	*p* value	*M*	*SD*
Psychological distress	.16		
Retired		50.36	14.40
Employed		60.91	19.13
Mental health index	.22		
Retired		170.73	24.31
Employed		152.64	39.91

Note. *M* = mean; *SD* = standard deviation.

[a]*n* = 11. [b]*n* = 11.

p < .05.

Table 7

Comparison of Group Means of Spousal Illness with the Norbeck Social Support Questionnaire

Support Category	p value	M	SD
Affect	.83		
No illness[a]		71.91	53.78
Illness[b]		76.50	46.96
Affirmation	.96		
No illness		62.18	46.24
Illness		61.33	40.87
Aid	.23		
No illness		44.00	43.06
Illness		66.67	44.23
Total functional support	.67		
No illness		178.09	138.08
Illness		202.00	128.42
Total network properties	.75		
No illness		99.36	62.46
Illness		106.83	49.47
Total loss	.15		
No illness		3.55	6.28
Illness		0.58	1.38
Number in network	.66		
No illness		10.18	6.65
Illness		11.33	5.58

(table continues)

Note. M = mean; SD = standard deviation.

[a]n = 11. [b]n = 12.

p < .05.

Table 8

Comparison of Group Means of Spousal Illness with the Mental Health Index

Well-Being Category	p value	M	SD
Anxiety	.62		
No illness[a]		25.40	8.82
Illness[b]		23.42	9.89
Depression	.52		
No illness		9.50	2.80
Illness		8.58	3.83
Loss of behavioral/emotional control	.21		
No illness		22.70	8.53
Illness		18.17	7.60
General positive affect	.59		
No illness		37.20	8.60
Illness		39.50	10.98
Emotional ties	.97		
No illness		8.80	2.70
Illness		8.75	3.31
Life satisfaction	.15		
No illness		4.30	1.49
Illness		3.42	1.24
Psychological well-being	.78		
No illness		53.60	12.76
Illness		55.25	14.82

(table continues)

Well-Being Category	*p* value	*M*	*SD*
Psychological distress	.31		
No illness		59.80	16.71
Illness		52.17	17.87
Mental health index	.50		
No illness		156.30	31.30
Illness		166.17	36.04

Note. *M* = mean; *SD* = standard deviation.

[a]*n* = 10. [b]*n* = 12.

$p < .05$.

Table 9

Comparison of Group Means of Race with the Norbeck Social Support Questionnaire

Support Category	p value	n	M	SD
Affect	.53			
White		13	66.54	47.54
Black		7	76.43	41.77
Other		3	103.00	78.82
Affirmation	.28			
White		13	57.46	40.47
Black		7	54.00	24.44
Other		3	98.33	76.97
Aid	.42			
White		13	51.62	40.28
Black		7	49.86	26.42
Other		3	88.00	88.79
Total functional support	.39			
White		13	173.31	122.53
Black		7	180.29	83.93
Other		3	289.33	243.98
Total network categories	.77			
White		13	98.39	55.56
Black		7	103.14	50.70
Other		3	124.67	77.80

(table continues)

Support Category	*p* value	*n*	*M*	*SD*
Total loss	.88			
White		13	2.15	5.13
Black		7	2.29	4.86
Other		3	0.67	1.16
Number in network	.68			
White		13	10.15	5.90
Black		7	10.71	5.47
Other		3	13.67	9.07

Note. *N* = 23; *M* = mean; *SD* = standard deviation.

$p < .05$.

Table 10

Comparison of Group Means of Race with the Mental Health Index

Well-Being Category	*p* value	*n*	*M*	*SD*
Anxiety	.92			
White		12	23.75	8.61
Black		7	25.57	11.91
Other		3	23.67	7.51
Depression	.29			
White		12	8.50	2.78
Black		7	10.57	4.12
Other		3	7.33	3.22
Loss of behavioral/emotional control	.67			
White		12	19.08	8.19
Black		7	20.57	8.52
Other		3	24.00	9.17
General positive affect	.97			
White		12	38.00	9.33
Black		7	38.86	8.92
Other		3	39.33	17.01
Emotional ties	.69			
White		12	8.25	3.39
Black		7	9.43	2.64
Other		3	9.33	2.31

(table continues)

Well-Being Category	*p* value	*n*	*M*	*SD*
Life satisfaction	.39			
White		12	4.17	0.94
Black		7	3.57	1.81
Other		3	3.00	2.00
Psychological well-being	.98			
White		12	54.00	13.33
Black		7	55.43	13.37
Other		3	54.33	20.74
Psychological distress	.92			
White		12	54.67	18.59
Black		7	58.00	18.39
Other		3	54.00	15.10
Mental health index	.94			
White		12	164.08	31.45
Black		7	158.43	38.47
Other		3	159.67	43.10

Note. *N* = 22; *M* = mean; *SD* = standard deviation.

$p < .05$.

Table 11

Comparison of Group Means of Sex with the Norbeck Social Support Questionnaire

Support Category	p value	M	SD
Affect	.73		
Male[a]		79.00	52.81
Female[b]		71.29	48.57
Affirmation	.83		
Male		64.22	46.99
Female		60.14	41.14
Aid	.96		
Male		56.44	37.16
Female		55.43	49.58
Total function	.79		
Male		199.67	130.95
Female		184.71	135.00
Total network properties	.85		
Male		106.11	56.72
Female		101.43	55.75
Total loss	.64		
Male		1.44	4.33
Female		2.36	4.89
Number in network	.79		
Male		11.22	6.22
Female		10.50	6.07

(table continues)

Note. M = mean; SD = standard deviation

[a]n = 9. [b]n = 14.

p < .05, one-tailed.

Table 12

Comparison of Group Means of Sex with the Mental Health Index

Well-Being Category	*p* value	*M*	*SD*
Anxiety	.0002***		
Male[a]		16.89	5.01
Female[b]		29.46	7.93
Depression	.19		
Male		7.89	3.06
Female		9.77	3.44
Loss of behavioral/emotional control	.0025**		
Male		14.79	3.38
Female		24.00	8.46
General positive affect	.049*		
Male		43.22	8.18
Female		35.15	9.74
Emotional ties	.46		
Male		9.33	2.69
Female		8.39	3.20
Life satisfaction	.03*		
Male		4.56	1.13
Female		3.31	1.38
Psychological well-being	.032*		
Male		61.67	11.40
Female		49.54	13.14

(table continues)

Well-Being Category	*p* value	*M*	*SD*
Psychological distress	.002**		
Male		42.89	12.79
Female		64.46	14.61
Mental health index	.003**		
Male		184.22	21.03
Female		146.08	32.09

Note. *M* = mean; *SD* = standard deviation.

[a]*n* = 9. [b]*n* = 13.

*$p < .05$, one-tailed. **$p < .01$, one-tailed. ***$p < .001$, one-tailed.

Table 13

Correlation of Age with the Norbeck Social Support Questionnaire

Support Category	*p* value	Age
Affect	.38	.068
Affirmation	.49	.002
Aid	.36	.084
Total functional support	.43	.044
Total network properties	.41	.051
Total loss	.16	-.228
Number in network	.39	.063

Note. *N* = 23.

*$p < .05$, one-tailed.

Table 14

Correlation of Age with the Mental Health Index

Well-Being Category	*p* value	Age
Anxiety	.08	-.315
Depression	.34	-.092
Loss of behavioral/ emotional control	.32	-.107
General positive affect	.35	-.088
Emotional ties	.02	-.467*
Life satisfaction	.45	.030
Psychological well-being	.26	-.147
Psychological distress	.28	-.138
Mental health index	.35	.090

Note. *N* = 23.

*$p < .05$, one-tailed.

Table 15

Correlation of Length of Time Married with the Norbeck Social Support Questionnaire

Support Category	*p* value	LTM
Affect	.04	-.379*
Affirmation	.02	-.446*
Aid	.06	-.356
Total functional support	.03	-.424*
Total network properties	.05	-.369*
Total loss	.46	.021
Number in network	.04	-.395*

Note. *N* = 23; LTM = length of time married.

*$p < .05$, one-tailed.

Table 16

Correlation of Length of Time Married with the Mental Health Index

Well-Being Category	*p* value	LTM
Anxiety	.48	.009
Depression	.50	.002
Loss of behavioral/ emotional control	.50	-.0007
General positive affect	.32	-.110
Emotional ties	.11	-.283
Life satisfaction	.24	.163
Psychological well-being	.32	-.111
Psychological distress	.32	.111
Mental health index	.44	-.035

Note. *N* = 23; LTM = length of time married.

*$p < .05$, one-tailed.

Table 17

Comparison of Group Means of Patient Presence with the Norbeck Social Support Questionnaire

Support Category	p value	M	SD
Affect	.97		
Patient absent[a]		74.61	45.94
Patient present[b]		73.20	65.96
Affirmation	.61		
Patient absent		58.39	37.97
Patient present		73.80	59.84
Aid	.85		
Patient absent		54.72	43.13
Patient present		59.80	53.11
Total functional support	.81		
Patient absent		186.06	120.79
Patient present		206.80	177.22
Total network properties	.86		
Patient absent		104.67	51.54
Patient present		98.20	72.36
Total loss	.045*		
Patient absent		2.56	5.09
Patient present		0.00	0.00
Number in network	.85		
Patient absent		10.94	5.67
Patient present		10.20	7.79

(tables continues)

Note. M = mean; SD = standard deviation.

[a]n = 18. [b]n = 5.

*p < .05.

Table 18

Comparison of Group Means of Patient Presence with the Mental Health Index

Well-Being Category	p value	M	SD
Anxiety	.037*		
Patient absent[a]		26.11	8.96
Patient present[b]		16.25	6.13
Depression	.036*		
Patient absent		9.61	3.31
Patient present		6.25	2.06
Loss of behavioral/emotional control	.004*		
Patient absent		21.72	8.25
Patient present		13.50	2.89
General positive affect	.040*		
Patient absent		36.50	9.40
Patient present		47.25	6.85
Emotional ties	.0001*		
Patient absent		8.11	2.89
Patient present		11.75	0.50
Life satisfaction	.0007*		
Patient absent		3.50	1.34
Patient present		5.25	0.50
Psychological well-being	.009*		
Patient absent		51.28	12.56
Patient present		69.00	7.83

(table continues)

Well-Being Category	*p* value	*M*	*SD*
Psychological distress	.042*		
Patient absent		59.44	16.02
Patient present		38.50	13.48
Mental health index	.013*		
Patient absent		154.22	31.58
Patient present		195.25	19.79

Note. *M* = mean; *SD* = standard deviation.

[a]*n* = 18. [b]*n* = 4.

**p* < .05.

Table 19

Correlation of Length of Time Patient Has Been on Hemodialysis with the Norbeck Social Support Questionnaire

Support Category	*p* value	LTH
Affect	.23	.173
Affirmation	.14	.257
Aid	.12	.269
Total functional support	.14	.248
Total network properties	.27	.142
Total loss	.12	.272
Number in network	.28	.136

Note. *N* = 23; LTH = length of time patient has been on hemodialysis.

*$p < .05$, one-tailed.

Table 20

Correlation of Length of Time Patient Has Been on Hemodialysis with the Mental Health Index

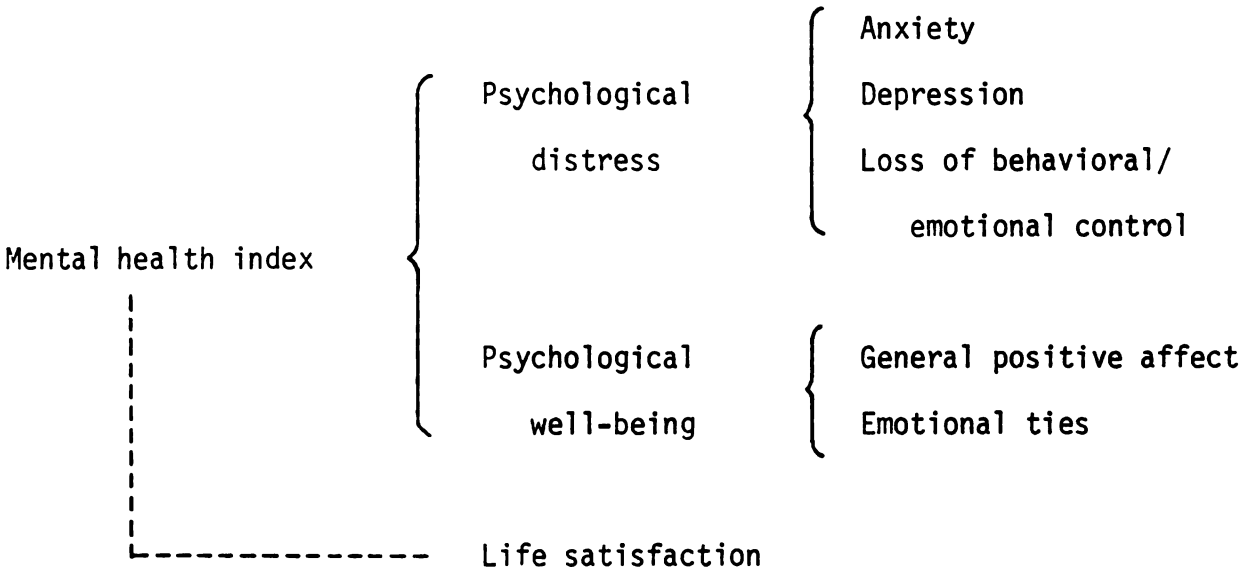
Well-Being Category	*p* value	LTH
Anxiety	.10	-.287
Depression	.07	-.336
Loss of behavioral/ emotional control	.11	-.285
General positive affect	.004	.560*
Emotional ties	.04	.399*
Life satisfaction	.03	.427*
Psychological well-being	.005	.547*
Psychological distress	.09	-.301
Mental health index	.03	.426*

Note. *N* = 23; LTH = length of time patient has been on hemodialysis.

*$p < .05$, one-tailed.

Figure 1

Mental Health Index Structure



Adapted from: Ware, J., Johnson, S., Davis-Avery, A., & Brook, R. (1979). Conceptualization and measurement of health for adults. In Rand Corporation (Ed.), Health insurance study: Vol. 3. Mental health. Santa Monica, CA: Author.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