

FACTORS AFFECTING NONPARTICIPATION IN
SUPPORT GROUPS FOR HEMODIALYSIS
PATIENTS

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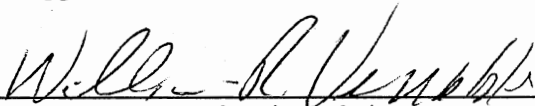
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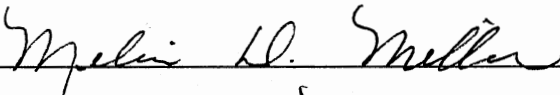
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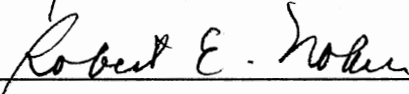
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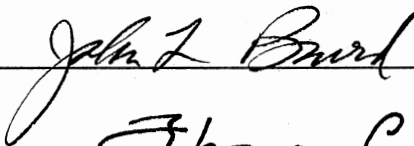
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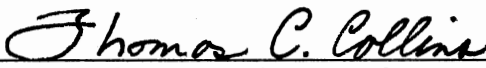


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CHAPTER I

INTRODUCTION

Persons experiencing permanent kidney failure must receive dialysis treatments two to three times each week for their entire lives unless they receive kidney transplants. These treatments serve to (1) rid the blood of poisonous toxins and (2) remove excess fluid from the body.

Although kidney patients are considered "terminally ill," they can potentially live for many years on dialysis. However, the disease and treatment processes produce changes in the patient's body chemistry, affecting many facets of a patient's life: "independence and freedom, energy and sexuality, employment and income . . . as well as family and social relationships" (Redman, 1988, p. 103).

Because of these factors, persons affected by kidney failure have formed "support groups" in the fashion of victims of other chronic illnesses, such as cancer (Conti, 1989). The proliferation of such groups has illustrated the value of self-help and empathy found among those who wrestle with similar illnesses, particularly the life-threatening ones. The success of such support groups contrasts with the apparent failure of treatment/therapy groups, which emphasize psychotherapy and group counseling (Stewart, 1983).

Support groups are designed with two purposes: education and empathy (Hosford and Bowser, 1986). Patients hope to learn about the disease and treatment options and methods that they face, as well as give and receive empathy as individuals who share a unique set of circumstances and experiences.

The American Cancer Society reported that during fiscal 1990-91, 20.1 percent of the estimated 1,200,000 cancer patients in the United States participated in support groups (ACS Annual Report, 1991). This percentage included a 66.2 percent participation rate for patients in the "Reach to Recovery" group for victims of breast cancer. By contrast, it was difficult to achieve a 15 percent participation rate for dialysis patients at a dialysis center in New York (Levin, 1991).

Problem Statement

Kidney dialysis patients are participating in support groups at lower percentages than are patients who suffer from other chronic illnesses like cancer.

Purpose of the Study

The purpose of this study was to identify factors related to patient nonparticipation in the renal dialysis support group in Tulsa, Oklahoma.

The Need for the Study

According to Conti (1989),

The value of patients helping patients has been known for some time. People who have been through the trauma of a life-threatening illness often have the desire to help others who are going through the same trauma They open up more easily to another patient and share personal information more readily (p. 66).

Matthews (1978) identified needs among kidney dialysis patients in Toronto, Canada for "information and peer relationships" (p. 77). Levin (1991) noted the importance of "patient education" through the use of supportive, self-help groups, as well as the difficulty in achieving participation by "more than 15 percent" of the patient population at his dialysis center in New York (p. 272).

Since this group was requested by the patients and such groups have been found to be helpful to patients, it is important to determine, if possible, factors related to nonparticipation. Such information may contribute to increased patient involvement and resulting benefits to patients.

Research Questions

The following research questions were asked in the study.

1. Did the demographic factors of age, marital status, and number of years on dialysis influence participation?
2. Did the logistical factors of distance from the meeting place, physical health, transportation and time and location influence participation?
3. Did the patient attitudinal factors of belief in the value of the group and lack of interest in the topics presented at the

group meetings influence participation?

4. Did patients believe that they had received enough information about the group in order to decide whether to participate?

Definition of Terms

Kidney Dialysis - The medical procedure which persons whose kidneys provide inadequate waste filtration and fluid removal undergo two to three times each week unless they receive kidney transplants.

Support Group - collection of individuals who share common problems and are organized for the purpose of receiving informational and/or emotional assistance. They are also identified as "self-help" groups, in order to distinguish them from "treatment groups" which are conducted by a professional counselor or therapist.

Patients - Individuals who receive kidney dialysis on an ongoing basis.

Nonparticipation - Lack of attendance by patients in the support group meetings.

Assumption

The dialysis patients who participated in this study were representative of all dialysis patients in the community who were able to participate in the support group.

Limitations

1. A single population of respondents was studied.
2. The study was conducted in a single metropolitan area.
3. The study may have been limited by variations in motivation by the patients and staff members of the dialysis centers to participate in the study.

CHAPTER II

REVIEW OF THE LITERATURE

Judith H. Hibbard, DrPH (1985), in an article entitled "Social Ties and Health Status: An Examination of Moderating Factors", wrote concerning the value of social support.

Programs aimed at strengthening naturally occurring helping networks and mutual assistance groups not only increase social ties but may also assist people in mobilizing support. This is particularly true for self help groups that have a specific focus of problem solving, empowerment and mutual support and guidance (p. 33).

"Social support" and how it affects members of society has been the subject of much study in recent years. Under the heading "Social Support Networks", there are some 450 listings in the APA's Psychological Abstracts during the first two years that it was an index listing (Brownell and Shumaker, 1984). Both informal and formal networks have been developed and evaluated by researchers. These networks provide individuals with " education, information, and an opportunity to share experiences and develop solutions to common problems" (Black and Drachman, 1985). For the purposes of this study, the findings were summarized concerning support groups in the following areas: the history of modern support groups and their growth; treatment and informational/relational group types; factors in the success and failure of support groups; and why individuals do not participate in the groups.

The History of Support Groups

The history of the study of support/self-help groups can be traced to a study of suicide by Durkheim entitled "Suicide: A Study in Sociology", which was originally published in 1897. This work, along with other writings by social scientists of the early twentieth-century, theorized that the migration of workers to cities produced a dissolution of social ties with family members, friends and churches. This "loss of social integration" was "anti-thetical to psychological well-being" (Brownell and Shumaker, 1984). Durkheim did a comprehensive study of suicide rates among Europeans in the 1880s. He compared suicide rates with such categories as race, heredity, gender, marital status, "psychopathic states" (p. 399), the presence of alcoholism, and methods of suicide used by the victims. He concluded that the social integration of an individual was a major factor in prevention of suicide (Durkheim, 1897). Following this landmark work, social scientists argued for the next several decades about the role of social change in producing social disorder, and the effects of social support in minimizing that disorder (Brownell and Shumaker, 1984).

John Cassel (1974a), a physician, attempted to address the relationship between physical health and interpersonal relationships. He stated in his article, "An Epidemiological Perspective of Psychosocial Factors in Disease Etiology," that "throughout history there has been a conviction in medicine that certain environmental factors are important in the etiology of disease" (p. 1040). After reviewing research on studies

of the relationship between socialization and disease occurrence among animals, Cassel concluded that:

. . . various social processes have also been shown to be protective (sic). Chief among these are the nature and strength of the group supports provided to the individual (p. 1041).

Cassel then evaluated such criteria as "social disorganization" and "social buffers" in humans as they relate to disease occurrence. He conceded that "the health consequences of social disorganization will not be universal, affecting all people in the same manner." However, he cited "the nature and strength of the available group supports" as one of several critical factors in disease control (pp. 1041-1042). In another work on the relationship between illnesses and stress, Cassel (1974b) concluded that:

With advancing knowledge, it is perhaps not too far-reaching to imagine a preventive health service in which professionals are involved largely in . . . identifying families and groups at high risk by virtue of their lack of fit with their social milieu and determining the particular nature and form of the social supports that can and should be strengthened if such people are to be protected from disease outcomes. The intervention actions then could well be undertaken by nonprofessionals, provided that adequate guidance and specific direction were given. Such an approach would not only be economically feasible, but . . . would do more to prevent a wide variety of diseases than all the efforts currently being made through multiphasic screening and multi-risk factor . . . intervention attempts (p. 480).

A review of the American Psychological Association's Psychological Abstracts between the years 1985 and 1990 reveals literally hundreds of articles and studies on unlimited types and numbers of support groups, from Vietnam veterans to gay and lesbian individuals. Many of the groups that are

represented are persons affected by health concerns: AIDS patients, parents of children with chronic illnesses, cancer patients and their families and other groups that have come together to share information and support.

Alcoholics Anonymous - The First
Modern Self-Help Group

The organization called Alcoholics Anonymous (AA) was founded in the mid-1930s by a stockbroker named Bill Wilson. Mr. Wilson, according to his own account, struggled with alcoholism for many years before developing, with the help of his physician, an organization of members who shared a common problem and dedicated themselves to (1) admitting the problem without reservation and (2) dedicating themselves to meeting regularly in order to encourage one another to maintain activities and attitudes that would not allow the problem to dominate their lives. In addition, they developed a "12 step" program for changing the attitudes of the members, which would result in better control of the lives of the members. "AA", as it has come to be known, has grown from a group of 100 in 1939 to a "conservative" estimate of 1,000,000 members worldwide as of 1976 (AA, 1976, intro.). In their 1991 annual report, AA reported that by 1990 the number of AA groups worldwide numbered 93,914, with an "active" membership of 2,047,469 persons. These figures included 1,100,155 members in the U.S. and Canada which comprised 51,496 groups, as well as 947,314 members in 42,418 public groups located outside of the U. S. and Canada, those in

correctional facilities and "lone members" not affiliated with a particular group (Source: Alcoholics Anonymous World Service Annual Report, 1991).

Many other self-help groups have adopted the AA style of self-help: Narc-anon, Overeaters Anonymous, and Cocaine Anonymous are several examples of contemporary support groups patterned after AA (Community Service Council, 1989). All of these groups function by allowing members to share their problems and concerns with those who are in similar situations. The growth of groups that follow the AA format would seem to argue for the fact that this method is perceived to be effective by participants in those groups, as well as by outside observers of the groups.

The Growth of Support Groups

Regarding the growth of this movement, Black and Drachman (1985) observe that "clearinghouses" exist in several states, including New York, California, Illinois, Tennessee, Texas, and Florida in order to provide a network of information about support groups in all areas of the country. These groups have been formed in an environment marked by shrinking healthcare resources and a desire to recapture control of health care services in the local communities.

Although the groups are for the most part self-directed, they may utilize a professional, such as a social worker, to provide consultation, information and direction to the group. However, the policies, procedures, and actions of the group are typically

provided by the members themselves (Lurie and Shulman, 1983). Self-determination seems to be at the heart of the self-help movement, as individuals come together for problem-sharing and problem-solving.

Types of Groups

"Support" or self-help groups are distinguished from "treatment" groups, also known as "group therapy". In therapy groups, a professional, usually a psychiatrist, psychologist or social worker supervises the verbal exchanges that occur during the meetings. The leader sets the topics to be discussed and directs the content and range of the topics at each meeting. He acts as the "expert" in the group, and the final authority over conclusions that are reached by the discussions. In the medical treatment arena, the "tendency of health care professionals to play the expert role increases with the complexity of the medical treatment" (Rounds and Israel, 1985, pp. 239-240).

By contrast, support groups provide, according to Chesler and Yoak (1983), five types of support: (1) educational/informational, (2) instrumental, such as help with transportation and other "activities of daily living"; (3) nonspecific, or "just being there," (4) emotional/relational, and (5) crisis assistance, when the illness becomes unmanageable (Chesler and Yoak, 1983, quoted by Rounds and Israel, 1985).

Black and Drachman (1985) observed that "although the literature on the interaction between professionals and self-help groups has been growing . . . the analyses have been based largely on impressionistic information rather than empirical study. In particular, few data exist on the types of groups with which social workers become involved and on the nature of those involvements" (p. 97).

Tucker et al. (1986), in a study of 70 hemodialysis patients at a dialysis center in Gainesville, Florida, developed and administered a Dialysis Patient Concerns Inventory (DPCI) survey to all of the patients. This survey, which was used to "assess concerns related to being a hemodialysis patient" (p. 51) was distributed for the purpose of developing a group counseling program for the patients. Patients were asked to rank the importance of such topics as dietary restrictions, nurse/physician communications with patients, anger, sexuality, blood tests, depression and death. Fifteen patients completed and returned the DPCI. A total of 55 patients participated in the five to 45 minute counseling sessions, which were conducted by nurses, social workers and psychologists. The format for the sessions included relaxation exercises, a presentation, and a question-and-answer period.

Follow-up interviews with the patients revealed the following:

- (1) Eighty percent of these patients reported improvement in coping with anxiety and depression.

- (2) Sixty percent reported feeling more positive about themselves.

(3) Seventy-two percent of participants indicated that the program experience had increased communication of their feelings to family members.

(4) Five percent of the participants reported that the sessions did not affect them or their relationships with family members.

(5) All participants, however, reported enjoying the group sessions. Reasons given were that: (a) "they gave or received support from other patients; (b) they shared concerns and personal problems, making them feel less isolated; and (c) the sessions made their time at the Center interesting and more enjoyable" (p. 59).

These findings seem to indicate that even where counseling is present, patients find much comfort in peer interaction. However, Armstrong, (1984), in an analysis of the effectiveness of "group treatment" noted that:

Despite the paucity of evidence that emotional insight helps renal patients, I believe that psychotherapists should encourage patients to understand their illness and the groups in which they live. To be sure, patient education and self-help are important, but the unique promise of any psychotherapy is in the active comprehension of one's life (p. 171).

The following is a summary of the characteristics of specific types of groups in specific areas of treatment.

Mental Health Groups

The treatment of mental illnesses during the 1980s was characterized by deinstitutionalization of patients into "community" settings. An outgrowth of this philosophy was the development of

"community support programs", in which chronically mentally ill individuals were housed in supervised living situations away from hospitals and clinics. These patients received psychiatric and psychological care from trained staff and received more individualized treatment in more comfortable settings. While the organizational and administrative strategies may vary, most of the programs are essentially similar in their design and approach to helping patients cope with chronic illnesses (Reinke and Greenley, 1986). While "many unanswered questions remain" (Cutler et al., 1984, p. 51) about the long-term effectiveness and funding of these groups, participation and effectiveness in the short-term treatment of mentally ill patients appears to be good.

Studies have shown that community support programs are more effective in treating the chronic mentally ill than traditional forms of aftercare (Brekke, 1988, p. 946).

Cancer Groups

As of 1984, two out of three families in the United States were affected by cancer. One out of two persons diagnosed with cancer survived the illness (American Cancer Society, 1980, 1984). In an effort to assist patients and their families in coming to terms with their illnesses and obtaining a sense of control over their lives, medical and mental health professionals developed "cancer treatment groups" for patients and family members. These groups are usually conducted by psychiatrists, psychologists or social workers in or near a hospital or clinic setting. Berger (1984), in her evaluation of one such group which called itself "Coping with Cancer," made the

following observations.

Cancer is both an acute and chronic illness which presents patients and their families with an ongoing series of crises. Psychosocial support for patients and their families have not always developed concurrently with achievements in medical oncology. [They] are in a state of continual emotional upheaval with ever-changing roles, needs and financial obligations Cancer patients and their families can be emotionally devastated by the illness if its impact is not dealt with (pp. 81-82).

Berger, an oncology social worker, made further observations of interest concerning the support group, which was conducted in Fairfax Hospital, Fairfax County, Virginia. Among them were the following:

1. "People come to the group not for psychotherapy, but for answers regarding their illness which in turn leads to a recognition of their feelings and relief from feeling guilty for having such feelings" (p. 83).

2. "Attendees have tended to utilize the group during crisis periods" (p. 84).

3. "In establishing the group there was a recognition that some individuals in the targeted population may not wish to return to the hospital setting and that the meeting time cannot meet the schedules of everyone" (p. 84).

4. "The support of physicians and hospital administration is essential" (p. 85).

5. "Not everyone is able to face the reality of cancer or to discuss it" (p. 88).

"The social worker . . . has served as the group's coordinator and has been responsible for all communications regarding the group.

When attendance in the group begins to drop, it is a sure sign to re-new communications" (p. 85).

Conti (1989) distinguished between groups that are led by "peers" and those led by "professionals" (p. 80). He states that "professionally-led groups may be found throughout the country" and that "professionals sometimes belittle the overly-enthusiastic language one often finds in materials published by self-help groups" (p. 80-81). While both types of groups have grown in size and numbers, "many people are not amenable to asking for, or receiving, counseling help" (p. 82). He concluded that "many workers have indicated that there is a need for further evaluation of the effectiveness of support groups, both those with untrained peer leaders and those led by persons with formal counseling training" (p. 81). This is said, however, while acknowledging the tremendous increase in the number of "peer" groups for cancer patients. The American Cancer Society reported that out of an estimated 1,243,948 cancer patients in the U. S. during fiscal 1990-1991, a total of 250,213, or 20.1 percent, attended self-help, support and patient-family education groups. In addition, of the 111,146 victims of breast cancer in the U. S., 73,617, or 66.2 percent, attended the "Reach to Recovery" support group for patients afflicted with that specific diagnosis (Source: American Cancer Society's "Program Activities Report on Service & Rehabilitation From National Headquarters", 1990-1991).

Conti also identified key patient needs: information, education, counseling and support (p. 84). These needs, presumably, are the components of a successful support group.

Conti (1989) further identified 17 different nationally-recognized support groups for cancer patients. One such group, called Make Today Count, was begun in 1973 by a newspaperman from Iowa named Orville Kelly. This group was founded for "those dealing with cancer or any life-threatening illness [and] has continued through today." This group is now recognized as an "international organization" (p. 69), illustrating again the growth of the self-help movement for cancer patients.

Kidney Dialysis Groups

According to the United States Renal Data System 1990 Annual Report published by the U. S. Department of Health and Human Services, 172,000 persons in the U. S. were diagnosed as having End-Stage Renal Disease (ESRD) and requiring dialysis therapy during 1988. However, no regionally or nationally based support groups have ever existed for dialysis patients. No organizations similar to the cancer support groups exist for kidney dialysis patients within the U.S. at present.

Support groups have been formed by individual centers, however. These groups follow the same format and have the same characteristics of other groups for patients with chronic illnesses. They share the "drop-in" characteristics of cancer groups, as well as the "ongoing" format. They, too, are led by both peers and professionals.

Matthews (1978), in a study of 347 kidney dialysis and transplant patients in Toronto, Canada, identified a high degree of

concern among the patients for "information, explanation and truth" (32.3%) and "peer-helping opportunities" (17.6%) (p. 77). That is, nearly half (49.9%) of the patients surveyed identified concerns that were not being met by the medical establishment. These needs could be met, at least partially, by peers. However, as with cancer patients, dialysis patients and their families have been found to be both "hungry for help and wary of any assistance or intervention" (Steinglass et al., 1983, p. 113).

In a study of "discussion groups for chronic hemodialysis patients and their families" in 1982, Steinglass et al., concluded that 1) literature on the effectiveness of such groups was essentially nonexistent (p. 112), and that recruitment of "[patients] and families for these groups proved to be difficult" (p. 113). Reasons for the difficulty in recruitment were not clear, but the research team was able to finally recruit eight patients and their families to a "multiple family [short-term] discussion group", in order to complete their study. However, a great deal of effort was required. Not only were letters and personal interviews necessary to recruit members for the group, but \$100 was given to each participant.

In "An Assessment of the Social Networks of Patients Receiving Maintenance Therapy for End-Stage Renal Disease", published in 1985, Smith, Hong and Feldman discovered that "the strength of an ESRD patient's network of significant relationships can be anticipated to be crucial to his or her perceived quality of life" (p. 54). Maher et al. (1984) attempted to evaluate psychosocial aspects of chronic

hemodialysis in a nationwide cooperative study. A conclusion reached by the study was that social support is a key indicator of perceived well-being in dialysis patients.

Lubell (1976), in a report on his therapy group for dialysis patients, pointed out a number of positive perceptions by the patients in his group. Among them were:

1. "More accurate information about their treatment and the alternative programs offered" (p. 174).

2. ". . . that they feel more free to approach the staff directly . . ." (p. 175).

3. ". . . that they express a wider range of emotions . . ." (p. 175).

4. ". . . and that newer patients seem to be experiencing fewer problems in adapting to the necessary restrictions [of the medical regimen]" (p. 175). However, he notes that "a sense of community has been strengthened, and the patients' depression seems to have decreased. A few of the long-term patients, however, have felt that the group is more useful for the newer patients in the program, and their attendance has begun to decline" (p. 175).

Levin (1991) reported that his dialysis center in New York attempted to organize a patient group for educational purposes, but experienced difficulties in obtaining participation from many of the patients. As he so bluntly described the dilemma:

There is no substitute for patient education. I'm sure we are all troubled by this in an era where we are dialyzing people for a shorter time. How do you get enough educational time to spend with the patient as nurses, technicians, nutritionists, social workers, and physicians? At Henry Ford [Dialysis Center], we were

able to get a group together once a month using different speakers. But even then not more than 15% of the patients actually come. Maybe if we had more inspiring teachers or a better place to meet, it would work better. When we deal with an educated middle class population it is generally easy to get a good response, but the challenge is with people who don't have the time because of their own social problems. They want to get home, they want to get to work, or they can't come when you want them to come. These are the difficulties (p. 272).

Summary

Support groups have become an increasingly common method utilized by individuals with similar needs for obtaining information and emotional assistance to better cope with the problem. Nowhere are these groups more utilized than in the health care field. Patients and their families, friends and caregivers struggling with such chronic illnesses as cancer, mental illness and kidney failure have sought the help of others in similar situations.

Kidney dialysis patients have needs for emotional support, information and education, as well as medical care. These needs are often met in group situations, whether through formal therapy or support groups, or informally through contact between patients and families. However, large numbers of patients and caregivers do not participate. Reasons for this are not clear from the literature. Also, there is a distinct lack of research on the problem of nonparticipation in support groups in any illness or social issue.

A description of the research methodology is presented in Chapter III. The findings are described in Chapter IV. Conclusions and recommendations are presented in Chapter V.

CHAPTER III

METHODOLOGY

The purpose of this study was to identify factors related to patient nonparticipation in the renal dialysis support group in Tulsa, Oklahoma. This chapter explains the methodology used in the study to evaluate (1) the population, (2) the instrumentation, (3) the administration of the instrument and (4) the analysis of the data.

Population of the Study

There are four dialysis centers in Tulsa County, Oklahoma in which patients may receive dialysis. Three of these centers are located within hospitals: Tulsa Regional Center (Osteopathic), Saint Francis Hospital Renal Center, and Hillcrest Medical Center - Renal Center. The fourth is a "free-standing" center operated by physicians, Tulsa Dialysis Center. These dialysis centers provide dialysis treatments for 246 patients each week. The patients are scheduled into one of several shifts or treatment times: Monday, Wednesday, and Friday, or Tuesday, Thursday, and Saturday, from 6:00 a.m. until 10:00 a.m. or 10:00 a.m. until 2:00 p.m. Three of the centers have evening shifts that run from 2:00 p.m. until 6:00 p.m. or 6:00 p.m. until 10:00 p.m. The evening shifts are primarily designed to accommodate persons who are employed during the daytime.

Most patients are not employed, however, and prefer to receive treatments during the morning hours of the day.

Dialysis patients are forced to remain in a chair or bed during their treatments because of the need to remain near the dialysis machines to which they are connected with needles and tubing. This means that their activities during the treatments are limited to whatever can be accomplished with limited mobility and the use of only one arm and hand. Consequently, they are a captive population and can easily complete a questionnaire or interview during their treatments. For this reason, a questionnaire was designed and administered. In addition, categories of responses were formulated that included most if not all of the possible reasons for nonparticipation by patients.

The Hillcrest Medical Center (HMC) social worker conducted six of the interviews at HMC and the Tulsa Dialysis Center (TDC) social worker conducted 21 interviews at TDC. All other interviews at the four centers were conducted by the researcher.

Selection of the Population

All hemodialysis patients who received treatments in the four centers in Tulsa were asked to participate in the survey. Exceptions were made for patients who were (1) disoriented or mentally ill, (2) too ill at the time of the survey to participate, or (3) unable to be aroused from sleep to respond to the survey. All patients who were not in one of these categories agreed to participate.

Instrument

The questionnaire was developed as a result of an interview with a panel of three experts. These experts were registered nurses on the staff at Saint Francis Hospital, Tulsa, Oklahoma. In addition, an interview was conducted with a panel of dialysis patients from the same center.

Subsequently, a pilot survey was conducted at Saint Francis Hospital. Three of the patients at that center were asked to complete the questionnaire and make comments concerning its value as an instrument. These patients were selected based on the panel's perception of them as reasonably intelligent patients who would be able to offer appropriate criticisms concerning the instrument. All of the patients had university degrees and had been employed as professionals prior to beginning dialysis. The results of their questionnaires were not included in the tabulation of results of the survey. The pilot study participants were not surveyed again at the time of the distribution of the instrument at the Saint Francis Hospital center.

As a result of the pilot study, a question was added to the list of reasons for nonparticipation, "Program content is not interesting enough". This question was included in the questionnaire before distribution was begun to the centers.

The questionnaire included (1) an introductory paragraph, explaining the purpose of the survey and soliciting the assistance of each respondent, (2) questions relevant to demographic data and levels of attendance at the group meetings, (3) questions regarding

the respondent's views of the value of the group and, (4) the list of "reasons for nonparticipation" by the respondent. An oral assurance of confidentiality preceded the distribution of the survey or initiation of an interview with each patient. The complete questionnaire is located in Appendix A.

In order to evaluate the ability of patients to participate in support groups, the following demographic information was obtained: the age of the patients, the city and county in which they resided, their marital status and length of time in years that they had been on dialysis therapy.

The age of the patients was obtained to determine the number of older patients who would tend to be less mobile than younger ones and not as able to participate in activities outside their homes, particularly in the evening hours when many might have difficulty with their eyesight. The instrument identifies several age categories of the participating patients.

The marital status of the patients was requested to get an idea of how many patients had significant others to assist them in traveling to the meetings. Given the previously discussed physical limitations of some patients, this was considered to be relevant. However, information was not obtained about the presence of other persons who might have been available to the patients, such as children, extended family members or friends.

The instrument identified the general area in which the patients lived. The instrument grouped separately those patients who lived in the City of Tulsa, those in Tulsa County but outside of the City of Tulsa, and those who lived outside of Tulsa County.

Information and education about dialysis were identified in the literature as important to kidney dialysis patients. As patients continue on dialysis therapy, they can be expected to learn more about their disease and treatment regimens and therefore require less informational and educational support. Therefore, length of dialysis therapy was identified as a possible factor in patient participation in support groups. The instrument reflects patient responses to the question of length of dialysis therapy.

The patients were then asked to report the total number of group meetings that they had attended in the previous 12 months. Of interest also was whether patients from specific centers were more active than patients from other centers. This information could then serve to identify factors related to nonparticipation by patients if combined with information on activities in the centers that served to increase participation in the support group.

Administration of the Instrument

The questionnaire was a one-page, single-sided document designed for ease of completion and clarity in communication. It was distributed at the beginning of each dialysis treatment shift and collected during the same shift as each respondent completed the questionnaire. After receiving instructions and an orientation to the survey, staff nurses and social workers in each unit assisted the respondents in (1) reading and interpreting the questions and (2) collecting the questionnaires from the respondents when they completed them. No review of the completed questionnaires was undertaken at the renal dialysis centers, either during the

distribution of the questionnaire or immediately after the collection, in order to protect confidentiality.

Since a high percentage of patients were unable to respond to the questionnaire due to (1) blindness, (2) peripheral neuropathy, or weakness in hands and/or fingers, or (3) both conditions, it was necessary to conduct interviews with those who could not participate in the completion of the questionnaire.

The demographic and opinion data were recorded and tabulated. The demographic information was then compared to the opinions given about the perceived value of the support group. The reasons for nonparticipation were reviewed in order to determine whether specific reasons for nonparticipation dominated the responses. The ages of respondents and the lengths of time on dialysis were examined in light of reasons for nonparticipation in the group meetings. A report of the data is presented in Chapter IV. Conclusions, recommendations, and implications are presented in Chapter V.

CHAPTER IV

PRESENTATION OF FINDINGS

This chapter presents the results of the survey conducted between July 24, 1991 and August 7, 1991 at four dialysis centers in Tulsa, Oklahoma. The results are analyzed and compared to identify factors relating to nonparticipation in support group meetings for dialysis patients.

Description of the Survey

The questionnaire was distributed to all patients while they received their dialysis therapy. Because patients frequently sleep during the initial portion of their treatment sessions, the survey was initiated during the last hour of their treatments.

Approximately one-third of the patients surveyed were not able to complete the questionnaire due to (1) poor eyesight, (2) poor motor coordination of their hands, or (3) both. In each case where a patient was unable to complete a questionnaire due to (1) poor vision, (2) peripheral neuropathy -inadequate hand function -or (3) inadequate reading/writing skills, an interview was conducted. Six of the interviews at Hillcrest Medical Center (HMC) and 21 of the interviews at Tulsa Dialysis Center (TDC) were conducted by the Center social workers, after the social workers received an orientation to the survey. The interviews consisted of (1) reading

the questions aloud to the patients, (2) explaining and interpreting the questions and (3) recording the responses of the patients.

Table I identifies the total number of patients at each of the four centers in Tulsa, Oklahoma, and the number of participants in the survey. The percentages of participants who completed the survey are indicated in parentheses.

The questionnaire was distributed to all patients unless they were unable to respond due to the previously mentioned limiting factors. Table II identifies the number of questionnaires, interviews and corresponding percentages of the total response that each figure represents.

Table III identifies several age categories of the respondents, while Table IV records their marital status. Table V identifies the general area in which the patients lived. The distance that a patient was forced to travel to activities has been identified by the panel of experts as a key factor in patient participation. Table VI reflects patient responses to the question of length of dialysis therapy. Table VII reflects the relatively low level of participant participation in group meetings.

TABLE I
TOTAL DIALYSIS PATIENTS, PARTICIPANTS AND PERCENTAGE OF
PARTICIPATION AT EACH CENTER

Center	Total Patients	Participants	Percentage
Hillcrest Medical Center (HMC)	77	59	76.6
Tulsa Dialysis Center (TDC)	67	55	82.0
Tulsa Regional Medical Center (TRC)	54	45	83.0
Saint Francis Hospital (SFH)	28	18	64.2
Totals	226	178	78.7

TABLE II
NUMBERS OF QUESTIONNAIRES, INTERVIEWS AND PERCENTAGES
OF EACH METHOD UTILIZED AT EACH CENTER

Center	Questionnaires	Interviews
HMC	39 (66.1%)	20 (33.9%)
TDC	23 (41.8%)	32 (58.2%)
TRC	25 (55.6%)	20 (44.4%)
SFH	16 (84.2%)	3 (15.8%)
Total	103 (57.9%)	75 (42.1%)

TABLE III
AGE OF RESPONDENTS BY CENTER

Age	HMC	TDC	TRC	SFH	Total
17-under	0	0	0	0	0
18-29	1	4	2	1	8
30-39	5	2	5	3	15
40-49	17	6	6	4	33
50-59	11	9	10	2	32
60-older	25	34	20	8	87
No Response	0	0	2	1	3
Total					178

TABLE IV
MARITAL STATUS OF RESPONDENTS AT EACH CENTER

Status	HMC	TDC	TRC	SFH	Total
Married	28	24	20	9	81
Single	27	28	24	9	88
No Response	4	3	1	1	9
Total					178

TABLE V
LOCATION OF RESPONDENTS BY CENTER

Home	HMC	TDC	TRC	SFH	Total
Tulsa (City)	47	43	26	10	126
Tulsa (County)	2	3	3	3	11
Other Counties	10	9	14	5	38
No Response	0	0	2	1	3
Total					178

TABLE VI
LENGTH OF TIME ON DIALYSIS FOR RESPONDENTS
AT EACH CENTER

Time	HMC	TDC	TRC	SFH	Total
Less than one year	13	21	7	7	48
One to three years	11	17	15	9	52
More than three years	35	16	21	3	75
No Response	0	0	2	1	3
Total					178

TABLE VII
ATTENDANCE OF GROUP MEETINGS BY RESPONDENTS
AT EACH CENTER

Attendance	HMC	TDC	TRC	SFM	Total
None	45	52	40	11	148
Once	4	1	1	4	10
Twice	4	0	0	2	6
Three or more	5	0	1	1	7
No Response	1	2	3	1	7
Total					<u>178</u>

Analysis of the Responses

Patients who participated in the survey were asked to indicate whether they believed that a support group for patients was a "worthwhile activity." The question was posed in this way in order to identify their views of self-help groups. Several patients indicated that they were unsure of the worth of a group. These responses are noted as "unsure" in Table VIII. This table indicated a participation level of 12.9 percent.

The survey asked respondents to indicate as many reasons as applied for their nonparticipation to the support group. Table IX reflects the responses of the patients to the possible reasons for nonparticipation. A total of five patients did not respond to this portion of the survey: three from SFH, and one each from TDC and TRC.

Discussion

A large number of patient lacked the physical abilities to complete a questionnaire and needed the instrument to be administered via interview. In most cases, the inability of the patients to complete a questionnaire was based on poor eyesight. Hearing difficulties and peripheral neuropathy, or lack of complete hand and finger function, were also factors. These physiological disabilities were reflected in many of the "no transportation" responses, as many patients depended upon public transportation, which could be difficult or dangerous in the evening hours when the meetings were held.

TABLE VIII
PERCEIVED VALUE OF SUPPORT GROUP BY RESPONDENTS
AT EACH CENTER

Worthwhile?	HMC	TDC	TRC	SFH	Total
Yes	48	33	39	16	135
No	1	10	1	0	12
Unsure	6	7	4	1	18
No Response	4	5	1	2	13
Total					<u>178</u>

TABLE IX
REASONS FOR NONPARTICIPATION GIVEN BY PATIENTS
AT EACH CENTER

Category	HMC	TDC	TRC	SFH	Total
Too sick or tired	17	15	10	6	48
Transportation	23	20	16	3	57
Inconvenient time	16	18	3	4	33
Inconvenient place	10	19	2	1	32
Inconvenient day	6	8	2	4	20
No information on group	27	21	27	3	77
Program content not interesting	4	0	1	1	6
Other	2	6	4	3	30
Total	105	107	66	25	<u>303</u>

Nearly four out of five (78.9 percent) of the respondents lived within Tulsa County, implying that distance from the centers per se was not a major consideration in attendance. The percentages of married patients (47.9%) and single patients (52.1%) were approximately the same.

Two fifths (42.1 percent) of the respondents indicated that they had received dialysis for more than three years. Another 29.1 percent had received dialysis for between one and three years, while 27.0 percent had received dialysis for less than one year.

A total of 87 patients, or 48.8 percent, were age 60 or older, and 119 patients, or 66.8 percent, were age 50 or older. As noted previously, the average age of dialysis patients has increased during the last decade. The center with the highest percentage of patients 60 or older, TDC, also had the highest percentage of patients who had not attended a single meeting in the previous 12 months, as illustrated by Table X. This table compares the percentage of patients who were age 60 or older with the percentage of patients who stated that they had not participated in the support group in the previous 12 months.

According to Table XI, the most frequent response to the question about reasons for nonparticipation was "not enough information about the group": 25.7 percent for HMC, 19.6 percent for TDC, 40.9 percent for TRC and 12 percent for SFH. The respondents were not asked to rank their answers according to relative importance. The reasons stated by patients for nonparticipation varied some what by center. However, "lack of information" about the group's activities was a frequent reason given for nonparticipation.

TABLE X
 PERCENTAGE OF PATIENTS AGE 60 OR OLDER VS. PERCENTAGE
 OF NONPARTICIPATION BY ALL PATIENTS AT EACH CENTER

Center	Age 60 or Older	Nonparticipation
HMC	42.3%	76.2%
TDC	61.8%	94.5%
TRC	44.4%	88.8%
SFH	42.1%	57.8%

TABLE XI
 PERCENTAGE OF RESPONSES BY CENTER

Response	HMC	TDC	TRC	SFH
Not enough information about the group	25.7			
No transportation	21.9			
Too sick or tired between treatments	16.2			
Not enough information about the group		19.6		
The place that the meetings are held is inconvenient for me		17.8		
No transportation		18.7		
The time that the meetings are held is inconvenient for me		16.8		
Not enough information about the group			40.9	
No transportation			24.2	
Too sick or tired between treatments				31.6
Other				26.3
The day of the week is unavailable				21.1

Since SFH is a "hospital-based" center, patients at that center were expected to have more medical problems. Physicians typically assign the more infirm patients to a hospital-based center, where they can receive a wider range of medical services on an as-needed basis. These patients cited health considerations as a primary reason for nonparticipation. The patients at TRC and HMC, which are also hospital-based centers, listed "lack of information" as a primary reason for nonparticipation. TRC has the largest number of patients who live outside of Tulsa County, and one-fifth of its responses (24.2 percent) cited "lack of transportation" as a reason for nonparticipation.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

The purpose of this study was to identify factors related to patient nonparticipation in the renal dialysis support group in Tulsa, Oklahoma. After a review of related literature and discussions with staff members at the four centers about reasons for the problem, a survey of the in-center hemodialysis patients at each of the centers was administered. An overall response rate of 78.8 percent was achieved, using a combination of questionnaires and interviews. The survey was conducted between July 24, 1991 and August 7, 1991. The survey results were then tabulated and analyzed to identify factors related to nonparticipation by patients.

The most frequent response given was "lack of information" about the group's activities. Other factors, such as health problems and a lack of transportation, were identified frequently by respondents as reasons for nonparticipation.

More than one-third of the respondents had received dialysis for three years or more, and nearly three-fourths of the respondents had received dialysis for a year or more.

Most respondents indicated that support groups were a "worthwhile activity." A majority of respondents indicated that a support/self-help group was a helpful activity for patients.

Respondents indicated that they lacked information about the group's activities. Patient nonparticipation was affected by meeting location and the availability of evening transportation.

Conclusions

1. In regard to research questions one and two, the data did not indicate any one demographic or logistical factor as more important than other factors in influencing the level of participation by respondents.

2. While it was found that there was a high level of belief in the "worthwhileness" of support groups, no data were produced which identified factors related to attitudes that hindered participation.

3. Patients need more information about the renal dialysis support group.

Recommendations for Further Research

Additional studies should be undertaken on this topic, based on

1. whether patients would participate in support groups that were more conveniently located, such as on-site at the dialysis centers;

2. the ranking of factors relating to nonparticipation by respondents;

3. whether different types of activities might increase participation by respondents; and
4. the frequency of meetings.

Recommendations for Practice

It is recommended that facilitators of hemodialysis support groups

1. increase efforts to improve patient awareness of meeting information;
2. explore the potential for patient "inservices," conducted by experts in relevant fields, rather than meetings conducted off-site;
3. explore the possibility of quarterly meetings, instead of monthly meetings, in order to improve participation; and
4. place more emphasis on recruitment of new kidney dialysis patients than on retaining those patients who have been on dialysis for long periods of time.

Implications

While most respondents believe that a support group is "worthwhile", their concept of what constitutes a support group worth attending may merit further investigation, given their high degree of nonparticipation. For the most part, the topics and programs that were presented were selected based on informal discussions with the staff members at the centers as well as with some of the participants. The efforts at achieving greater participation may be more effective if they are formalized through

the use of opinion gathering methods and include a broader range and larger number of patients.

While the respondents indicated that a support group is a "worthwhile" activity, no mention was made of the frequency of meetings. Therefore, a change in the frequency of meetings may be more effective in increasing participation.

Given the age of the respondents and the physical hindrances to travel that they have experienced in terms of both physical health and available transportation, meetings scheduled at the dialysis centers may result in increased participation.

A majority of respondents expressed a "lack of information" about the group's activities. In spite of the use of fliers and posted announcements in the centers by the staff members, new methods of communicating the group's activities may need to be considered. Increasing the frequency of communications may result in increased participation by the patients.

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HELLO!

Your social workers and nurses have organized a kidney dialysis support group for patients and family members in the Tulsa area. However, attendance has not been as high as hoped for. We're trying to find out why this is so, in order to better serve the patients and families in the area. Please take a minute to complete this survey, so that we can work toward improving services in the area. Thanks!

1. Please circle the correct answer:

My age is: 17 or younger 18-29 30-39 40-49 50-59 60 or older

My City is: Tulsa Other (please list) _____

My County is: Tulsa Other (please list) _____

My marital status is: Married Single

Number of years on dialysis: Less than one year 1-3 years More than three

2. I have participated in the support group [in the last 12 months]:

No attendance Attended once Attended twice Attended three
or more

3. I believe that a kidney support group is a worthwhile activity: yes no

4. If you have not participated regularly in the support group, please check all of the reason listed below (check as many as apply to you):

___ I'm too sick or tired between treatments to attend.

___ I don't have adequate transportation.

___ The group meets at an inconvenient time.

___ The meetings are at an inconvenient place.

___ The day of the week that the meetings are held on is unavailable.

___ I don't have enough information about the group meetings.

___ The program content is not interesting enough.

___ Other: _____

Please list any suggestions that you have for improving the group on the other side of this sheet, and return it to your nurse when completed.

THANK YOU FOR YOUR HELP!

VITA

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