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SOCIAL SUPPORT AND DECISION FOR TRANSPLANTATION IN DIALYSIS PATIENTS

A Thesis

Presented for the

Master of Science in Nursing

Degree

The University of Tennessee, Knoxville

Sandra Kaye Williams

May 1989

DEDICATION

I dedicate this work to the many dialysis patients I have known. Some have been good friends and I have been privileged to share special moments with most of them. I am an admirer of their resilience and cheerfulness in the face of overwhelming obstacles. They are indeed special people.

ACKNOWLEDGEMENTS

I wish to thank my thesis committee chairman, Dr. Sandra Thomas, for her enduring support and guidance throughout the course of this study. I also express gratitude to Dr. Mary Lue Jolly and Dr. John Jozwiak, my committee members, for their assistance in the completion of my research. I extend my appreciation to the directors of the dialysis centers who provided access to patients. Because of their cooperation, I was permitted the privilege of looking into an exciting but somewhat neglected area of human behavior.

I express my deepest affection and gratitude to my husband and my father. My husband, Shane, supported and encouraged me continuously. My father, Lloyd, demonstrated an abiding interest during great personal loss from my mothers death, and lovingly presented me with the funds to complete this work.

ABSTRACT

The option of kidney transplantation is one that most hemodialysis patients will consider at some time during their course of treatment. It requires all the resources and personal ability of the person making the decision. This study was undertaken to explore the influence of social support on decision for transplantation in dialysis patients.

Past research has shown a strong inverse relationship between social support and stress. The literature supports the relationship of social support as a stress reducer and the relationship of the decision to stress. Decision-making is required during times of stress. According to Lazarus and Folkman (1984), after encountering a stress, most persons decide to take no action, or decide on a course of action.

Forty-five dialysis patients were asked to fill out the Norbeck Social Support Questionnaire. They were then divided into two groups--a group choosing transplantation and a group deciding against transplantation. The results indicated that the patients were almost always in agreement with their social networks' decision for transplantation. The majority (15 of 22) of subjects in the "yes" group (those who had opted for transplant) had 100 percent network agreement with their decision. In contrast, among subjects in the "no" group (those who had not chosen transplant), the majority (16 of 23) reported that their network members were undecided. In every aspect, the scores on the Norbeck instrument for social networks of the "yes" transplant group were higher than the "no" transplant group. Specifically, scores on the ability to make one feel liked, loved, esteemed, or valued

(affect) were much higher for persons choosing transplantation.

Size of network, age, income, marital status, length of stay on dialysis, and education were not significantly different between the "yes" and "no" transplant groups. However, the person in the "yes" transplant group was found to have been on dialysis for a mean of 28 months as opposed to 45 months in the "no" transplant group. Although not statistically significant, the difference was large enough to suggest a possible optimum time for decision on transplantation.

White women were three times more likely to choose transplantation than White men. Black males and females were equally likely to choose transplantation. However, 63 percent of the Blacks in this study chose transplantation as opposed to 40 percent of the Whites. In light of the strong agreement between the patient's decision and his network's decision for transplantation, and stronger social support in the "yes" transplant group, it is possible that lower socio-economic White males have weaker social support structures than White females or Blacks. Recommendations for nursing practice and future research were offered.

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CHAPTER I

INTRODUCTION

The concept of social support has been around since man first began. Genesis 2:18 states that it is not good for man to be alone. This is the first recorded acknowledgment of humanity's need for others. Eve entered history and man has since behaved in terms of his relationships to others. When one begins to read about social support he or she soon realizes that social support means different things to different people--social bonds, social networks, social contact, availability of confidants (Turner, 1983). Tilden and Galyen (1987) discuss the dark side of social support referring to those relationships that produce conflict, sometimes known as negative support. Kahn (1979) adds the idea of a social convoy implying the dynamic and changing nature of one's social support network throughout life.

Cobb's definition of social support is one of the most widely accepted. It simply states that social support is information that one is cared for, loved, esteemed, valued, and belongs to a network of common purpose or obligation (Cobb, 1979). Cobb defines four kinds of support (a) social support, (b) counseling, (c) mothering, and (d) material support of goods and services. The most important of these is social support and it has three components:

(1) Emotional support leading the recipient to believe that she is cared for and loved. (2) Esteem support leading the recipient to believe that she is esteemed and valued.

(3) Network support leading the recipient to believe that she has a defined position in a network of communication

and mutual obligation. (Cobb, 1979, p. 93)

In the last 20 years social support has consistently shown a significant positive relationship to health outcomes (Tilden & Galyen, 1987). In keeping with this idea, Norbeck (1985,1988) and Kane (1988) have developed similar models of social support in relation to health. Both models illustrate the relationship between support and health, although Kane's model (depicted in Table 1) confines its scope to family support.

Table 1. Conceptual Model Of Family Social Support: Antecedents And Consequences. (Kane,1988, p. 24)

ANTECEDENTS			CONSEQUENCES
Family Characteristics -	Family Social Support -	Family Function -	Health & Resources
*Social Network *Family Structure *Esteem *Stability	*Reciprocity *Advice/Feedback *Emotional Involvement	*Versatility *Resourcefulness	*Information *Goods & Services *Help in Crisis

The central idea of Kane's concept is that "social support is not an outcome or a resource, but is a process of interaction through which the family develops versatility and resourcefulness and consequently achieves health" (Kane,1988, p. 24).

Norbeck (1985, 1988) enlarged the paradigm of social support, including its relationship with stress as well as health. She borrowed from House (1981) and credited him with the development of the model in

Figure 1. Figure 1 explains social support as one type of buffering variable that affects the stressors and health outcomes directly (a- and c+), and indirectly influences (b) the relationship between stress and health (d-).

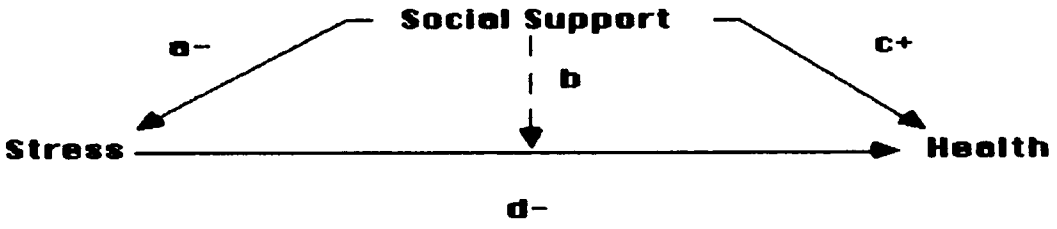

Figure 1. Simplified Conceptual Model of Stress, Social Support, And Health. (Norbeck, 1988, p. 87)

For example, an adequate social network may directly reduce stress by sharing in problem solving when stress is present. When stress is not apparent, the social network supplies assistance with activities of daily living and directly enhances health. In addition, social support indirectly affects stress and health by changing the person's perception of how stressful these events are for him or her. Norbeck has, however, adapted House's concept of social support to nursing research and has developed a social support instrument widely used by nurses.

The theoretical base for this study is fourfold: Lazarus' (1984) cognitive appraisal theory; Janis & Mann's (1977) anatomy of decision; attachment theory (Norbeck, 1985); and Norbeck's adaptation of House's

social support model. Social support has the unique ability to change one's perception of stress by confirming reality, sharing the burden, and supplying assistance. Thus, others affect the decisions one makes by altering the individual's perception of the problem. Sometimes the problem is changed. Many times the focal person is able to view the problem with a new perspective.

Perceptions have been addressed by Lazarus (1984) in his cognitive appraisal theory. Lazarus uses the term transactions and assumes that each person has a unique perception of a situation, even when the transaction is shared by many people. These perspectives are shaped by past experience, present emotional set, current demands in life, and confidence in one's resources. There are three basic assumptions to Lazarus' theory: (a) each person has a unique perception of the situation, (b) the perception of the situation transacts with the situation and with the response to it, and (c) the evaluation of the situation is influenced by many factors from within the person and from the situation itself.

According to Lazarus a person's coping response works something like this. One receives a stimulus that triggers an evaluation of well-being--the primary appraisal. The question is asked, "Am I OK, or am I in trouble?" The primary appraisal results in an evaluation of the situation as (1) irrelevant, (2) benign-positive, or (3) harmful. Irrelevant and benign-positive answer the question with "Yes, I am OK". The third category identifies harm/loss, threat, or challenge and requires the person to ask, "What am I going to do about it?"--the secondary appraisal. Secondary appraisal embodies the adequacy of coping in relation to a harmful event. A person's coping resources depend on his general health, problem solving skills, specific

practical resources, and the nature of his support network.

Underpinning the concept of social support is the theory of attachment. According to attachment theory (Norbeck, 1985) support is necessary to successfully manage the roles (spouse, worker, parent,etc.) of daily living. Support is especially important when encountering stressful life events and transitions. Bowlby (cited in Norbeck, 1985) says that people are happiest and function more efficiently when they believe there are trusted persons available to help them if the need should arise.

Decisional theory (Janis & Mann, 1977) is based upon the belief that man has a proclivity toward procrastination and a tendency to invent rationalizations for ignoring worrisome doubts that make it difficult to decide. These characteristics make man the reluctant decision maker. Based on decision theory (Janis & Mann, 1977), after receiving an authentic warning of impending danger a person may respond in one of five ways: (1) decide the risks are not serious, (2) decide the risks warrant taking the most available protective action, (3) avoid making a decision, (4) panic--no time to deliberate--make any available decision, or (5) search for all the facts and make the best possible decision. All of the above responses except number five are considered defective coping if the danger materializes. Lazarus' cognitive appraisal theory and Janis and Mann's decision theory are similar in that they require one to evaluate a stimulus and decide if it warrants action.

There are difficulties inherent in describing a desirable social support network for the population as a whole. What is ideal for some persons may be grossly inadequate for others in terms of the network's density, size, etc. In addition, what is ideal for persons at one time in their life may not meet

their need at a different age or under different circumstances. Norbeck's model is simplified. It does not directly address Kahn's (1979) concept of the changing nature of our social network or convoy, or Kegan's constructive-developmental (cited in Ellison, 1987) approach that one's needs are met by different types of social support structures at different times of life. Norbeck has conceptualized the relationships between social support, health, and stress in the broadest sense. There is a need for more specific research. Therefore, it is the purpose of this study to examine the social support of a particular group of people (dialysis patients) who are in a similar stress situation of end stage renal disease (ESRD), in relationship to the decision they have made about kidney transplantation.

Nominal Definitions

1. Dialysis: Refers to hemodialysis, a process by which a machine (kidney machine) is used to remove certain elements from the blood.

2. End Stage Renal Disease (ESRD): A progressive condition whereby kidney function deteriorates to a point incompatible with life. There are many different etiologies of the disease process.

3. Patient: person presently undergoing hemodialysis.

4. Social Support Network: All those persons who usually provide social support to the focal person. They may include spouse, family, friends, health care providers and workers, other patients, neighbors, and ministers.

5. Social Support: Supportive relationships that protect persons encountering stressful life circumstances from physical and emotional

decline (Mishel & Braden, 1987).

6. Transplantation: Synonymous with kidney transplantation.

Statement of Problem

This study was conducted to determine the relationship between social support and decision making regarding kidney transplantation. The following research questions were asked:

Research question one. What is the relationship between the patient's decision and his social network's opinion about kidney transplantation?

Research question two. Do age, education, income, and network size have a relationship to decision for transplantation?

Research question three. How do the social networks differ between the patients deciding for transplantation and those deciding against transplantation?

Research question four. Do the dialysis staff and fellow patients supply more support in the yes transplant group?

Assumptions

1. All answers were honest and given from the patient's perspective.

2. The Norbeck Social Support Questionnaire (NSSQ) is a valid measure when read and completed by the respondent, or when read and completed for the respondent by a trained person.

3. Making the decision for kidney transplantation is a difficult process

and incurs an additional stress load for the patient, family, and staff.

Limitations

1. Convenience samples limited generalization of the findings.

2. All data were collected while the respondents were undergoing dialysis, which may have interfered with their cognitive ability.

3. The researcher was known by most of the patients and therefore, could have led to development of a socially desirable response.

4. Causal relationships could not be established due to the inability to develop an experimental design.

5. The unknown influence of different physician groups could have influenced the patients' decisions.

Need for the Study

Social support research has enjoyed a grace period of 20-30 years during which the vast majority of correlational studies support the idea that social support is somehow related to health outcomes. The prevailing concept is that the more appropriate (larger, denser, closely integrated, etc.) one's social support, the better one's health. However, continued research in this area needs to be directed toward causal research such as that supported by longitudinal study (Mishel & Braden, 1987; Norbeck, 1985; Rook & Dooly, 1985), and identification of behaviors of special groups as possible points of intervention.

Dialysis is stressful for the patient and his family. Patients

undergoing home training for hemodialysis (Nichols & Springford, 1984) found the nurses to be overly positive about the physical and emotional difficulties the patients experienced. Twenty-five percent of the patients were ashamed because they had problems with anxiety reactions and 31 percent were ashamed of feeling depressed. The general impression was that the emotional difficulties of the trainees were unwelcome and misunderstood by the nurses, and that the patients developed negative self-images when they expected to feel and perform better due to the optimism of the staff. Nurses did not know how to relate therapeutically to these patients. In spite of all the difficulties associated with home training, home dialyzing patients had higher levels of family emotional support than in-center dialyzing patients (Piltz-Kirkby & Fox, 1982).

In view of the ever increasing number of people who are added each year to Medicare's rolls on chronic maintenance hemodialysis, it is the intention of this study to explore the relationship between social support and decision making in dialysis patients as a possible point of nursing intervention. Although all dialysis patients are not transplantable (over half are), all must decide on a type of dialysis to maintain life. This study has examined the decision on transplantation , but the researcher's intention is to represent the broad concept of decision making as it relates to social support in dialysis patients. As nurses add to the knowledge base of decision process and social support, they may begin to improve the patients' quality of life by assisting them in making more appropriate decisions.

CHAPTER 2

REVIEW OF LITERATURE

Introduction

The concept of social support has evaded a unified theory and a timely plan for patient intervention the last 20 years. In addition, social support researchers have failed to identify causal relationships of interaction between social support and health outcomes. Some of the problems with social support research have been lack of longitudinal research, poor social instrumentation, and lack of information about special populations.

The prevailing attitude is that social support reduces stress and its effects by either acting directly on the stress or indirectly buffering stress during high peak periods. These two different views are called the "direct effect" and the "buffering hypothesis" (Pilisuk, Boylan & Acredolo, 1987). Researching the differences between direct and indirect effects is beyond the scope of this study. By definition, a chronic disease requiring dialysis is a stressful condition. The direct and indirect effects of social support on dialysis patients have been considered together as stress moderating.

"Stress" and its effects on health is one of the most researched subjects of modern times. The identification of factors that moderate the effects of stress is important because it improves our understanding of health outcomes when one is exposed to stress. Learning about stress also enables us to understand how people adapt to stressful conditions (Sandler & Lakey, 1982). Nurses are particularly suited to discovering those entities

that moderate stress. As nurses learn more about stress and health they will become more active in teaching wellness lifestyles.

The following literature review will discuss medical help seeking and stress as they relate to social support in a general sense. Following that review is a discussion on the dialysis patient and social support, adjustment, coping, and control. This chapter ends with a summary of the literature review.

Medical Help Seeking

The relationship between social support and seeking medical help is not clear, but two important concepts have emerged. First, the use of medical professionals appears to be based on the value of professional help held by the person and his or her network (Roberts,1988). Roberts identified network density (social embeddedness--multiple numbers of significant others are interconnected), and self-esteem as determining the strength of the network's influence. Second, continued use of health professionals is affected by the professional's ability to communicate concern, sincerity, sensitivity, and commitment to current health improvement tasks (DiMatteo, Hays & Prince, 1986; Roter, 1984).

McKinlay (cited in Roberts, 1988) describes the transition from person to patient and back. When one encounters a problem requiring professional help, he or she experiences the following stages: (1) onset of the problem, (2) response to the symptoms, (3) lay consultation, referral, self-medication, (4) entry into the medical system, and (5) rehabilitation or death. The potential patient usually first consults with, and may also be

treated by, his social network. Social networks are usually described by characteristics such as size, role preparation, and density. Size refers to the number of persons in the network and role preparation is the role occupied by persons in relation to the subject (wife, child, etc.). Roberts has also identified network density (social embeddedness-- multiple numbers of significant others are interconnected), and self-esteem as determining the strength of the network's influence. The denser the network, the more likely the subject is to conform to the network's opinions. Increased self-esteem seems to be associated with increased social support, but the exact nature of that connection is unknown.

Looking at the effects of social support on medical help seeking, Pilisuk, Boylan and Acredolo (1987) conducted a study involving 437 adults in a health maintenance organization (HMO) during a five year span. Men and women over the age of 40 were monitored for medical care utilization and interactions between life stress, social support, and age. The over 40 age group was chosen to eliminate medical utilization subsequent to pregnancy. Participants were administered two questionnaires at the beginning of the study (Holmes Schedule of Recent Experiences and the Schedule of Social Functioning) designed to measure stress and social functioning. They were followed by the number of outpatient clinic visits over the next five years. Stress and social functioning were not measured again. Although the longitudinal research involved a large number of subjects, the design was remiss in assuming that stress and social support would remain the same for five years. However, the report yielded some significant results. Pilisuk and associates (1987) found that higher stress resulted in increased clinic visits for men and older women. (Older was not defined, but the

entire sample was between ages 40 and 65.) High social support resulted in fewer clinic visits for both men and women. An unexpected discovery was that the combination of male gender, low income, and high stress resulted in a marked increase in clinic visits; more than high income men under a similar level of stress. The same was not true for low income women under high stress. Women in general participated in more clinic visits than men, but lower income women exhibited an increase similar to high income women when under stress. The authors discussed the possibility that women have the ability to develop and maintain social networks independent of their socioeconomic status. Therefore, the stress moderating effects of the social network were present regardless of the women's income. Conversely, men tend to interpret their worth by their income and, possibly due to lower self-esteem, may have limited ability to develop social support in a low socioeconomic state.

Patients' satisfaction seemed to be the determining factor in continued utilization of health professionals (DiMatteo, et al., 1986). Quality of communication, verbal and nonverbal, was the main determinant in patients' satisfaction. Positive factors included in verbal communication were: (1) the more that was said, (2) the more questions, direct and indirect, the patients felt free to ask, and (3) negative affect in tone coupled with positive spoken words (Roter, 1984). The professionals' negative tone was interpreted as task oriented and was acceptable in professionals when it was coupled with positive words conveying concern and sincerity. Important nonverbal communication by patients included facial expressions, body movements, and voice tones that communicated the patients' emotions. Crucial to the patients' appointment compliance was the health

professionals' capacity to understand the patients' nonverbal communication. When health professionals also had the capacity to express emotion through nonverbal cues, their workloads (number of patients) increased.

Stress and Social Support

Nuckolls, Cassel, and Kaplan (1972) published a landmark paper outlining the stress mediating effects of social support on the complications of pregnancy. They found that pregnant women who had high life change scores either before or during pregnancy scored lower on pregnancy complications, if they had high favorable psychosocial assets (social support). In the absence of high life change, there were no significant relationships between social support and pregnancy complications. Nuckolls and associates had been studying the quality and quantity of life events since 1949, and coined the term "life crisis". They later evolved the measurable concept of life change units (LCU's) and assigned significant values to each. Their early research supplied the base for the 1971 study of pregnant women in which 271 out of 340 women responded to questionnaires. The respondents answered questions indicating their LCU's and their psychosocial assets. The pregnancy complications were designated by preselected parameters of blood pressure, pre-eclampsia, threatened abortion, hyperemesis, premature rupture of membranes, prolonged labor, low apgar scores, low birthweight, abortion, stillbirth or neonatal death. Psychological assets were defined as self strengths, marital relationships, extended families, social resources, and subjective definitions of pregnancy. One can readily see that social support

was a major factor in psychological assets, but so were the subject's feelings about pregnancy, self esteem, ego strength, loneliness, adaptability, trust, crying, and perception of health. Although some of these factors may be related to social support, one could argue that Nuckolls et al. confounded social support with psychological strengths. They, in fact, did not claim to research social support, but the findings were significant for those interested in the stress mediating effects of social support.

Barrera and Balls (1983) undertook a similar study in examining the stress moderating effects of social support on new, young mothers. As with Nuckolls et al. (1972), the outcome variable was the number of complicated pregnancies and deliveries. Seventy-four young mothers were asked to fill out three social support measures in an attempt to identify approaches to needs assessment research. The most salient predictor of birth complications and psychological symptomatology was satisfaction with support. The more satisfied one was with her social support, the fewer complications she experienced during her pregnancy and labor. Interestingly, network size and supportive behaviors could not be related to satisfaction ratings. It did not seem to matter how large the network was or what the actual helping behaviors were; the expectant mothers' perception of their support was paramount, not the actions of their support network.

Others have studied the relationship between social support, physical health, and psychological health. Most of the literature promote the concept that social support has a buffering effect on physical and psychological health. Psychiatric patients (suicidal and nonsuicidal) have been shown to have smaller support systems when compared with the normal population

(Mullis & Byers, 1987). Twice as many suicidal persons did not participate in religious activities when compared with the nonsuicidal group. Severely disabled schizophrenics (disabled by withdrawal or aggression) in a rural community were found to have low levels of social support (Turner, 1979) when compared to nondisabled schizophrenics.

Brock and O'Sullivan (1985) found that old age and the lack of a social support network were major predictors of institutionalization in the elderly rather than health, locus of control, and attribute variables such as education, ethnic background, and gender. The older the individuals were, the smaller their networks. Loneliness, isolation, and alienation were listed as major symptoms of old age by the subjects.

In addition, Magilvy (1985) found that the best predictors of quality of life in deaf and hearing-impaired older women were social hearing handicap (not totally deaf, but socially handicapped by hearing loss), functional social support, and perceived health. It seems that women who identified with the deaf community (hearing impaired at an early age) indicated a higher quality of life than older women who had always been part of the hearing community and experienced old age onset social deafness. One could interpret the difference in the two groups as the mediating effects of social support on the deaf persons' perception of health and hearing handicap.

Social support has been suggested as a process for reducing occupational stress. Allanach (1988) proposes that nurses experience more occupational stress when they perceive less supportive behaviors. Revicki and May (1985) surveyed a random sample of 320 physicians measuring demographics, medical education, medical-practice characteristics, occupational stress, depression, social support, and locus of control. They

found that occupational stress exerted a direct influence on the development of depressive symptoms. The depression was moderated directly by family (social and emotional) support and indirectly by internal locus of control. The path analysis indicated that family support reduced the impact of occupational stress on depression and personal control moderated the perception of stress. These findings and others (Sandler & Lakey, 1982; Thomas & Hooper, 1983) have suggested that individuals with a strong sense of internal locus of control are able to mobilize beneficial support systems in the presence of stressful situations. One problem in the Revicki and May (1985) study was the respondents' (physicians) knowledge of psychosocial theory which possibly influenced their answers.

Dialysis and Social Support

The stress buffering effects of social support are also addressed in dialysis literature. Dialysis patients spend 12 hours per week with the same group of patients and staff. This process continues until transplantation, home dialysis, or death. It is not surprising that patient satisfaction on hemodialysis highly correlated with nursing and physician activities (Ferrans, Powers, & Kasch, 1987). Nurses' support was high on the patients' list of satisfaction, especially the nurses' ability to understand the personal needs and concerns of the patient and the management of emergencies. Physicians were also important to the patients' satisfaction. In addition to the patients' perception of the physicians' concern and medical management, patients held physicians accountable for avoiding unnecessary financial expenses.

The stress buffering effects of social support associated with physical and psychological health are impressive in dialysis patients. Some have recommended formal patient support group intervention (Payne & Harrison, 1984). Others have emphasized staff education focused on sensitizing the staff to the psychological needs of the patients and providing the staff with basic skills to meet those needs (Nichols & Springford, 1984). However, there is no empirical evidence of that staff expertise in directing support groups, or meeting basic psychological needs will improve physical and psychological health in dialysis patients. Patient and staff comment in favor of the need, but more research is needed to establish cause and effect.

Adjustment to Chronic Illness

The ESRD patient and his or her family make major adjustments in their life style--diet, activity, medication, dialysis, relationships, employment. The support network surrounding the patient contributes to the quality of adjustment he or she experiences. When one discusses social support, one usually portrays the positive effects it can generate. As Tilden and Galyen (1987) have pointed out, not all social support is helpful. Some relationships require effort and produce conflict.

Reiss, Gonzalez and Kramer (1986) completed a study of 23 families, each containing an adult patient with end stage renal disease (ESRD) who was dialyzing in center. They found that patients who were members of strong family units had a lower survival rate than patients whose family units were categorized as less strong. Strong families were defined as: (1)

highly coordinated in group activities, (2) higher educational achievement and income, (3) increased longevity of relationships, and (4) more intelligent. The finding of poor survival associated with strong families was not expected and several explanations were discussed. First, it is possible that although a highly coordinated family may rally effectively for acute family emergencies, it may make the family more vulnerable over the long course of a chronic illness. Second, educational achievement is usually associated with more time commitment to work. This leaves the ESRD patient alone and unprotected. Third, longevity has the potential of placing more generations within the family unit thereby increasing the stress of the family--adding the problems of each generation. Intelligence was measured by the ability to resist distraction, organize complex data, and to define structure. The more intelligent families were associated with poorer survival. "It is possible that the families whose cognitive functioning is influenced by distractions cannot grasp the full impact of what is happening to them" (Reiss et al, 1986, p. 8). According to this reasoning, lesser intelligence would then afford a measure of protection.

The overwhelming majority of the literature addresses the positive results of social support. There are reports (Davis, Hess, Harrison & Hiss, 1987; Follick, Smith & Turk, 1984; Northouse, 1988; Webb & Wilson-Barnett, 1983) of chronic patients adjusting better to a variety of conditions--breast cancer, hysterectomy, ostomy's, and diabetes-- when social support is present. In these studies social support was positively correlated to adjustment and subsequent control or level of functioning. One of the key sources of support was the marriage partner. Spouse and family support were associated with the patient's shorter recovery, more

positive outlook, and higher level of functioning. The sad discovery was that although most of the patients perceived fair to excellent professional support, the majority of the spouses and families felt excluded from professional support, especially in those conditions peculiar to women's health--mastectomy, hysterectomy, and childbirth. When the spouses were "left out", the patients performed worse and perceived less support from their spouses.

Similar to hemodialysis patients, other patients with chronic diseases also benefit from social support. Most of the studies (Dimond, 1979; House, 1987) defined social disability as a poor level of functioning within family, marriage, work, social network, and friendship. Social support was defined as expression of positive affect, endorsement, and aid. The researchers discussed different aspects of support, but quality of life, and physical and psychological adjustment to chronic illness were improved by increased family cohesiveness and open expression.

When a new patient begins dialysis, he or she is challenged to become compliant. Compliance in hemodialysis patients has been defined as acceptable blood levels of serum potassium, serum phosphorus, and inter-dialytic weight gain between treatments (Betts & Crotty, 1988; O'Brien, 1981; Tracy, Green & McCleary, 1987). The traditional hypothesis has been that the more compliant patients are better adjusted and enjoy improved health. Recent results did not support this hypothesis and called for a new definition of compliance. Tracy et al. found "super-compliance" (consistently compliant with diet, weight gain, and medication) associated with withdrawal, negativism, social alienation, and a poor prognosis for adaptation. On the other hand, poor compliers were more depressed

initially, but by three months on dialysis were the least depressed. Fluid abusers exhibited high denial; phosphorus abusers did not have a problem with denial and also had the ability to prevent a global negative attitude. Betts and Crotty questioned the existence of noncompliance as it is now defined when they could not find a significant correlation between inter-dialytic fluid gain, phosphorus, and potassium; or any association of these three to adjustment (adjustment measured by the Response to Illness Questionnaire) to dialysis. They suggested that we may be seeing different levels of compliance in separate areas of medication (phosphorus control), diet (phosphorus and potassium) and fluid intake.

Another researcher (O'Brien, 1981) indicated that perceived support of family and care givers was consistently positively correlated with compliance. When the groups were controlled for education, the expectations of the caregivers (i.e. nurses, physicians) were found to be more powerful predictors of compliance for the less educated dialysis patient overall, and for the more educated patient after several months of dialysis.

Still another dimension was added when noncompliance was found to be associated with longer survival (Reiss et al., 1986). Is it possible that compliance is associated with risk in survival and emotional adjustment? Could noncompliance serve as a stress mediator allowing the patient more control and thereby "flagging" a denial of their condition? Conversely, compliance would mean acceptance of one's fate, eventually being excluded from the family due to the life style changes required by ESRD. Is our definition of compliance in hemodialysis patients invalid? In any event, researchers are beginning to question recommendations for using social

support as a means for improving compliance as it is now defined in dialysis literature.

Coping

Personality variables such as optimism, hardiness, and locus of control seem to have an impact on health and coping with chronic illness. The following researchers looked at personality characteristics in relation to health, and some of them correlated these traits with social support. However, all of these topics seem to be related to social support and merit attention.

One of more difficult aspects of dialysis is the patients' loss of control. They are instructed what to eat, what medication to take, and what activities to plan. In addition, travel is almost impossible and the dialysis treatment is difficult. It is similar to a person submitting to three outpatient surgical procedures per week for the rest of their life. There are no options except transplantation, death, or divine intervention. Locus of control has been suggested as a factor in the coping process. Locus of control may be categorized as internal or external. The internally oriented person interprets life events as consequences of one's own actions, whereas the externally directed individual sees events as unrelated to one's behavior (beyond his control).

Bacon's study (1983) dealt with locus of control and adjustment of female spouses whose husbands were on hemodialysis. The patient's well-being appeared to be related to the spouse's adaptation to the stress of chronic illness. Fifty-six spouses' (all wives) locus of control and

emotional adjustment were measured by five different self-reports. In general, external locus of control was related to poorer adjustment; but an internal locus of control was not found to be related to better adjustment when compared to a neutral group. A subgroup of home dialysis spouses exhibited more internal locus of control than the in-center wives, but LOC was not related to better adjustment in either group. Two conclusions were offered: (1) a strong perception that one is in control may not be functional in the face of a truly uncontrollable condition, and (2) Externally oriented female spouses faced with the stress of living with chronic disease may not be able to adapt as easily as internally oriented women. Although this study implied better patient adjustment with improved spouse adjustment, it may be beneficial to direct future research toward the patients' locus of control and social support as well as the spouses' locus of control and social support.

Other research (Sandler & Lakey, 1982; Thomas & Hooper, 1983) on locus of control has also supported the positive relationship between better health, social interaction, and internality. Externally oriented persons exhibited more anxiety when encountering negative life events, and surprisingly possessed larger social support networks. However, internals had the ability to benefit from the stress buffering effects of social support where externals did not.

Optimism has also been suggested as a factor in coping with disease symptomatology. A group of undergraduate college students who initially reported high optimism were less likely to report being bothered by physical symptoms than were subjects who initially reported low optimism (Scheier & Carver, 1985). The authors theorized that optimistic persons, defined as

possessing generalized outcome expectancy, should be more likely than pessimistic persons to conclude that the obstacles facing them can be overcome. Therefore, optimistic personalities would exhibit less physical stress symptoms.

In addition, stress was shown to have a direct impact on illness in both hardy and nonhardy groups. Hardy individuals, defined as a "personality composite of control, commitment, and challenge" (Wiebe & McCallum, 1986, p. 427) may be healthier because they practice better health related behavior. The hardy group was able to maintain better health practices while under stress than the nonhardy group. The conclusion was that hardiness did not change the direct effects of stress, but mediated the persons response through his health related behavior. One can only speculate about the support networks of these two groups, but it would have been interesting to determine the relationship between hardiness and social support.

Control

The connection between control and locus of control may be explained by one's perception of the dominating influence or authority in one's life. Both the internal and the external person believe that there is control; the difference is that the internal person believes he has personal control over those things that happen to him. An externally focused person views control in the hands of fate, luck, chance, or a "powerful other". Generally speaking, one with an external locus of control believes that his actions will not change what happens to him. It is conceivable that many people have mixed

expectancies; i.e. most of us possess both internal and external loci of control.

Theoretically, people have a desire to control those things that affect them. Somehow they believe that they or some powerful other can direct their life better than anyone. Based on this assumption, many believe that personal control will help reduce stress, improve outlook, and contribute to overall improved physical and psychological health (Averill, 1973; Binik et al., 1982; Curbow, 1986; Kirschenbaum, Sherman & Penrod, 1987; Pohl & Fuller, 1980). Averill defines personal control as distinguished by three discrete types: (1) behavioral, direct action on the environment resulting in regulation or modification of a harmful stimulus, (2) cognitive, the interpretation of potentially harmful events, and (3) decisional, having a choice among alternative courses of action.

Researchers (Binik et al., 1982; Johnson, Kurtz, Anderson, et al., 1984; Wauters, Hunziker & Brunner, 1983) have hypothesized that increased patient control during dialysis treatments has a salutary effect on the patients' well-being. Behavioral control was the basis of a study by Binik and associates. They described the pain in 53 hemodialysis patients and examined whether or not self-care hemodialysis resulted in a reduction of pain. All of the subjects were dependent on dialysis for existence and were therefore not able to circumvent the experience (stimulus). However, based on Averill's (1973) behavioral control theory, it could have been possible to regulate or modify the stimulus through self-care. Fifteen of the patients were home care, 19 hospital self-care, and 19 were hospital staff care. The researchers employed the use of the McGill Pain Questionnaire (MPQ) and personal interviews to measure perceived control and pain response. The

report is not clear about how perceived control was measured (probably by interview). Actual control was identified as a construct of the different types of dialysis, with home dialysis affording the most control, hospital self-care providing intermediate control, and hospital staff-care supplying the least control. The actual degree of control was not found to be associated with a reduction in pain during dialysis. However, an increase in perceived control was correlated with a decrease in reported pain during dialysis. Social support was not measured in the study.

Autonomy in one's preference of treatment type has not been shown to increase longevity. The survival rates of the different types of dialysis (in-center hemodialysis, in-center self-care, continuous ambulatory peritoneal dialysis (CAPD), and home hemodialysis do not vary significantly (Johnson, Kurtz & Anderson et al.,1984; Johnson, Kurtz & Mitchell III et al., 1984; Kalman, Wilson & Kalman, 1983; Kurtz & Johnson, 1984; Wauters, Hunziker & Brunner, 1983). Concepts such as cost containment, more control, quality of life, and better rehabilitation are emphasized as benefits as one moves toward increased autonomy in his dialysis regimen.

Other researchers (Kirschenbaum et al., 1987) have developed a cognitive-behavioral approach to self-directed dialysis. The purpose of their study was to test the efficacy of cognitive-behavioral intervention in dialysis. Preparation for the program included initial rationale, decisional counseling, behavioral contracting, self-monitoring, and staff support/problem solving. Four subjects with a mean age of 70 years were given a list of 25 self-care tasks they could complete during each dialysis treatment. Over a period of one month, the participants checked off completed behaviors with each treatment. One of the subjects could not

complete the project due to poor health. The combined approach of behavioral and cognitive ("making sense") control of the procedure, resulted in an improvement in mood, perceived well-being, and better fluid regulation in the three patients who completed the research. The researchers did not measure social support so one can only speculate about the influence of support from the staff. Since the elderly are known to have dwindling social support networks (Brock & O'Sullivan, 1985; Magilvy, 1985), their motivation for improvement could have been increased social interaction as well as increased control.

Among the different aspects of control, decisional control has inspired the most research with different patient populations. In recent years, health care has been redirected with the notion of informed consent. Present thinking has embraced the concept (Alvino, 1986) that the patient has the right to make his own decisions regarding his health care. Coupled with this idea is the health professional's responsibility to supply the patient with the necessary information to make a decision. In response to these changes, nursing care plans have been designed requiring the patient to make decisions about his care in order to combat powerlessness (Fuchs, 1987).

The research on choice (decisional control) corroborates the hypothesis that increased ability to choose is associated with positive outcomes. Restriction of patient choice of Medicaid services resulted in negative perceptions about health care (Curbow, 1986). Choice in students resulted in improved grades (Kirschenbaum, Tomarken & Ordman, 1982). Adult college students took part in a study improvement program. Some of the students were given daily and monthly planners with choices, and some

were presented daily and monthly planners without choices. The choice groups outperformed the no choice groups with respect to grades. The monthly choice group performed the best.

Choice was also studied in the elderly. Pohl and Fuller (1980) examined 50 residents in a nursing home with respect to health, choice in relocation, income, perceived choice within the institutional environment, and social interaction. These variables were correlated with various dimensions of morale: agitation, attitude toward own aging, lonely dissatisfaction, and combined morale factors. Perceived choice (decisional control) guided the research. The variables found to be significant in relation to improved morale were: (1) increased perceived choice within the institution, and (2) increased social interaction. The study did not examine the relationship between choice and social interaction, but it is possible that there was some association between perceived choice and social interaction as well as morale.

What happens when the ESRD patient chooses his course of treatment and the results are unfavorable? Wagener and Taylor (1986) interviewed 29 individuals who had undergone cadaveric kidney transplantation. Thirteen of the patients had successful transplants (several weeks to three years), and 16 had returned to dialysis secondary to graft rejection. The researchers used cognitive dissonance theory as a theoretical base and predicted that the subjects would respond to adverse outcomes by modifying their cognitions about their decision. The altered cognitions took the form of three possible choices: (1) minimize personal responsibility (place blame on someone else), (2) decide that the consequences were not very severe, or (3) decide after the fact that no other decision was possible. Wagener and

Taylor found that failed transplant patients chose the third option. One of the participants who was dying as a result of side effects from the transplant expressed herself this way:

> I received the letter saying you might call, and I just wanted to tell you that I know I did the right thing. I really didn't have any other choice. On dialysis, we couldn't travel or anything. I know that, even though I am dying from this transplant, it was the only thing we could have done. (Wagener & Taylor, 1986, p. 491)

Summary of Literature Review

The literature supported the concept that social support is a stress moderator resulting in improved psychological, physical, and occupational health. The exact mechanism was unknown. Researchers found that more contact with social support, increased satisfaction with support; and/or in some cases larger social support networks were associated with better health, increased morale, increased adjustment to chronic illness, improved compliance and seeking medical help. Whether or not one decided to seek professional help depended on the value of professional help placed by the subject and his support network.

In addition, personality characteristics such as optimism, hardiness, and internal locus of control as well as increased perceived control were shown to have a stress moderating effect. Control taxonomy included behavioral, cognitive and decisional control. There were subtle differences, but they all implied the subject's ability to direct his affairs by action, cognition, or decision. More control and more perceived control were

associated with decreased negative health symptoms and favorable mood, increased well-being, better performance, better morale, and increased compliance.

Although increased control and increased compliance seem to be desirable factors, they failed to correlate favorably with survival in dialysis patients. A zero correlation seemed to exist between control and survival in dialysis patients. At least one study (Reiss et al., 1986) demonstrated a negative correlation between compliance and survival in dialysis patients. Other researchers (Tracy et al., 1987) associated "super compliance" with poorer adjustment in dialysis patients. Since researchers failed to find a relationship between the components of compliance in dialysis patients, and failed to find a positive relationship between compliance and improved adjustment and survival; the current definition of compliance in dialysis patients was questioned (Betts & Crotty, 1988). Social support was associated with increased compliance, but it is dubious whether social support should be used to enhance compliance as it is now defined for dialysis patients.

One should keep in mind that none of the research cited in this paper was causal. The relationships were correlational with the exception of Revicki and May's (1985) path analysis showing family support directly reducing stress, and personal control directly moderating the focal person's perceptions of stress. In any event, there were strong negative correlations between social support and stress, as there were between personal control and stress. Social support also exhibited strong influence on the patient's decision to comply with and seek professional help.

Social support and personal control (decision) have been studied in

relation to their ability to reduce stress. The question remains that when health related decisions are called for in dialysis patients, what is the impact of social support? More specifically, how is social support related to dialysis patients' decisions concerning transplantation?

CHAPTER III

METHODOLOGY

Introduction

This study was undertaken to explore the relationship between social support and decision making in dialysis patients. One of the most important decisions an ESRD patient makes is whether or not he will have a kidney transplant. For that reason the social support network of each patient was examined in light of his and his network's decision for transplantation. Four research questions were investigated. The remaining part of this chapter is devoted to the research design, sample selection, sample characteristics, and the method used for measuring the concepts of social support and decision.

Research Questions

Research question one. What is the relationship between the patient's decision and his social network's opinion about kidney transplantation?

Research question two. Do age, education, income, and network size have a relationship to decision for transplantation?

Research question three. How do the social networks differ between the patients deciding for transplantation and those deciding against transplantation?

Research question four. Do the dialysis staff and fellow patients

Research question four. Do the dialysis staff and fellow patients supply more support in the yes transplant group?

Research Design

This research used a comparative, descriptive, approach, comparing social support and demographic variables of the "no" transplant group with the "yes" transplant group. Age, gender, education, income, network size, ethnicity, affect, affirmation, aid, and support roles were compared in the "yes" and "no" groups. Staff and physician roles in patient support were examined for their presence and their relationship to the patient's transplant decision. In addition, the subjects' decisions concerning transplantation were examined in relation to their agreement or disagreement with their support groups.

Sample

The subjects in this study were hemodialysis patients from two chronic hemodialysis centers in East Tennessee. The participants were obtained from different dialysis centers in an attempt to increase the representativeness of the sample. The nonprobability samples obtained were strengthened by a high rate of participation. The dialysis staffs were similar. They consisted almost entirely of dialysis nurses. Dialysis technicians occupied less than five percent of the staff. In addition, each center contributed one nutritionist, one social worker, and several physicians. However, the patients' medical plans were directed by their

primary physicians. Permission to access these subjects was obtained from the administration of each dialysis center.

Sample Selection

The study targeted hemodialysis patients who perceived they were physically eligible for transplant and had made a decision about kidney transplantation. The limited availability of potential subjects necessitated including everyone who consented to participate, and had made a decision about transplantation.

One center (Center A) reserved the right to direct purposive sampling. There were 13 participants in this group. Center A had an extremely high elderly population (over 65) who were not eligible for this study. An estimated 20-25 persons could have been accessed from Center A. Sixteen of these were given the opportunity to respond, and three refused.

The second center (Center B) imposed no restrictions and all eligible persons were included in the project. There were no refusals. However, six questionnaires were discarded due to missing data in the decision category. A total of 32 subjects from Center B, and 13 subjects from Center A made a total of 45 participants in the study.

Center A supplied subjects from three satellite locations. Out of 13 subjects from Center A, two were from location 1, four from location 2, and seven from location 3. Even though the dialysis staffs were different, the same group of physicians were associated with all three locations.

Subjects from Center B were dialyzed in the same location. A different group of physicians and staff serviced Center B.

Data Collection

After approval was obtained from the University of Tennessee, Knoxville, Committee on Research Participation; permission was solicited from two dialysis centers. Approval and permission from these governing bodies allowed the researcher to approach the potential subjects. Final permission was granted by the subject when each consented to participate in the study. The responses were kept confidential. See Appendix B for the cover letter that accompanied the NSSQ questionnaire.

All eligible subjects, except four, were approached by the researcher while they were on dialysis and asked if they were interested in filling out a questionnaire that would contribute toward research in patients on dialysis. All materials necessary for completion of the task were then provided by the researcher. Most of the patients read and marked their own forms. However, if they could not write or read for any reason (illiteracy, writing hand connected to machine, glasses not available, etc.), the researcher read the questionnaire to the subject and marked it. The four participants who were not approached personally were from one of the satellite locations of Center A. They were contacted and returned their forms by mail.

The data collection took place over five days. The locations with more patients required two days each. Four different locations (connected with two main centers) in East Tennessee were included in the study.

Sample Characteristics

Table 2 presents the sample's demographic characteristics. The subjects from both dialysis centers were combined. It is apparent that the most frequently occurring subject was a married, White female, 56-65 years of age, with a high school education. Length of stay on dialysis and income are presented in Table 3. The largest groups in this table are subjects with an income of < ten thousand dollars per year, who have been on dialysis between 6 and 12 months. However it must be pointed out that the majority of participants have been on dialysis in excess of 1.5 years. The unknowns were answers left blank by the subjects.

Measurement

The broad concept of social support embodies all interpersonal interactions and is too global to research. To remedy the problem, researchers have called for studies that deal with special populations, causal relationships, and focused models of stress-distress relationships. The idea that one pattern of social support fits everyone is too broad to be of any use. Barrera (1986) suggests that the concept of social support be divided into social embeddedness, perceived social support, and enacted support.

Social embeddedness is "that social support concept that refers to the connections that individuals have to significant others in their social environments" (Barrera, 1986). One may approach the study of social embeddedness by using broad indicators like marital status, participation in

Table 2. Frequency Distribution And Percentage For Demographic Variables (N = 45).

Variable	n	%
Gender		
Unknown	3	7
Male	23	51
Female	19	42
Ethnicity		
Unknown	4	9
Black	8	18
White	33	73
Marital Status		
Unknown	1	2
Widowed	5	11
Divorced	8	18
Single	8	18
Married	23	51
Age		
18-25	3	7
26-35	4	9
36-45	8	18
46-55	11	24
56-65	14	31
>65	5	11
Education		
Unknown	4	9
7 years	2	4
8 years	5	11
9 years	4	9
10 years	3	7
11 years	4	9
12 years	15	33
13 years	1	2
14 years	1	2
15 years	1	2
16 years	4	9
18 years	1	2

Table 3. Frequency Distribution And Percentage For Income And Length Of Stay On Dialysis (N = 45).

Variable	n	%
Income		
Unknown	6	13
>50,000	1	2
26,000-49,000	4	9
10,000-25,999	7	16
<10,000	27	60
Length of Stay on Dialysis		
Unknown	1	2
<.5 year	5	11
.5-1 year	10	22
1-1.5 years	5	11
1.6-2 years	7	16
3 years	4	9
4 years	3	7
5 years	3	7
6 years	2	4
8 years	1	2
10 years	2	4
12 years	1	2
14 years	1	2

community organizations, and contact with friends. The idea is that the more socially embedded one is, the more potential resources he has in a crisis.

Another approach is the social network analysis. Individuals who have important relationships with the focal subject are identified. The network is then described in terms of density, size, and reachability. Both

approaches describe one's connections with others.

Perceived social support "characterizes social support as the cognitive appraisal of being reliably connected to others" (Barrera, 1986). This definition is compatible with Lazarus' (1984) theory of perception and interactions, and the theory of attachment (Norbeck, 1985). The perceived social support instruments incorporate perceived availability and adequacy of supportive ties.

Enacted support refers to rendering assistance to the focal person. Enacted is distinguished from available support by implying actions performed when support is rendered (Barrera, 1986). Although the NSSQ has questions about specific helping behaviors, it primarily measures the respondent's perception of what the person in question would do in a contrived situation. It is assumed that, although the situation is theoretical, the respondent may base an answer on similar past experience with the designated person.

Instrumentation

Norbeck's Social Support Questionnaire (NSSQ) was used to measure social support in hemodialysis patients. Norbeck bases her instrument on Kahn's (1979) concept of social support. The NSSQ is compatible with Barrera's (1986) construct of perceived social embeddedness, perceived social support, and enacted support by identifying persons who have important relationships with the focal subject, and retrieving the subject's perception of these relationships. The instrument assesses affect, affirmation, aid, number in network, duration of relationship, frequency of contact, and loss (see Appendix C).

Reliability and Validity

The NSSQ was tested for subject's response bias by the Marlowe-Crowne Social Desirability Scale (MCSDS). This self-report instrument measures the subject's bias toward selecting socially desirable or undesirable answers. The NSSQ was determined to be free of social response bias (Norbeck, Lindsey, & Carrieri, 1981). The correlations ranged from .01 to .17 showing a nonsignificant relationship between the NSSQ and the MCSDS.

Concurrent validity of the NSSQ was also tested to determine the degree to which the NSSQ corresponds with known measures of social support. Cohen and Lazarus' Social Support Questionnaire (SSQ) was administered concurrently with the NSSQ to 42 subjects (Norbeck et al., 1981). The SSQ was divided into three segments--Tangible Support, Informational Support, and Emotional Support--and correlated with Total Functional, Total Network, and Total Loss in the NSSQ. The results were mixed. The NSSQ and the SSQ correlated significantly (range .44 to .56) on approximately half of their content overall. The strongest correlations were between Emotional (SSQ) and all sections of the NSSQ except Total Loss. However, Total Loss (NSSQ) showed a significant correlation with Tangible Support in the SSQ (-.44, $p < .01$). An important fact is that the NSSQ and the SSQ correlated significantly with each other in every category.

In addition to comparing social support instruments, construct validity was studied by scrutinizing the relationship between the NSSQ and the theoretically relevant variables of psychiatric symptomatology and life stress. To test psychiatric symptomatology the Profile of Mood States

(POMS) was administered in conjunction with the NSSQ to 75 subjects from one group (Norbeck et al., 1981). None of the mood subscales or the total negative mood score of the POMS were significantly related to affect, affirmation, and aid in the NSSQ. However, the depression and confusion subscales (POMS) correlated significantly ($p < .05$) to total loss in the NSSQ.

Looking at another facet of construct validity, the POMS, NSSQ, and the Sarason Life Experiences Survey (LES) were administered to a group of 33 to study social support as a moderator of life stress (Norbeck et al., 1981). Total negative mood score from the POMS was used as a dependent variable in a multiple regression analysis. The NSSQ three main variables and the negative life experiences score from the LES were used as predictor variables. No significant relationships were found between any of the questionnaires--NSSQ, POMS, or LES. However, Norbeck and associates felt that the sample may have been too small since no significant relationships were found between negative mood (POMS) and negative life experiences (LES); one would expect to find a relationship between these two constructs.

Reliability of the NSSQ was examined (Norbeck et al., 1981) by test-retest, and internal consistency measures. Test-retest was accomplished by administering the NSSQ to 75 subjects initially and again to 67 one week later. All the functional and network property items (affect, affirmation, aid, number in network, duration, and frequency of contact) had a high correlation ranging from $r = .85$ to $r = .92$. Kendall Tau B correlation coefficients for test-retest in the persons lost division ranged from .83 to .71 ($p < .0001$). Overall test-retest showed strong reliability in the NSSQ.

Internal consistency was tested through intercorrelations among all the items in the NSSQ (Norbeck et al., 1981). The correlations ranged from

.69 to .97 ($p < .0001$) between all the network functional and network property items. There were no significant relationships between loss items and network functional or network property items ($r = .54$ to $r = .68$). Still, reliability was considered a strong success relying on high internal consistency for most of the NSSQ and high test-retest values.

Two years after her development of the NSSQ, Norbeck (Norbeck, Lindsey, & Carrieri, 1983) began working on establishing norms for employed adult subjects by using the NSSQ. The amount, type of support, and sources of support available for this group of male and female respondents were described. No other studies attempting to synthesize normative data using the NSSQ were found. Certainly, dialysis patients do not have this type of data available.

Modification of NSSQ

Norbeck's questionnaire (NSSQ) was adapted for dialysis patients in this study (see Table 4). This modification involved addition of questions regarding sociodemographic characteristics. However, the original questions remained intact, and Norbeck's Likert response format was retained. The original NSSQ had the subjects list by name each person in their support group. In order to make it easier for dialysis patients to respond, this questionnaire listed 16 possible positions (wife, brother, etc.) for the subjects. This differs from Norbeck's questionnaire in that she did not limit the number of listings. However, 16 positions were found to be more than adequate since no one listed more than 12 persons in their network. All questions were formatted to fit into two pages (see Appendix C).

Table 4. Anatomy Of The Norbeck Social Support Questionnaire: Adapted For Dialysis Patients.

Variables	Question Number
Affect	6-7
Affirmation	8-9
Aid	10-11
Number in Network	5
Duration of Relationship	12
Frequency of Contact	13
Identify Loss	14
Number Lost	14
Position Lost	not measured

The objective was to limit writing since many dialysis patients were handicapped by illiteracy and/or upper extremity vascular shunts requiring immobilization while on dialysis. The subject needed only to circle the appropriate person and write in a number beside the name. The projected time required to complete the questionnaire was 5 to 20 minutes (Norbeck et al., 1981).

The only other difference between Norbeck's original form and the one used in this research was that this questionnaire did not ask the respondents to identify the third subset "positions lost". Undoubtedly loss was significant, but so far it has only been shown to relate to tangible support and depression (Norbeck et al., 1981). Since this paper was primarily interested in support as it related to decisions, identification of the presence of loss was considered adequate.

Operational Definitions

Social Support and decision were operationalized as the following definitions.

Decision was operationalized as the subject's answer of "for", "against", or "undecided" concerning his or her obtaining a renal transplant. Further, the subject's perception of the decision of each person in his or her support network was recorded--questions 4 and 15 in Appendix C.

Affect was defined as the numerical score on questions six and seven of the NSSQ, items which reflect the ability of another person to make the subject feel liked, loved, respected, or admired (Norbeck et al., 1981)--Appendix C.

Affirmation was operationalized as a numerical score on questions eight and nine of the NSSQ, items which reflect the subject's perception of how much he can confide in the other person, and how much that person agrees with or supports the subject's actions or thoughts (Norbeck et al., 1981)--Appendix C.

Aid was operationalized as a numerical score on questions 10 and 11 of the NSSQ, items which reflect the subject's perception of another's response in two different hypothetical situations requiring the other person to lend help or aid to the subject (Norbeck et al., 1981)-- Appendix C.

Duration of relationship was operationalized as a numerical score on question 12 of the NSSQ, the item which reflects the length of time the subject has known the other person, and how often the subject has contact with him (Norbeck et al., 1981)--Appendix C.

Frequency of contact was operationalized as a numerical score on

question 13 of the NSSQ, the item which reflects how often the subject sees the other person (Norbeck et al., 1981)--Appendix C.

Number in network was operationalized as the sum total of persons on question five of the NSSQ, the item reflecting the number of persons important to the subject's life (Norbeck et al., 1981)--Appendix C.

Loss was operationalized as the subject's response on question 14 of the NSSQ, the item indicating if the subject had lost any important persons in his network in the last year due to death, divorce, etc.--Appendix C.

Subject Decision was operationalized as subject's answer "yes" or "no" regarding his or her wish to undergo kidney transplantation.

Support Group Decision was operationalized as the subject's answer "for", "against", or "undecided", regarding his or her support group's opinion about the subject having a kidney transplant.

Plan of Analysis

Analysis of the data obtained in this report was accomplished by use of the StatWorks statistical package designed by Cricket Software for the Apple Macintosh computer (Rafferty, Norling, Tamuru, McMath & Morganstein, 1985). Nonparametric procedures such as chi-square (X^2), and descriptive statistics were utilized for reporting data and comparing differences between some of the variables in the "yes" transplant and "no" transplant groups. Independent samples *t*-tests were used to compare the means of all continuous variables.

Descriptive statistics such as means and percentage distributions were reported for age, marital status, education, dialysis time, network size,

loss, and income. A comparison of agreement between the patient's decision on transplantation and his or her network's decision on transplantation is presented in a table of percentages. Ethnicity, and gender were cross-tabulated (X^2) with respect to the subject's decision regarding transplantation.

In addition, the support groups were examined for staff (primarily nurse), physician, friend on dialysis, friend, spouse, family, neighbor, and minister differences between the "yes" transplant and "no" transplant groups. Independent samples t-tests were used to compare the means for each of these roles.

Affect, affirmation, aid, duration of relationship, and frequency of contact, were also analyzed by t-tests. The composite raw scores of the "yes" transplant group were compared with the raw scores of the "no" transplant group. All numerical data were computed by using Norbeck's method of scoring the NSSQ. In general, the higher the raw score, the more social support available to the subject.

CHAPTER 4

RESULTS AND DISCUSSION

The purpose of this study was to explore the relationship between social support and decision in dialysis patients. Social support and demographic data were analyzed by comparing variables of the "yes" and "no" transplant groups. The "yes" group consisted of subjects who had made a decision to have a kidney transplant. The "no" group were those subjects who had decided not to have a kidney transplant.

Transplant Decision

Research question one. What is the relationship between the patient's decision and his social network's opinion about kidney transplantation?

The results indicated that there was a strong positive relationship between the patient's decision and his social network's opinion. In general, the subject did not choose opposite his network's choice. Table 5 contains the data used to address research question one. Out of 22 subjects in the "yes" group, 15 persons had 100 percent network agreement for transplantation; 7 persons showed 50 percent or greater agreement for transplantation. None of these subjects designated anyone in disagreement with their decision. However, 7 subjects from the "yes" transplant group listed 10 to 50 percent of their network as undecided.

There were 23 subjects who decided not to have a transplant. Two persons listed 100 percent disagreement; two designated greater

Table 5. A Comparison Between The Subjects' Decisions For Or Against Transplant And Their Social Networks' Agreement, Disagreement, or Indecision.

Congruence Between Network and Subject Decision	Subject "Yes"[a] (n = 22)			Subject "No"[b] (n = 23)		
	Network Support			Network Support		
	Agree	Disagree	Undecided	Agree	Disagree	Undecided
100% Agree	68% (15)			9% (2)		
50-90% Agree	32% (7)			4% (1)		
10-49% Agree				13% (3)		
100% Disagree					9% (2)	
50-90% Disagree					9% (2)	
10-49% Disagree					22% (5)	
100% Undecided						40% (9)
50-89% Undecided			5% (1)[c]			30% (7)
10-49% Undecided			27% (6)			13% (3)

Note. The numbers in parentheses refer to the number of subjects.

[a]Subject "Yes" group refers to those persons deciding for transplantation.

[b]Subject "No" group refers to those persons deciding against transplantation.

[c]This subject's support group was 50 percent undecided.

than 60 percent disagreement; and five less than 38 percent disagreement. This group differed from the "yes" group in that it had only 6 out of 23 support groups showing some level of agreement. The most prevalent category in the subject "no" transplant group was undecided. Sixteen out of

23 subjects had support groups with greater than 50 percent undecided about the subject's decision. Nine of the 16 were 100 percent undecided. Only four subjects in the "no" transplant group chose to refuse transplantation while their support group was 60 percent or more in favor of transplantation.

Although the results in the "no" transplant group were striking in that it was uncommon for persons to choose opposite their network's choice, dialysis patients in the "yes" transplant sample were in stronger agreement with their support groups. These findings were congruent with Janis and Mann's (1977) decision theory explaining man's tendency to procrastinate with and rationalize away difficult decisions. It seems logical that if (a) difficult decisions are hard to make, and (b) if deciding for transplantation is more difficult than doing nothing, then (c) one may need more support to make a difficult decision--for transplantation.

Demographic Variables, Network Size, Length Of Stay On Dialysis

Research question two. Do age, education, income, and network size have a relationship to decision for transplantation?

The subjects were questioned in terms of their age, education, income, network size, and time on dialysis. The means for the "yes" and "no" transplant groups are displayed in Table 6. One can readily see that the mean size of the network, education, and income were very similar for both groups. Although the social networks of the "yes" group tended to be slightly larger in this sample, the difference was not enough to be statistically significant. None of the differences in Table 6 were significant by *t*-test.

Table 6. Descriptive Comparisons Between The "Yes" Transplant And "No" Transplant Groups.

Subjects (N = 45)	Means			
	"Yes" Transplant		"No" Transplant	
	Mean (n = 22)	SD	Mean (n = 23)	SD
Persons in Network	7.5	2.9	6.2	3
Education (years)	11.1	3.3	11.2	3.1
Time on Dialysis (months)	27.7	36.3	42.5	40.0
Annual Income (dollars)	15400	8764	15263	7155
Age (years)	43.6	13.7	49.6	15.3

The subjects opting for transplant tended to be younger by approximately six years, although this was not statistically significant ($p = 0.172$).

A comparison of length of time on dialysis did not yield a statistically significant difference, but there are some pragmatic considerations. As shown in Table 6, the "yes" group had been on dialysis approximately 28 months as compared to the "no" group with a mean of 42 months. This difference could be a reflection of the deteriorating physical condition of the long term dialysis patient, therefore removing him or her from the possibility of a transplant. However, it could also reflect an optimal time for deciding in favor of transplantation.

Some interesting unexpected findings were the differences in gender and length of stay on dialysis in the "yes" and "no" groups. Approximately 75 percent of the "yes" transplant group were women. Almost the exact opposite, 78 percent men, was true for for the "no" transplant group. The

sample consisted of 45 percent female and 55 percent male subjects. This negated the possibility that more women chose transplantation because there could have been more women in the study. There were in fact more men in the sample. Women in this sample were at least three times more likely to choose transplantation than men, (see Figure 2), $X^2(1, \underline{N} = 42) = 11.3, \underline{p} < .001$.

Cell Count Row % Column % Total %	Female	Male	Totals
"Yes" **Transplant**	14 73.68 73.68 33.33	5 26.32 21.74 11.90	19 45.24
"No" **Transplant**	5 21.74 26.32 11.90	18 78.26 78.26 42.86	23 54.76
Totals	19 45.24	23 54.76	42 100.00

Figure 2. Cross Tabulation Of Transplant Decision By Gender.

Cultural influence was also questioned as a possible confounder with gender. There were eight Blacks in the sample. Four were male, three were female, and one's gender was unknown. Two of the Blacks choosing transplant were males and two were women. This indicates that it was the White male who was reluctant to agree to kidney transplantation. Figure 3 indicates that Blacks in this sample were more likely than

Chi-Square: 2.09
Significance .16

Cell Count Row % Column % Total %	**White**	**Black**	Totals
"Yes" **Transplant**	13 72.22 39.39 31.71	5 27.78 62.50 12.20	18 43.90
"No" **Transplant**	20 86.96 60.61 48.78	3 13.04 37.50 7.32	23 56.10
Totals	33 80.49	8 19.51	41 100.00

Figure 3. Cross Tabulation Of Transplant Decision By Ethnicity.

Whites to choose transplantation. Thirty-nine percent Whites chose transplantation and 61 percent did not. These figures sharply contrasted with 63 percent Blacks choosing transplantation and 37 percent refusing. If one considers this information with the fact that 12 Whites choosing transplantation were female and only three were male, it is readily apparent that the female dominance in the "yes" group was primarily due to White females. Why were Black males just as likely as Black females to decide for transplantation and White males only 25 percent as likely as White females to choose transplantation? One possible explanation is the social support network surrounding the different subgroups. In agreement with Pilisuk et al. (1987) findings concerning the limited social support structures of lower socioeconomic males, it is possible that White females

and Blacks have the ability to maintain better support structures, enabling them to obtain the necessary support for important decisions under stress. There were only 8 Blacks in the study compared with 33 Whites, therefore one may question the stability of the ethnic comparisons. Each Black subject constituted 12.5 percent of Blacks, whereas each White subject was only 3 percent of Whites.

Marital status did not appear significantly different in the "yes" transplant and "no" transplant groups. Approximately 50 percent (n = 11) of the subjects were married in the "yes" group; 55 percent (n = 12) married in the "no" group; 18 percent single in both groups (n = 4); 18 percent divorced in both groups (n = 4); 14 percent (n = 3) widowed in the "yes" group; and 9 percent (n = 2) widowed in the "no" group. The difference in percentages in the married and widowed groups was meaningless since there was a difference of only one person between the "yes" and "no" groups.

Affect, Affirmation, Aid

Research question three. How do the social networks differ between the patients deciding for transplantation and those deciding against transplantation?

The social networks were examined in terms of affect (ability to make one feel liked/loved), affirmation (agreement with), and aid. These three functions were subjected to independent samples t-test to determine significant differences in the means between the "yes" transplant and "no" transplant groups. See Table 7. No statistically significant differences were found although affect approached significance at p = .07. Close

observation reveals that the "yes" transplant group scored approximately 20 percent higher in all three categories-affect, affirmation, and aid. This indicated a stronger relationship between the subject choosing transplant and his or her support group.

Table 7. Comparison Of Affect, Affirmation, And Aid In The "Yes" Transplant And "No" Transplant Groups.

Group	n	Mean	SD	t	df	p
Affect "Yes" Transplant	22	66.7	25.6	1.86	43	.070
Affect "No" Transplant	23	51.5	29.0			
Affirmation "Yes" Transplant	22	58.8	28.2	1.17	43	.247
Affirmation "No" Transplant	23	48.8	28.8			
Aid "Yes" Transplant	22	55.1	24.0	1.38	43	.174
Aid "No" Transplant	23	45.0	25.0			

Note. The means reflect the raw scores on the NSSQ. Greater numbers indicate more support.

Duration, Frequency, Loss

Research question three. How do the social networks differ between the patients deciding for transplantation and those deciding against transplantation?

The social networks were analyzed by comparing duration (length of time the subject had known the significant other), frequency of contact, and loss. Loss was measured by indicating (yes or no) loss of a significant other within the previous year. Number of persons lost and position (wife,etc.) of

persons lost were not addressed. Eight subjects (35 percent) in the "no" group claimed loss within the previous year, compared with five subjects (23 percent) in the "yes" group. The results of duration and frequency of contact were compared by t-tests and are displayed in Table 8. None of the results were statistically significant, but duration and frequency of contact scores were higher in the "yes" transplant group, indicating longer duration and more frequent contact.

Table 8. Comparison Of Duration Of Contact And Frequency Of Contact In The "Yes" Transplant And "No" Transplant Groups.

Group	n	Mean	SD	t	df	p
Duration "Yes" Transplant	22	31.3	11.9	.99	43	.330
Duration "No" Transplant	23	27.5	13.8			
Frequency "Yes" Transplant	22	30.4	13.4	1.64	43	.108
Frequency "No" Transplant	23	24.4	10.9			

Note. The means reflect the raw scores on the NSSQ. Greater numbers indicate more support.

Network Roles

Research question four. Do the dialysis staff and fellow patients supply more support in the yes transplant group? If they do, could they influence the patient's decision for transplantation?

Staff member, physician, and friend on dialysis in the "yes" and "no" transplant groups were compared. In addition, the roles of spouse, family, friend, neighbor, and minister were examined in like manner (see Table 9).

Table 9. Comparison Of Spouse, Family, Friend, Friend On Dialysis, Neighbor, Staff, Physician, And Minister Support In The "Yes" Transplant And "No" Transplant Groups.

Group	n	Mean	SD	t	df	p
Spouse "Yes" Transplant	22	15.8	13.8	.33	43	.714
Spouse "No" Transplant	23	14.4	14.9			
Family "Yes" Transplant	22	84.4	34.7	1.40	43	.169
Family "No" Transplant	23	67.7	44.4			
Friend "Yes" Transplant	22	17.1	11.4	1.52	43	.136
Friend "No" Transplant	23	11.7	12.2			
Dialysis Friend "Yes" Transplant	22	8.2	10.6	.87	43	.389
Dialysis Friend "No" Transplant	23	5.7	9.3			
Neighbor "Yes" Transplant	21	9.1	12.1	.81	42	.422
Neighbor "No" Transplant	23	6.2	11.1			
Staff "Yes" Transplant	22	18.9	18.7	.20	43	.843
Staff "No" Transplant	23	17.7	19.2			
Physician "Yes" Transplant	22	15.0	11.6	1.27	43	.213
Physician "No" Transplant	23	10.6	11.7			
Minister "Yes" Transplant	22	12.3	13.1	.06	43	.953
Minister "No" Transplant	23	12.1	13.1			

Note. The means reflect the raw scores on the NSSQ. Greater numbers indicate more support.

No statistically significant results were obtained by t-tests. The raw scores in Table 9 favored stronger support for the "yes" group in all roles. The mean scores indicated the mean support in each role. The higher the

score, the more support available. The "yes" transplant group scored higher support in every role. The scores of spouse, staff member, and minister were almost equal regardless of the patient's decision on transplantation. This possibly indicated deference to the patient's decision making. It could also mean a stability inherent in the role of spouse, staff, and minister. The level of support required by these roles may remain unchanged independent of the patient's decision process. In a manner of speaking, these people have to live with the patient whatever his or her decision. Only the focus of support may change as a result of the patient's decision.

The roles of physician and friend on dialysis indicated approximately 30 percent more support in the "yes" group. Indeed, scores reflected about 30 to 40 percent increase in support in all roles of the "yes" transplant group except for spouse, staff, and minister. If dialysis patients perceive spouse, dialysis staff, and minister as core support in their network; it may be the support of other network roles such as family, friend, physician and neighbor that makes the difference in the decision process for kidney transplantation.

CHAPTER 5

CONCLUSIONS

Summary

Almost every activity of life requires decisions albeit small or large. This study has found a relationship between social support and decision making in dialysis patients. Almost always, the dialysis patient and his network were in agreement on transplantation in the "yes" group. Among subjects in the "no" group, the majority reported that their network members were undecided about transplantation. Neither group was inclined to make a decision opposite his network's opinion, although it did occur some (18 percent) in the "no" transplant group.

The results were overwhelming in that there was close to 100 percent agreement in the "yes" transplant subject group. Fifteen subjects in the "yes" group were in 100 percent agreement with their support groups. Seven out of 22 subjects indicated 50 percent or more agreement with their networks (see Table 5, p. 47). No one in the "yes" group was in disagreement with their support group regarding the decision for transplantation. These findings support the positive relationship between subject and network agreement on decisions in dialysis patients.

The results were almost as remarkable in the "no" transplant subject group. Six out of 23 subjects indicated some level of agreement with their support group. Only four chose no transplant when the majority of their networks were in favor of transplantation. However, 16 subjects (70

percent) in the "no" group perceived 50 percent or more of their network as undecided. Nine subjects listed their networks as 100 percent undecided. Although it was rare for the subjects to be in disagreement with their support groups, nonsupport in the form of indecision was associated with the "no" transplant group. It is possible that the persons in the 70 percent (undecided) possessed an opinion, but the subjects had not reached the degree of intimacy required to know their networks' opinion.

Subject's age, network size, and education seemed to have no relationship to the decision on transplantation, although the "no" transplant group was about six years older and listed a slightly larger support group (Table 6, p. 50). However, gender, ethnicity, and length of dialysis history demonstrated some differences. White females were three times more likely than White males to choose transplantation. Black females and Black males were equally likely to choose transplantation. Since the results have shown that the social network's agreement is positively related to the subject's decision for transplantation, and the "yes" transplant group has approximately 30 to 40 percent more support from their network members; the answer probably lies in the white male's lack of support. He may receive less support from family, friends, friends on dialysis, physician, and neighbors. Dialysis staff, spouse, and minister support remained fairly constant irrespective of the subject's decision. Perhaps the increased support of family, friends, physician, and neighbors is a necessary ingredient in the decision for transplantation. It might be interesting in the future to look at the network support of specific groups in comparison to ethnicity, gender, and the decision of the subject.

The mean length of stay on dialysis in the "yes" transplant group was

28 months. The "no" transplant group averaged 42 months on dialysis. Although not statistically significant by t-test, the difference is enough that one may question an optimum readiness for transplantation. Further research is needed to establish the relationship between readiness for transplantation and length of stay on dialysis.

In general, affect, affirmation, and aid each had scores about 20 percent higher in the "yes" transplant group. This was interpreted as the subject's feeling more liked, loved, esteemed, valued, in agreement with, able to confide in, and can expect more tangible help from his support network. However, statistical significance for group differences was not achieved.

None of the measured variables were statistically significant except gender and the comparison between decision on transplantation in the subjects and decision on transplantation in their support groups. These results indicated a high level of congruence between the subjects and their support groups regarding the decision for transplantation, Table 5 (p. 47). The results also indicated a high level of nonsupport in the decision against transplantation. Gender was statistically significant with White females choosing transplantation more than White males ($p < .001$). Affect approached statistical significance ($p = .07$). When one works with human behavior, practical considerations and trends in relationships are important. It is very significant that all the network variables scored higher (more support) in the "yes" transplant group.

This research supports the conclusion that there is a strong relationship between the dialysis patient's decision and his network's opinions about that decision. Since there is a high level of congruence in the

decision, it is likely there is a significant amount of interaction in the decision process. Second, spouse, dialysis staff, and minister support are probably perceived as constant by the dialysis patient irrespective of his decision. Indeed, the "no" transplant group indicated less support in all other roles. In addition, the "no" group perceived 70 percent nonsupport (undecided) in their decision against transplantation. An important decision such as transplantation may require increased support from other network members--family, friends, physician, and neighbors.

Implications For Nursing

Most dialysis patients will make a decision on transplantation at some time during their life. Nurses should not be concerned about manipulating the patient's decisions. However, nurses should be concerned with the support needed for patients to make the best decisions they can. In the past, nursing has readily initiated support groups for different kinds of patients. The appropriateness of these groups has been a much discussed issue. In view of the results of this study, a nurse-directed support group for dialysis patients should be focused to include the family of the dialysis patient. Since the patients and their networks almost always agree on transplant decisions, some of the group activities should be geared toward providing correct information about all aspects of ESRD. If there is a causal relationship between social support and making decisions, nurses can provide correct information and schedule expert speakers as a basis for decision making.

Social and teaching functions should be designed to include the dialysis

patient's family and friends as well as staff and physicians. An occasional open house is a good idea. Dialysis nurses should encourage the socialization of their patients within the community and with other patients, as well as unit based activities.

Home visits are another option for encouraging the inclusion of the dialysis patient's family. Many times the patient is taught and supported by the staff, and the family is ignored. Results from this research illustrate the possibility that patients making decisions need support from others in addition to staff, spouse, and minister. The nurse's thrust should be toward providing support directly to the patient, and indirectly through expanded networks.

White males made fewer decisions for transplantation and were part of the group most lacking in social support in this study. If they make fewer decisions for transplantation because they do not have the social support structure to provide for such a decision, nurses can encourage their socialization by planned activities--patient representation, structured group support, one on one encouragement, personal counseling, and including their families and friends in appropriate unit activities. The nurse can also act as a catalyst between physicians and male patients, encouraging patients to discuss pertinent medical issues with their physicians, and encouraging physicians to speak to the medical options available for the patients.

The nurse is part of a team that delivers total dialysis support--medical, nursing, dietary, and social. It is the nurse who is in a position to assess the comprehensive response of the dialysis patient; and, it is the nurse's obligation to direct nursing care plans for optimum decision making.

Strengths And Weaknesses

The strengths of this study began in a sound concept. The review of the literature made a strong case for social support as a stress reducer. Also, Janis and Mann (1977), and Lazarus and Folkman (1984) talked about stress requiring decision making. One under stress makes the decision either to do nothing or take some course of action. If social support and stress are related, and stress and decision are related, then it is highly possible that social support and decision are related. The problem with social support definitions is that they have attempted to squeeze everyone into one mold. One of the strengths of this paper is that it not only questioned the relationship between social support and decision making, but it applied the construct to a special population-- dialysis patients.

Another strength was the instrument. The NSSQ had good reliability and validity. It was reported to be free of social bias and has been used since 1981 for measuring social support in the USA as well as around the world.

A strength of the sample was that the subjects were evenly split between the "yes" transplant and "no" transplant groups. There were 22 subjects choosing transplantation and 23 subjects deciding against transplantation. The subjects were from different dialysis centers which helped in generalization.

Weaknesses of the study include the small sample (N = 45). The sample was too small to control for cultural effects, differences between dialysis centers, and age. Although gender and ethnicity were cross-tabulated with decision, culture was not controlled in the other variables. All persons who

indicated a decision on transplantation, regardless of age, were included in the study. Even though the decision was the focus, it is possible that the over 60 years of age person made a biased decision knowing the improbability of undergoing a transplant operation.

Other weaknesses resulted from the nature of the study. The findings described relationships and thus causal implications cannot be made. This limited the application to real life interventions. Also, there were no social support norms established for dialysis patients. One does not know what was poor, average or even good support. One can only say that some support scores were higher than others.

Depending on one's view, the subject's perception of his support may have been a strength or a weakness. The subjects' perceptions may not have been accurate. On the other hand, does it matter if their perceptions were not based in reality? The fact is, their personal decisions in the "yes" transplant group agreed almost 100 percent with their perceptions of the support groups' decisions. On the other hand, the decision against transplantation was highly congruent (70 percent) with an undecided support group. The subject's personal view of reality and the social support available may have been the basis for the decision process.

Recommendations

Future research in this area should look for causal relationships between social support and decision. Longitudinal designs are recommended to examine the nature of this relationship in dialysis patients. Following patients from initiation of dialysis through transplantation or

non-transplantation would be enlightening in terms of the changing social support structures. In addition, research focused on establishing social support norms for dialysis patients would contribute toward nursing intervention.

Gender, ethnicity, age, and length of stay on dialysis should be controlled in future research. These variables were found to have large differences between the "yes" and "no" groups. Although this study questioned a possible optimum time for transplant decision, further research is necessary to corroborate this finding. If there is such a time/s, health care professionals could provide the patient with choices at the appropriate time/s.

The results obtained from this research point to a strong correlation between social support and decision making in dialysis patients. The dialysis team needs more answers concerning this relationship. Only then can the ESRD team feel that they have provided their patients with the best possible circumstances to make the important decisions affecting their lives.

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APPENDIXES

APPENDIX A

LETTER OF REQUEST

LETTER OF REQUEST

Date

Address

Dear

I am interested in the social support network of the dialysis patient. There is indication in the literature that one's significant others influence his decision making. If nursing researches a better understanding of how the dialysis patient's family, friends and health care providers affect him, I am hopeful that nurses will offer superior intervention in the future. I believe the quality of dialysis will be improved through patient satisfaction.

The study consists of a three page questionnaire to be filled out by patients presently on dialysis. The researcher will be present to pass out the forms and to collect them for each shift two days in a row. The forms require approximately 10 minutes to fill out and the researcher will answer any questions. All data will be anonymous.

There are no risk factors to your staff or patients. Participation is voluntary. By giving your permission you will be contributing to nursing research.

Sincerely,

Sandra K. Williams

APPENDIX B

QUESTIONNAIRE COVER LETTER

COVER LETTER

Dear Participant:

You are invited to take part in a research study designed to measure support for dialysis patients. Your participation will involve the completion of the following questionnaire. These forms will take about ten minutes to fill out.

There are no known risks related to your participation. Your responses will be anonymous. All data will be stored in a locked filing cabinet in the researcher's office. All data will be summarized for any presentations or publications that arise from the research.

Participation in this project is voluntary and your consent for participation may be withdrawn at any time prior to completion of the data analysis by contacting the researcher listed below. There is no penalty for withdrawal from the project.

If you have any questions about your participation in the study, please feel free to contact me. Thank you for your consideration of this request.

Sincerely,

Sandra Williams

573-9050

APPENDIX C

NSSQ QUESTIONNAIRE

(CIRCLE ONE OR FILL IN THE BLANK)

Age- (18-25) (26-35) (36-45) (46-55) (56-65) Sex- M F Race- Black White Other

Marital Status-SINGLE MARRIED DIVORCED WIDOWED Highest grade or degree completed-_____

Annual Income-**Less than $10,000** **$10,000-25,999** **$26,000-49,999** **Over $50,000**

1. How long have you been on dialysis? **years**_____ **months**_____

2. Are you on the transplant list? **Yes** **No**

3. Are you physically eligible for transplantation? **Yes** **No**

4. Have you made a decision to have a kidney transplant? **For** **Against** **Undecided**

5. Please **circle each important person in your life** below. Consider all the persons who provide personal support for you.

Wife	Son	Friend on dialysis	Doctor	Other_____
Husband	Friend	Daughter	Sister	
Mother	Pastor	Dialysis staff person	Brother	
Father	Priest	Dialysis nurse	Neighbor	

6. How much does this this person make you feel liked or loved? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___	Son___	Friend on dialysis___	Doctor ___	Other_____
Husband___	Friend___	Daughter___	Sister___	
Mother___	Pastor___	Dialysis staff person___	Brother___	
Father___	Priest___	Dialysis nurse___	Neighbor___	

7. How much does this person make you feel respected or admired? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___	Son___	Friend on dialysis___	Doctor ___	Other_____
Husband___	Friend___	Daughter___	Sister___	
Mother___	Pastor___	Dialysis staff person___	Brother___	
Father___	Priest___	Dialysis nurse___	Neighbor___	

8. How much can you confide in this person? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___	Son___	Friend on dialysis___	Doctor ___	Other_____
Husband___	Friend___	Daughter___	Sister___	
Mother___	Pastor___	Dialysis staff person___	Brother___	
Father___	Priest___	Dialysis nurse___	Neighbor___	

9. How much does this person agree with or support your actions or thoughts? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

10. If you needed to borrow $10, a ride to the doctor, or some other immediate help, how much could this person usually help? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

11. If you were confined to bed for several weeks, how much could this person help you? (**same people & fill in the blank**)
not at all= **1** a little=**2** moderately=**3** quite a bit=**4** a great deal=**5**

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

12. How long have you known this person? (**same people & fill in the blank**)
1-6 months=**A** 6-12 months=**B** 1-2 years=**C** 2-5 years=**D** over 5 years=E

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

13. How frequently do you usually have contact with this person? (**same people & fill in the blank**)
once a year=**F** a few times a year=**G** monthly=**H** weekly=**I** daily=**J**

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

14. During the past year, have you lost any <u>important</u> relationships due to moving, a job change, divorce or separation, death, or some other reason? **No** **Yes**
If yes, specify the number of persons who are no longer available to you. ___

15. What does this person think about you having a kidney transplant? (**same people & fill in the blank**) **For=K** **Against=L** **Undecided=M**

Wife___ Son___ Friend on dialysis___ Doctor ___ Other___
Husband___ Friend___ Daughter___ Sister___
Mother___ Pastor___ Dialysis staff person___ Brother___
Father___ Priest___ Dialysis nurse___ Neighbor___

VITA

Sandra Kaye Williams was born Sandra Kaye Page in Eunice, Louisiana May 15, 1947. She lived there with her family until she entered Louisiana State University in 1965. From 1970 to 1977, Sandra traveled and maintained residence in Philadelphia and Seattle. She moved to Johnson City, Tennessee in 1977, and lived there for ten years with her husband, Shane A. Williams, until she decided to attend the University of Tennessee, Knoxville in 1987.

From early childhood Sandra's career goal was nursing. She obtained her Bachelor of Science in Nursing from Louisiana State University in 1970. From 1970 through 1975 Sandra held positions as a staff nurse, assistant head nurse, and head nurse, as well as learning a new skill--hemodialysis. Between 1976 and 1979 she temporarily left nursing to have children. However, children did not materialize and Sandra ultimately found that she missed nursing. She returned to hemodialysis in 1979 and has been an active nurse since that time. Sandra entered the University of Tennessee in 1987 and was awarded her Master of Science in Nursing in 1989. She was honored by an invitation to Sigma Theta Tau honor society and was inducted in 1989.