An examination of empowerment at a kidney center as experienced by persons who receive hemodialysis treatment for End-Stage Renal Disease
by Thomas Dominique Bordelon

A thesis submitted in partial fulfillment of the requirements of the degree of Doctor of Education
Montana State University
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Abstract:
The purpose of this study was twofold; to delineate a method of empowerment that emphasizes community awareness, and to determine if recipients of hemodialysis treatment for End-Stage Renal Disease experience the process of empowerment as described in the body of theory. Empowerment is a process by which hemodialysis recipients are able to embrace the reality of their social world. With a sense of personal power, recipients develop relationships with each other to make meaningful changes that affect the welfare of other recipients at the kidney center. A qualitative research design was employed to query 20 hemodialysis recipients about their experience with hemodialysis treatment at a kidney center. Questions used in this study were derived from the theoretical basis for empowerment at a community level as reported in the literature. The recipients’ responses to the questions were compared to the theoretical bases for empowerment identified in the literature.

The findings of this study indicate that hemodialysis recipients’ awareness of the opportunities and limitations of their social environment made it possible for them to achieve a good quality of life as they perceived it to be. This awareness of self and others seemed to lead to changes within the kidney center community that encouraged treatment recipients to fully participate in their care in partnership with other recipients and medical personnel in the kidney center. Moreover, the medical professionals did not seem to be an oppressive force preventing recipients from enjoying full participation at the kidney center. This study indicates that recipients’ relationships with both medical staff and other recipients are essential to facilitating empowerment on a community level.

The quality of life recipients perceived themselves as attaining at the kidney center was found to be attributable to the sense of relatedness they experienced with others. Participation and relatedness to each other provides a basis for understanding empowerment on a community level in a health setting. The sense of empowerment that recipients develop at the kidney center may contribute to participation more fully in society outside of the kidney center.
AN EXAMINATION OF EMPOWERMENT AT A KIDNEY CENTER AS EXPERIENCED BY PERSONS WHO RECEIVE HEMODIALYSIS TREATMENT FOR END-STAGE RENAL DISEASE

by

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A thesis submitted in partial fulfillment of the requirements of the degree of Doctor of Education

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April, 1997
APPROVAL

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

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ABSTRACT

The purpose of this study was twofold; to delineate a method of empowerment that emphasizes community awareness, and to determine if recipients of hemodialysis treatment for End-Stage Renal Disease experience the process of empowerment as described in the body of theory. Empowerment is a process by which hemodialysis recipients are able to embrace the reality of their social world. With a sense of personal power, recipients develop relationships with each other to make meaningful changes that affect the welfare of other recipients at the kidney center. A qualitative research design was employed to query 20 hemodialysis recipients about their experience with hemodialysis treatment at a kidney center. Questions used in this study were derived from the theoretical basis for empowerment at a community level as reported in the literature. The recipients’ responses to the questions were compared to the theoretical bases for empowerment identified in the literature.

The findings of this study indicate that hemodialysis recipients’ awareness of the opportunities and limitations of their social environment made it possible for them to achieve a good quality of life as they perceived it to be. This awareness of self and others seemed to lead to changes within the kidney center community that encouraged treatment recipients to fully participate in their care in partnership with other recipients and medical personnel in the kidney center. Moreover, the medical professionals did not seem to be an oppressive force preventing recipients from enjoying full participation at the kidney center. This study indicates that recipients’ relationships with both medical staff and other recipients are essential to facilitating empowerment on a community level.

The quality of life recipients perceived themselves as attaining at the kidney center was found to be attributable to the sense of relatedness they experienced with others. Participation and relatedness to each other provides a basis for understanding empowerment on a community level in a health setting. The sense of empowerment that recipients develop at the kidney center may contribute to participation more fully in society outside of the kidney center.
CHAPTER I

INTRODUCTION

There is a large literature base for understanding some of the many psychosocial changes people experience associated with the chronic illness, End-Stage Renal Disease (ESRD). High incidence of stress, depression, disruption in daily routine, loss of hope for the future, and lowered socio-economic status can result from receiving treatment for ESRD. For these reasons, the federal government and perhaps even the medical community has regarded persons who have ESRD as disabled; disenfranchised from being able to participate in society as fully functioning human beings because of their renal failure. Despite this, an emerging research base is developing that strongly suggests that persons with ESRD who receive renal replacement therapy show a willingness, desire, and need to be more fully participating and contributing members in society. Additionally, this belief is recently brought on by vast improvements in medical technology and treatment that is provided routinely to persons with ESRD, and encouragement from renal care providers to be more active.

Becoming fully participating and contributing members of society has not been linked to how well persons with ESRD engage in an empowered manner with the hemodialysis community that comprises a kidney center in which they belong. There, a
common language is spoken, and similar values are expressed by both recipients and renal health care providers. The applications of empowerment in health care to better understand the phenomenon of persons learning to become aware of a hemodialysis community within the structure of hemodialysis treatment has not been done. Most of the research in the area of hemodialysis has been done for the purpose of developing and evaluating programs that provide hemodialysis recipients with information about renal failure or with the management of their hemodialysis treatment regime.

It is assumed by health care providers that information about dialysis treatment will encourage individuals to be participants in their treatment, laying the foundation for compliance with medical treatment. People with ESRD do not receive the health benefits of improved medical care and technological advancements if the basic problem of compliance with the medical regime is not better adhered. For persons with ESRD, compliance involves a complex and time consuming array of behavioral expectations as compared to other health related problems. For example, compliance includes following strict and complex dietary and fluid restrictions, taking multiple and costly medications as prescribed, maintaining reasonable physical activity (such as walking a few blocks on non-dialysis days), keeping routine appointments with their nephrologist, and attendance at their hemodialysis treatments. Adhering to the treatment recommendations as a result of having End-Stage Renal Disease is one of the most costly and time consuming health problems faced by a person with a chronic illness. Compliance within the structure and
regime required of persons who receive hemodialysis treatment is critical, as a host of severe and life threatening consequences occur if persons do not attend to these important aspects of their medical treatment.

Hemodialysis treatment is costly, and kidney centers only receive payment on a composite rate. Therefore, only essential renal health care providers are available to assist persons receiving hemodialysis treatment. If a person who has not been compliant with fluids becomes hypotensive during the course of dialysis treatment and requires certain medications to increase blood pressure, for example, the kidney center may not be reimbursed for the use of that medication. That particular hypotensive individual requires more nursing care at the time of a hypotensive crisis increasing the demands placed on the nursing staff who must also care for other treatment recipients. Since kidney centers are arranged so that renal care providers are able to easily see and access persons receiving hemodialysis, other recipients easily notice if someone is in distress. Thus, people receiving hemodialysis treatment are aware of the problems that other people on hemodialysis are experiencing as well as the increased stress on the renal care providers.

Hemodialysis treatment is very structured for renal health care providers who have to ensure state and federal authorities that all the conditions for providing appropriate treatment are continuously adhered, in addition to keeping the kidney center fiscally responsible. Hemodialysis treatment is also very structured for the recipients of treatment. There are issues of compliance with other aspects of treatment that can play a dramatic role in how the kidney center as a community is affected. Recipients are
expected to arrive fifteen minutes early for each three to four hour dialysis treatments three times each week. They are also expected to prepare themselves for treatment, to the degree that they are able, so as to enable their nurse to begin treatment expediently. Even though recipients are typically on time for their appointments, the system can break down in any kidney center when, for example, a person arrives late or cannot keep their regularly scheduled appointments on time. If a person is late arriving in the morning, all the hemodialysis treatment recipients can be late for the entire day. This problem can cause persons to be late for work, miss other appointments, and create havoc for transportation services in the outside community. Additionally, this and other problems that might occur in a day can have an accumulative impact on the entire hemodialysis community by increasing the stress experienced by both treatment recipients and renal health care providers.

Another dimension of how treatment recipients’ presence or absence affects each other can be expressed in the concern that the kidney center community has when one of its members is absent. Treatment recipients ask renal health care providers if that person is being treated in the hospital or if the missing person has expired. Concern for the well-being of others, even if the names are not known, is indicative of having a sense of community affiliation.

The demanding structure of both providing and receiving hemodialysis treatment engenders certain behaviors in its participants. For the recipients of renal health care, the structure of receiving hemodialysis treatment may seem strict and unyielding, restricting
them so that they are possibly unwilling or unable to develop a sense of empowerment within the context of the kidney center community. Of the renal health care providers, the structure may demand of them to instruct recipients to follow their prescribed treatment without variation, for to do otherwise may not only endanger their health, but also increase the work of the care providers and jeopardize the financial responsibility of the kidney center. Through traditionally paternalistic recipient education, health care professionals may unwittingly become the instruments for socializing renal health care recipients into docility, whereby they accept the structure of the kidney center community as static. Compliance with medical care may become a battlefield between recipients and renal health care professionals. Equally disabling, treatment recipients may accept their lack of power to envision changes that could empower themselves and others to affect meaningful change in their kidney center community.

Since the focus on recipient education has been on how recipients learn their individual treatment regime, it is unknown if treatment recipients are able to engage in a learning process that incorporates the experience of other recipients within the kidney center community, and in what relation this has to the paternalistic education that is provided to them. With a new attention on empowerment among recipients of renal health care, it may be possible to assess whether an empowering learning process is occurring at a kidney center. The recognition of a yet unseen force as empowerment may be vital to understanding the dynamics of a kidney center community.
Problem Statement

There is a preponderance of research dealing with recipient education in the renal literature. This focus on recipient education largely deals with programmatic issues relating to dispersing information that is important for persons with End Stage Renal Disease (ESRD) to know so that they successfully comply with the regime of hemodialysis treatment. Recipient education literature does not, however, discuss the ESRD population in terms of a community, nor does it suggest that empowerment is or should be a focus of learning. An emphasis on developing a community awareness through empowerment as an essential component of being a recipient of hemodialysis treatment may be a useful means for recipients to attain a greater understanding of their treatment, be more compliant with their treatment regime, have a greater participation in their treatment, and be better satisfied with their lives. It may also help renal health care providers recognize an important and useful dynamic that may give rise to greater participation from renal health care recipients.

Empowerment as an emerging model of participation in health care can be used as a framework for understanding problems that affect a community of people such as persons who receive dialysis treatment. Hemodialysis recipients may be viewed as a community interconnected by the values and expectations of those who are interdependent on each other. How and if treatment recipients develop a sense of empowerment in the kidney center, however, remains unknown. The kidney center is a
unique setting to discover if treatment recipients are able to develop a social consciousness about others in the hemodialysis community, and if this awareness leads to action that may benefit the kidney center community.

The loci for research on these issues and others, such as compliance, have been too narrow to understand how treatment recipients develop an understanding of their illness and the rationale for complying with treatment regimens. This focus also encourages renal health care providers to provide information to treatment recipients in a paternalistic fashion. The literature shows that research to date has been primarily rooted in an individualistic psychological perspective. These studies have brought a better understanding of the dynamics of this chronic illness, and enhanced an understanding of depression, anxiety, and other psychological reactions endemic to ESRD. However, they have not broached a broader and potentially meaningful area of what factors contribute to recipient empowerment, how treatment recipients learn to develop a sense of community with other treatment recipients at the kidney center, and how empowerment transforms the quality of their life and the lives of others.

It is unknown if hemodialysis recipients develop a sense of community as a result of being treated at a kidney center for ESRD. To what extent an awareness of the community to which one belongs relates to empowerment has not been studied at a kidney center. The likely place to investigate whether persons being treated for renal failure develop an awareness of each other that encourages a sense of community awareness is at a kidney center. The development of relationships with one another over
time coupled with a need to learn the treatment regime common to renal recipients is fertile ground to investigate the relationship between community awareness and empowerment. For renal recipients to experience empowerment they must develop an awareness of themselves and others as a part of a community. If community awareness is achieved as a result of empowerment, then issues such as compliance and a good quality of life become a community issue in addition to an individual issue. This awareness of self and other treatment recipients may lead to change in the kidney center community that encourages recipients to fully participate as partners in the hemodialysis treatment. Empowerment, then, may be viewed as the path to a good quality of life and fuller participation in the community to which one belongs.

Purpose of the Study

The purpose of this study is twofold; to delineate a process of empowerment as experienced by hemodialysis recipients that emphasizes community awareness, and to determine if persons who are treated for ESRD experience a process of empowerment as described in the body of theory pertaining to empowerment. Following are research questions that will explicate the purpose of this study:

1. How does the theoretical basis for empowerment relate to community awareness with recipients of hemodialysis treatments?
2. What factors contribute to hemodialysis recipient's experience of empowerment or lack of empowerment?

3. If empowerment does occur, how does the process of empowerment of hemodialysis treatment recipients lead to changes in the behavior of treatment recipients within the kidney center community?

**Objectives**

The following questions are addressed in this study so that the research questions can be answered. The questions are derived from the theoretical bases of empowerment selected from the literature review. The answers to these questions will describe to what degree the theoretical basis to empowerment is present in the hemodialysis community, and to what degree they affect participant's perception of their own empowerment.

1. Through dialogue with other hemodialysis recipients, how do hemodialysis treatment recipients name the elements of their world (the kidney center) to give these objects a subjective meaning?

2. How is critical reflection necessary to develop an understanding of the reality of one's world (the kidney center) and envision change?

3. How is awareness of self within a community of other hemodialysis recipients necessary to experience empowerment?
4. How is praxis necessary to experience empowerment within a community of hemodialysis recipients?

5. How do hemodialysis recipients experience changes in their behavior, attitude, and perspective on life resulting from empowerment as they develop an awareness of the experience of other hemodialysis recipients in the kidney center community?

**Threats to Empowerment**

These questions take into consideration the forces that may prevent empowerment from occurring at the community level. The answers to these questions are necessary to fully explore the research questions of this study.

1. How does the dominant medical culture bestow power to individuals receiving hemodialysis treatment as charity?

2. How do hemodialysis recipients become accustomed to the stability and comfort of the kidney center so that they become oppressed?

3. How do hemodialysis recipients accept the meaning, values, and beliefs of the dominant medical culture without reflection?

4. How do hemodialysis recipients become dependent on the rewards that the dominant medical culture provides?
Significance of the Study

An understanding of the process of how hemodialysis recipients learn to develop an awareness of the hemodialysis community will contribute valuable conceptual information to an emerging model of empowerment in health care. With a focus on empowerment beyond the individual level, renal care recipients’ process of community awareness of the needs and concerns of others receiving hemodialysis treatment will provide information about the process by which recipients are able to more fully participate in treatment at the kidney center. By identifying and describing a process of empowerment, this study will contribute important empirical information to the assumptions made in how people develop a sense of empowerment in a health care community setting. The results of this study may also illuminate and perhaps encourage a process that can be applied to other areas in health care with a concern for recipient empowerment.

Assumptions of the Study

1. Hemodialysis care has focused on the behavior of the individual in isolation of others.
2. Renal health care focuses on compliance on an individual level, and does not in itself encourage the development of an awareness of a community of hemodialysis recipients and renal health care providers.
3. Empowerment is derived from hemodialysis recipient’s ability to articulate a definition of a good quality of life that includes an awareness of the reality of their situation as a hemodialysis recipient.

4. Health care provider’s encouragement of recipient compliance as individuals is for the most part paternalistic and ineffective. This didactic form of communication is not effective because it does not engage the treatment recipient in reflecting on his or her unique understanding of the advice given by health care providers.

5. Persons with End-Stage Renal Disease can enjoy full status in the kidney center community through empowerment. Empowerment may even lead to hemodialysis recipient’s fuller participation in society despite their chronic illness.

**Delimitations**

1. Interviews conducted for this study were obtained from persons who receive hemodialysis treatment (rather than other forms of treatment for ESRD).

2. The interviews with hemodialysis recipients were acquired from one kidney center.

3. Interviews were conducted on the small sample of 20 persons who have ESRD.

4. Interviews were conducted with those hemodialysis recipients who were physically and emotionally able to respond to my questions. (For example, persons who are unconscious, profoundly demented, or suffering from other co-morbid conditions that rendered them incapable of responding to my questions were not used in this study).
Definitions of Terms

**End-Stage Renal Disease** occurs when the kidneys are no longer able to remove fluid and metabolic waste products from the blood to the degree in which death by uremic poisoning is the expected outcome unless a treatment alternative such as hemodialysis is selected.

**Quality of life** is the state of being in which hemodialysis treatment recipients achieve a sense of comfort, control, and satisfaction of their life.

**Compliance** is the quality of adhering to a medical regime. Compliance is also an interaction between recipient’s and renal health care provider’s efforts to maintain adherence to a medical regime.

**Empowerment** is the process that engages recipients to develop a sense of personal power and self-efficacy (Fahlberg, 1991), articulating a definition of a good quality of life (Simmons and Abress, 1990), and developing a social consciousness that accounts for an appreciation of others in the social reality (Horton, 1990). A social consciousness develops an awareness of others within the individual that gives him or her the potential for action so as to make an impact in the world (Freire, 1995).

**Hemodialysis** (also called renal replacement therapy and dialysis) is a method of cleansing the blood of a recipient with ESRD. The process removes fluid and metabolic waste products from the recipient’s blood stream by means of an artificial access. The access for hemodialysis treatment is typically located in the forearm of the recipient. For
the recipient, this procedure involves sitting in a reclining chair for about three hours, three times per week.

**Community** is a group of people who share similar values and concerns through interaction, and rely upon each other to conform to certain joint expectations of behavior (Merriam-Webster's Collegiate Dictionary).

**Critical reflection** is a process of becoming aware of one’s presuppositions and challenging them in the context of one’s worldly encounters. Critical reflection is necessary to have a transformed experience through challenging one’s self-concept, and risking one’s social stability (Mezirow, 1989).

**Praxis** is the act of putting into practice the products of critical reflection. Action is modified by critical reflection, then is modified by practice continuously.
CHAPTER II

LITERATURE REVIEW

Overview of the Literature on Empowerment

The intent of the literature review is to provide a basis for understanding the treatment recipient’s learning that occurs on a community-wide basis at the kidney center. The literature will show that there is a preponderance for teaching recipients on an individualistic level. Further, the literature is steeped in programs that seek to develop cognitive competencies for understanding information paternalistically given to recipients without consideration for subtle socialization for unempowered behavior that is expected of recipients when they begin renal replacement therapy at the kidney center.

Recipients’ compliance to medical treatment is often related to renal health care professionals’ interaction with recipients and their family members in the effort toward achieving compliance. Encouraging compliance by staff is a time consuming, often frustrating, and perhaps the most vexing problem when failure is the perceived outcome met by both recipient and health care provider. There is probably no other area in treating the ESRD recipient that engenders the paternalistic advice giving than related to attempts
towards achieving compliance. Measures of compliance are easily and quickly obtained through routine laboratory studies, putting renal health care professionals in an authoritarian role of telling recipients how they are not “measuring up” to their need to comply with treatment.

Failure to comply with medical treatment not only impacts the relationship that health care providers have with recipients, but it also influences the stability of the recipient’s other responsibilities to his family and other social obligations. Failure to comply with the medical regime also burdens society with the increased health care costs to treat problems that could easily have been avoided if recipients were to comply with their medical treatment. The underlying assumption in health care is that compliance is the rubric for measuring a recipient’s successful coping with chronic illness, and the many rigors encompassed in receiving renal replacement treatment. This point is demonstrated within this review of the current literature. The literature also indicates that compliance is achieved through efforts made by recipients to learn about kidney failure and the available treatment options to the recipient and family as usually provided by health care providers at a kidney center. Research in this area tends to focus on the effects of using various teaching methods that foster didactic advice giving and therefore paternalism (Brantly, Mosley, Jr., McKnight & Jones, 1990; Szczepanik, 1995; Brundage, Swearengen, 1994). The focus is predominantly centered on cognitive gains measured by educational methodology, and an interest in program effectiveness so as to increase recipient’s compliance with medical treatment.
The focus of this research on compliance has primarily been from an individualistic psychological perspective. These studies have brought a better understanding of the dynamics of this chronic illness, and enhanced an understanding of depression, anxiety, stress, and other psychological reactions endemic to ESRD. Additionally, they have equated the alleviation of these psychological reactions with compliance, which leads to a good health and therefore a good quality of life (Kimmel, Weihs & Peterson, 1993; Petrie, 1989; Phillips, 1986; Gokal, 1993; O'Brien, 1990; Simmons, Abress, 1990; Kimmel, 1990; Courts, Vacci, 1994). It is assumed that compliance with medical treatment is the path to a good quality of life and fuller participation in society that also limits their dependence on society. Beyond the individual level, the broader implications of ESRD have been studied in the areas of impact on the family and their ability to provide care and support to the recipient, and the cost of providing dialysis treatment to society. The sociological perspective is usually focused on the measures involved in determining the costs of providing renal replacement therapy to recipients.

Recipients become disenfranchised from participating in their treatment with a focus on an individual’s compliance that leads to control issues, passive aggressive behavior, dependence, depression, and despair. This focus keeps staff feeling frustrated and impotent, and recipients dependent and hostile. The process of recipients’ sense of empowerment, which veers away from paternalism, is a potentially better means of
assisting recipients achieve a sense of a good quality of life as they define it, and does not have compliance as the focus of the efforts of recipients and staff (Fahlberg, 1991).

Community empowerment is an approach used to encourage social change among the poor, illiterate, and oppressed (Horton, 1990; Freire, 1995). Since the federal government has designated recipients with ESRD as eligible for disability, those persons with ESRD have been treated as disenfranchised people. Disability status suggests that a person is incapable of working and enjoying a full share of the opportunities that society offers to its more fit members. In health care, community empowerment has been used on specific target populations to allow the members of these groups to discover their own ability to identify and solve shared problems; particularly the problem of their lack of awareness or their dependency on a dominant and oppressive force (Overbo, Ryan, Jackson, and Hutchinson, 1994). Central to an understanding of empowerment on a community level is the problem of individuals becoming aware of themselves in a social context. It is necessary, therefore, to discuss the relevant research conducted on how individuals use empowering tools to develop a sense of community, and how that awareness potentially impacts a community.

Psychosocial Issues Affecting Renal Recipients

Renal recipients are marked as being different from the general and health care population by their lack of renal functioning and subsequent dependence on renal replacement therapy. The constraints to living normally have been demonstrated by the
recent literature on the psychosocial issues affecting dialysis recipients. A common problem amongst dialysis recipients that is discussed in the literature is depression. It is suspected that depression occurs more frequently in the dialysis population than it does in the non-dialysis population. As many as eight percent of the dialysis recipients studied were found to have a current Major Depressive Episode, and an additional twelve percent had a history of depression. Characteristics of Major Depressive Episode in these recipients demonstrated a higher occurrence for those who received dialysis treatment twenty-four or fewer months, lived alone, were unemployed, and were female (Graven, Rodin, Johnson & Kennedy, 1987). Even higher rates of depression have been reported in recipients who receive hemodialysis treatment—up to thirty percent greater than the general population of non-dialysis recipients. Fifty-five percent of these recipients said that coping with the emotional problems inherent in their adjustment to dialysis treatment was the most difficult problem they ever experienced in their life (Hong, Smith, Robson & Wetzel, 1987). Symptoms of major depression that were found among dialysis recipients were suicidal ideation, discouragement, and depressed mood. However, other symptoms of depression such as weight loss, fatigue, and insomnia were not strongly associated with a diagnosis of major depression in dialysis recipients (Henrichsen, Lieberman, Pollack & Steinberg, 1989).

Dialysis recipients experience more psychiatric disorders than the non-dialysis population. These disorders are predominantly mood disorders.
Social disability was more definitely linked to treatment status, regardless of its duration. One illustration of this point is the higher level of sexual and marital dysfunction in dialysis recipients. This finding can be attributed in part to the physical effects of dialysis and in part to the greater social constraints imposed by the treatment. Disability was also associated with the measure of mutual dependence in relationships. These observations support the conclusion that social disability is a function of the individual’s circumstances, while psychiatric disorder is a more transient manifestation of the individual’s current state of adjustment to those circumstances (House, 1987, p. 450).

Stress appears to account for much of the psychological difficulties associated with dialysis treatment. The death rate for dialysis recipients is 100 times that of the general population. For completed suicides, the death rate jumps to 400 times that of the non-dialysis population.

There is general agreement that dialysis patients are subjected to very specific stressors. These include: i) Stress arising from the dependency imposed by the treatment (that is, dependency on the machine and dependency on the medical staff); ii) Stress associated with the threat of death, iii) Stress arising from the severe restrictions imposed by the dialysis regimen, especially fluid and dietary restriction; iv) Stress arising from the physical complications of the illness and its treatment; v) Stress associated with the losses incurred by the illness, for example: loss of employment, loss of financial status, loss of freedom and loss of self-esteem; vi) Stress related to changes in the body image (Israel, 1986, p. 37).

Chronic hemodialysis recipients report being troubled by physiological stressors more than psychosocial stressors. The lengths of time recipients are on dialysis is associated with the type of coping strategies they used. The recipients receiving
treatment the longest used problem-oriented strategies as opposed to affective-oriented strategies (Gurklis & Menke, 1988).

Quality of life is determined by physiological and psychosocial factors and refers to the renal recipient's adaptability to adjust to the adverse effects of dialysis treatment, and report satisfaction with their life (Gokal, 1993). Quality of life has been associated with physiological markers, such as hematocrit levels. Low hematocrit levels cause anemia, which causes fatigue (Paganini, 1994). An important source of satisfaction with life has been identified as employment. Employment gives recipients a sense of identity and purpose, as well as other tangible benefits such as higher income and health insurance (The Life Options Rehabilitation Advisory Council, 1994).

Supportive measures have been seen as a means of helping renal recipients adjust to these psychosocial problems. Supportive groups for dialysis recipients and family members can take the form of a program, recognizing that family members need support as much as recipients. Programs can benefit those who participate. For example, they can reduce levels of tension and depression, and help recipients and their family members develop a greater degree of empathy for other participants in the program (Hastings, 1982).

Social support has been found to be a significant factor in acting as a buffer between recipients and the stresses associated with long-term dialysis treatment (Burton, Kline, Lindsay & Heidenheim, 1988). Another benefit of supportive groups is the intimate interaction of recipients, family and renal health care providers in the process of
sharing experiences regarding dialysis treatment. These groups offer a place where people can gain mutual understanding about each other. They are helpful in focusing on issues of anger towards others, having an incurable disease, and increased dependence on others ( Cornell, 1986). There are clear benefits for recipients and family members to form supportive networks amongst themselves, yet the literature does not indicate that recipients and family members initiate nor sustain support groups.

Recipient Education

Efforts made by health care providers to educate recipients ranges from commitment to an ideal that recipients have a right to know and to understand their treatment across their lifespan (Rendon, Davis, Gioiella & Tranzillo, 1986) to arousing fear that recipients could sue the health care provider for not adequately informing them about treatment (Smith, 1987). These concerns may be manifest in the desire to see that recipients understand information on the cognitive level. The reasoning may be that the greater the quantity of information given, the safer the health care provider is from being sued, and the more likely recipients may understand their treatment. This concern has brought about a number of studies that encourage health care providers to present learning material that is easily comprehensible to recipients. For example, literacy experts suggest that written materials be presented to recipients not exceeding the fifth grade reading level (Dixon & Park, 1990).

As a function of providing recipients with education, learning style differences in the ways in which recipients process information and prefer to receive information has
been considered (Garity, 1985). With a focus on individual learning styles, the contention is made that teaching plans done by nurses can be quickly developed so that they are able to increase recipients competence and their quality of life. Also, teaching according to recipient learning styles has been thought to decrease hospital readmissions, outpatient visits, and visits with doctors (Higgins, 1988). Not surprisingly, another reason for providing recipients with information about their care is for monetary purposes. For example, a patient education program studied in a children’s hospital found that medical procedures that resulted from noncompliance were significantly reduced by health care providers who simply gave information to family members of hospitalized children (Karam, Sundre, & Smith, 1986).

This literature search indicates that recipient education programs tend to meet institutional needs as much as a recipient’s needs. Related to the issues of cost management and the recipient’s right to understand their treatment is a concern for recipient compliance. One of the problems with compliance is getting recipients to believe that it is not the nurse or the doctor who is solely responsible for the recipient’s treatment (Izzo, 1991). In the area of health care where recipients may feel intimidated by experts, recipients may easily fall prey to the belief that it is only the expert’s efforts, not the recipient’s efforts, that positively affects treatment outcome. However, strict compliance with medical treatment may not be at all healthy. Reiss (1990) found a counterintuitive relationship between recipients who comply with medical treatment and a shortened survival rate. This suggests that recipients who exercise reasoned
noncompliance live longer. He also found that family support in which members were too involved with the details and discomforts of the recipient’s treatment resulted in the same consequences that ritual compliance did to reduce the lifespan of the recipient. Reiss indicates that recipients and their family members enjoy a better quality of life along with duration in life if they do not focus on the morbid aspects of treatment.

It appears that compliance behaviors of the recipient tend toward serving both the needs of the recipients and health care institutes. Improving compliance with medical care, therefore, seems to be at the heart of many educational endeavors. Even though some recipients will choose to be noncompliant (Wilson, 1995), health care providers are expected to assess recipients' goals and priorities and thereby develop good communication with the recipient to at least understand the basis for their noncompliance.

An Emergence of Empowering Concepts in Renal Health Care

Rather than replacing a paternalistic health care model, recipient education that proposes empowerment can take the form of simply disguising the health care model it was thought to replace when power is not relinquished to the recipient. This is demonstrated by renal education that focuses on instructing recipients and family members as to what the health care provider thinks is important for them to know (Szczepanik, 1995). As Freire (1995) notes, it is the truly liberating education that is not given to others out of guilt or charity. Empowerment is liberation in the sense that recipients become the instruments of their own need to know what is important to them.
In this vein, health care providers must move away from education for recipient compliance to methods that allow recipients the opportunity they need to develop skills and competencies to participate in the treatment of their illness.

Only through the interchange between recipient and health care provider that is characteristic of dialogue can recipients develop a realistic appraisal of the condition of their health, and the ability to understand, manage, and accept treatment. The use of dialogue is the means for recipients to take continuous action and reflection on their situation (Freire, 1995). Dialogue brings the health care provider, who poses problems to the recipient in regard to his health, into the world of the recipient. Problem posing rather than information giving empowers recipients and professionals. However, empowerment at this individual level is not complete without some consideration for other recipients who are in similar situations, namely that of being hemodialysis recipients. Freire underscores the importance of individuals becoming acutely aware of their world through a recognition of others who share their world. “The pursuit of full humanity, however, cannot be carried out in isolation or individualism, but only in fellowship and solidarity; therefore it cannot unfold in the antagonistic relations between oppressors and oppressed. No one can be authentically human while he prevents others from being so” (p. 66).

A review of the literature in renal health care as it is concerned with empowerment reveals obstacles to empowerment beyond health care providers understanding of their role as recipient educators. There too are barriers to recipient empowerment that reside within the structure of the organization and the territoriality of
health care providers who serve as recipient educators. The structure of the organization may restrict professionals from feeling free to devote the time necessary to recipient education. The territoriality of health care professionals may cause delays in responding to recipients' need for education. Additionally, inadequately trained providers and an administrative structure that does not place a high importance on educational services (Webber, 1990) can confound efforts to take the time to help recipients build competencies.

Empowerment at the kidney center may be thought to influence recipients to improve whatever informational deficits they may have, so that they may be able to participate as a team member with renal health care providers. Yet there seems to be a belief that the dispensation of accurate information alone will allow recipients to be able to make decisions that may influence their course of treatment. (Hudson, Porcelli, & Brockstein, 1994). This belief is broadened by health care providers who desire limited participation of recipients in response to their teaching; testing recipients informally as a means to test the recipient's newly acquired knowledge after a learning session. Holland (1991) sums what is typically the role of the recipient educator: "We have looked at ways in which you can extend a range of learning opportunities to your patients and clients by giving accurate information, making links with their social context in a meaningful way, encouraging them to learn experientially, providing them with the opportunity and encouragement to learn from each other and to seek out things for themselves independently" (p. 62). Increased attention has been paid to health care
providers to collaborate with recipients. It is believed that recipients will participate in the health care provider’s teaching if the recipient is able to identify some of his or her own health care needs (Rothrock, 1987).

Recipient education has also been viewed from the perspective of the recipient's relationship with the physician. When the physician establishes an empathic relationship with the recipient, the recipient is less resistant to medical advice, and the alliance between physician and recipient becomes the vehicle for accepting recipient education (Berg, 1987). These efforts to involve recipients in their own treatment fall short of cogent analysis on the part of recipients and health care providers. Although these attempts to bring recipients and health care providers to a closer understanding of the ramifications of illness and treatment, they fall short of recognizing the potential for recipients to construct a meaningful perspective of their own based on the reality of their illness and need for treatment. How recipients become aware of themselves and the reality of their world must be explored within the framework of empowerment.

Developing Empowerment

Learning must be defined in the context of empowerment to understand how it leads to liberation. For learning to lead to empowerment, it must comprise the elements of a meaningful experience to the learner, critical reflection, and praxis. Mezirow (1990) demonstrates the elements of a meaningful learning experience by introducing dimensions of the individual making meaning. The first is explained as a process of
structuring meaning, which is accomplished by the learner at a habitual level of establishing rules that are exemplified by cause and effect relationships. New learning is acquired by assimilation and interpreting experience to form perspectives of meaning, and involve abstract constructs such as beliefs forming principles of interpretation of meaning to guide the learner. These meaning perspectives are largely developed during childhood and result from affective relationships with authorities. “When experience is too strange or threatening to the way we think or learn, we tend to lock it out or resort to psychological defense mechanisms to provide a more compatible interpretation” (p. 4). Elaboration and reflection on previously learned meanings are processes that are at the heart of adult learning, according to Mezirow. Reflective action is based on critically examining assumptions about previous learning, and using the product to solve a present problem. Reflection leads to correcting distortions of learning, and acting upon new interpretations.

Mezirow regards learning as discussed above is essentially empirical, but communicative learning is different insofar as the individual learner appraises the soundness of what is learned from others. “Communicative learning is less a matter of testing hypotheses than of searching, often intuitively, for themes and metaphors by which they fit the unfamiliar into a meaning perspective, so that an interpretation in context becomes possible” (p. 9). Validating meaning is an evaluation by the learner of what meanings hold true in the context of particular situations. These meanings are contested by engaging in dialogue, and the resulting interpretations of meaning are biased.
by the learner’s perspective. Dialogue is crucial to understanding not only the learner's world, but also the world of other individuals. Through dialogue, the learner becomes aware that he is not alone, and his assumptions are given weight by the consensus of others. Without reflective learning achieved through dialogue, the learner accepts what is meaningful to him without critical evaluation. This leads the learner to naively accepting habitual conceptualizations of meaning. The learner does not exercise a fundamental right to make meaning out of his experience. "Free, full participation in critical and reflective discourse may be interpreted as a basic human right" (Original emphasis. p. 11).

Critical Reflection

Mezirow (1989) observes that critical reflection requires the learner to become aware of his presuppositions and challenge them in the context of worldly encounters. Critical reflection demands transformation, and transformation requires the learner to take risks. There are risks to the learner that challenge self-concept and social stability. The transformation predictably occurs as a result of an external force that induces the learner to take action. Through the disorientation of a crisis or a situation that does not fit the learner's scheme can arise questioning of the previously held assumptions of the learner's world as a source of meaning and action.

Mezirow (1990) notes that ideology is pre-reflective, and can be accepted by the uncritical learner to legitimize his dependency on exploitative social systems. “Such
social amnesia is manifested in every facet of our lives—in the economic, political, social, health, religious, educational, occupational, and familial” (p. 16). Through critical reflection the individual arrives at a choice to act or not to act. Critics of Mezirow conclude that praxis leading to social and political action is a necessary element in emancipatory education (Clark & Wilson, 1991; Collard & Law, 1989). However, Mezirow (1991) does not see this as an essential component of critical reflection. To him, it is the learner’s achievement of rationality through consensus and empirical testing that repels authoritarian and other unjust social systems that is the aim of adult learning.

Mezirow (1991) points out, however, that even Horton and Heaney constrain themselves when encouraging learners to understand their dependency on oppressive social systems. He notes that these two leaders of social action do not become spokespersons for their learners, but help them to understand the importance of their experience and ability to take action for themselves. To challenge conformity, self-concept, stability, comfortable beliefs, and relationships with friends and family are sizable obstacles to transformatory learning. There is a great personal adjustment to be made in emancipation, and much to sacrifice for potential failure.

The potential for failure, and the emotive struggle to be critically reflective has not been well addressed in the literature until Brookfield (1994) looked at the experience of adult educators to become critically reflective. Brookfield notes that the general concepts of empowerment, critical reflection, and other descriptions of transformatory learning experiences have their dark side—the side that involves the learner’s quest to
reframe his experience, challenges his assumptions, and incorporate new ideas. Among adult educators, Brookfield found that many of them experienced strong feelings of doubt about their own transformatory learning. They experienced feelings of inauthenticity, based on their perceptions of not being worthy of their adult education duties to others. They worried about becoming excluded from their peers who were not engaged in a process of critical reflection and empowerment education. These adult educators experienced the difficulties of letting go of their previously held notions, but particularly the notion that if they worked hard enough there would be certain rewards for their efforts. They experienced stages in their learning that fluctuated with advancement and regression. Self-appraisal occurred when certain events provoked deep reflection. Brookfield notes that these periods evoked a sense of depression, alienation, and even denial. Yet these phases were important in the formation of support systems amongst each other—the adult educators who were challenging themselves with a liberating education based on empowerment and critical reflection.

Transformational Learning

Wildemeersch and Leirman (1988) points out that there are stages in developing a transformed life-world resulting in a process suggested by Mezirow. They suggest that these stages are the Self-Evident Life-World, the Threatened Life-World, and the Transformation of the Life-World. The self-evident life-world is characterized by the routine nature of daily life. It encompasses the everyday experiences of acting
spontaneously and automatically. This stage operates on an almost unconscious level. If problems are encountered that challenge the stability of this self-evident life world, they are generally neutralized and set aside. The threatened life-world, however, recognizes powerful threats to stability, and responds with action and reflection. The need for dialogue at this stage becomes important to understand the meaning of challenging ideas or events. It is at this stage that an individual may explore new perspectives, or return to previously held perspectives as experienced in the self-evident life-world. Wildemeersch and Leirman state that, “The inhibition or facilitation of this, however, depends on contextual factors, autobiographic antecedents, gender, race and class differences, or educational elements” (p. 22). Transformation of the life-world is the last stage of growth. “The third stage in the growth process is defined as regeneration, a stage characterized by a regaining of reflexive and practical confidence. This confidence is based upon a narrative dialogue, enriched by a transactional and discursive communication, a competence and motivation which has grown stronger, a reframed view of existential contradictions, and finally, a regenerated routine of aspirations and actions” (p. 28).

Zacharakis-Jutz (1988) expresses his concern that the word “empowerment” is stock and undiscerning. He is concerned that a focus on individualism is a tool used against people by the dominant culture. “Focusing on the individual leaves most people in isolation and profoundly powerless relative to the state or dominant institution” (p. 43). Zacharakis-Jutz continues his argument by saying, “Education, as a schooling process,
rewards the student who conforms and achieves with recognition and self-esteem. Those who fail are denied self-respect and are pushed out of school. Failure, all-too-often, becomes the fault of the student rather than of the system” (p. 43). There is an appeal to join forces with the dominant culture, for it rewards those who conform to its standards. There can be a great deal to lose by working to become socially transformed.

Empowerment is not a charitable process where power is given or bestowed upon powerless people. Instead it is revolutionary, always antagonistic, and many times violent, since one group is taking the power it was previously denied...Empowerment is not an individualistic process. How could one person challenge society’s dominant culture and demand more power? Empowerment, from a pragmatic perspective, could only occur within the context of a collective or community of similar interests. (p. 45)

Mezirow (1989) discusses the role of action in transformative learning as follows.

Action is an integral and indispensable component of transformative learning. Each transformation of a meaning perspective requires a disorientating dilemma; a recognition of a critical analysis of presuppositions, the way that cultural norms have impacted to shape old ways of understanding and the consequences of these taken-for-granted habits of perception; access to alternative meaning perspectives; role models; new skills as well as understandings; a realignment of relationships; a decision to act and acting upon newly acquired insights. (p. 172)

Empowerment Principles as Applied to Community

There is scant research describing how empowerment functions at various levels due to a lack of a unified framework for understanding empowerment (Paul, 1992). Despite the lack of theoretical unification, most of the ideas on empowerment are not in
conflict. The study of empowerment at an individual level seems to yield an understanding of self-efficacy and self-awareness, whereas a study of empowerment at a community level develops competencies for empowered behavior to all its inhabitants. A kidney center appears to be a community that is disenfranchised from the larger population because its members are considered to be disabled, and education is relegated to didactic information giving by the health care providers who staff the kidney center. However, it is not clear if recipients are able to engage in a personal critically reflective process without becoming aware and involving the kidney center community in this process.

On an individual level, empowerment engenders a sense of personal authority to make decisions for oneself, and be responsible for the consequences of one's choices. Empowerment education directs individuals to discover their own personal reality about life. Empowerment education encourages individuals to recognize both the personal and social constraints placed on them by their environment. Empowerment as a concept is not complete unless it instructs individuals to acknowledge the validity of the personal and social reality of others. Collectively, these realities increase a group's capability to face their environment with feelings of power. This power is the catalyst that moves people to develop new skills to identify and confront their problems, trust their perceptions and knowledge, and increase their sense of worth through their own accomplishments. For individuals who may feel shame because of their sense of powerlessness, empowerment allows them to succeed (Falberg, 1991).
Community empowerment goes beyond a concept of personal empowerment in the sense that its goals establish a basis for social justice. The means toward a state of social justice is to extend community resources to reduce poverty, revitalize communities, and deepen an awareness of community needs. The ultimate aim of empowerment is to improve the quality of life in a community. Community empowerment mobilizes groups of people to participate with those who do not own a proportionate share of the community's resources. The community is powered by the desire to create equity among people, and the expectancy that they will be able to develop their own leadership. Leadership enables people to define their own problems, and choose among methods to resolve them. This type of change cannot be achieved through perpetuating models of community education that are fundamentally paternalistic. Rather, empowerment education must instill a sense of responsibility within groups participating in changing the reality of their social conditions. If not, resentment and powerlessness will result in those who instead need to be bolstered to make the changes for themselves (Eisen, 1994).

"Community education is the over-arching conceptual base, while programs are the activities related to the solution of specific community needs. Thus, enrichment opportunities, recreation programs, cultural activities, avocation offerings, and political and civic programs are partial ways of resolving certain community problems" (Minzey 1994). Community problems that are resolved by embracing the elements of empowerment may be well illustrated in the following example.
Ovrebo, Ryan, Jackson, and Hutchinson (1994) reported using empowerment techniques with homeless, pregnant women in an urban setting in the United States. These women appeared at shelters at night with their children. They slept together on the floor, ill and without the benefit of receiving prenatal care. These homeless women were overwhelmed with the problems of poverty: abuse, hunger, and substance dependence. Rather than maternalizing these women, the researchers provided these homeless women with the opportunity to participate in a dream that their baby might be healthy.

"Pregnancy offers a unique opportunity for empowerment and change. A pregnant woman has power over the life of her unborn child, and she alone is capable of bringing a healthy child into the world" (p. 195). The researchers found that their use of empowerment techniques was effective because they as researchers believed in the inherent potential to do good deeds that exist within all people. Also, they found that participants of their community program returned to "give back" to the program by helping new mothers at the shelter.

Giving back to the program that helped a participant promotes the perpetuation of empowerment at a community level. The key elements of empowerment education are derived from many educators, but one educator seems to embody the empowerment philosophy. He is the Brazilian educator, Paulo Freire. A discussion of his and other's ideas illuminate how participants develop a sense of self-worth sufficient to allow them to experience social consciousness, or "giving back" behavior.
Oppression's Effect on Learning

Paulo Freire (1995) maintains that oppressed people are unable to become fully human in the shadow of those who do not trust them to make decisions in their behalf or are afraid of losing their position of dominance over them. If the oppressors are able to enter the thoughts, concerns, and fears of the oppressed through dialogue, then they are able to assist the oppressed in a struggle towards recognizing their ability to alter their condition. "People will be truly critical if they live the plenitude of the praxis, that is, if their action encompasses a critical reflection which increasingly organizes their thinking and thus leads them to move from a purely naive knowledge of reality to a higher level, one which enables them to perceive the causes of reality" (p. 112). Freire objects to education that indoctrinates the learner to a view of the world as seen by the instructor. He refers to this type of education as "banking education," because its intent is to fill learners with information as one would fill an empty receptacle. The instructor makes a deposit of knowledge, and the learner, not possessing any knowledge worthy of the instructor's consideration, awaits to be filled. This type of education leads to the myth that the oppressor's reality is the true reality, and that the oppressed are unable to construct a meaningful world without being "filled" with information. Over time, unempowering education seems to follow this course as the natural order of the universe. For this reason, Freire believes that the oppressed must identify a meaningful world of their own through the symbols and themes that they generate. Through their experience of critically reflecting and taking action on their learning, the oppressed gain the ability to
understand the realities in which they live, develop the confidence to reject the myth of their impotence, develop leadership, and unite in the cause of liberation from the oppressors.

The oppressors are anyone who removes the rights of others to engage in the praxis that is a fundamental right of being human. As in the program that helped pregnant homeless women, the target population for empowerment seems to have a culture, whether it is poverty, homelessness, or drug dependence. The culture, as Freire sees it, must not be invaded upon by the oppressors with their slogans to correct the situation for the oppressed; rather, the oppressed must find the words to describe their world and take action to remedy its problems.

**Participation in Learning**

There too are other segments of the population that may benefit from empowering community education. Echoing Freire's philosophy of engaging adults in a student-centered learning experience, Johnston (1992) stated her belief that adult learners should begin their educational experience by being asked what they have to offer, "In terms of skills, experience, knowledge and ideas" (p. 74). Johnston feels that starting an educational process must begin with allowing adults to have an equal footing with the teacher. To understand community education for adults, one must appreciate the complexity of an adult's social world. Adults live in a world of personal and social responsibility with many restrictions placed on them. The reasons for which adults do
not participate in adult education as Dao put it (cited in Merriam & Caffarella, 1991, p. 87), are a lack of time, personal problems, cost of the program, difficulty succeeding in learning, concerns that it is against social norms to participate, negative feelings towards educational institutions, previous failure in education, belief that their efforts will not be valued, indifference, and unawareness that educational opportunities are available to them. Those adults who do participate in adult education are, “Persons whose major social roles are characteristic of adult status undertake systematic and sustained learning activities for the purpose of causing changes in knowledge, attitudes, values, or skills” (Darkenwald & Merriam, 1982, p. 9).

It too is possible that many adults do not participate in adult education because it does not allow them to be full partners in their educational endeavors, allowing them to plan what they need to know to incorporate a better understanding of their social reality. Fundamental to assisting disenfranchised adults to participate in adult education is establishing programs that lead to empowerment. On a community level, adults are encouraged to participate in identifying community needs, help themselves by assuming responsibility, develop local leadership, make public institutions responsive to changes in the community, establish collaboration between social agencies, and be accessible to everyone in the community (Decker & Boo, 1995). The process of establishing community education may in itself be empowering for the disengaged adult.

An important component of forming community empowerment is to emphasize the process orientation of community education (Warden, 1979). The process of
community empowerment includes organizing tactics, developing networks of allies, and use of conflict as a means of creating a means of involvement and action in society. The reforming of American education is to bring conflict into the open between various agencies of learning. "Cooperation among socializing agencies will not bring dead-level uniformity to educational policies and programs but will rather bring conflicts between the goals and assumptions of various agencies of education into the open. Today, they are hidden from public view by specialization, bureaucratic organization, and propaganda from the ruling elites" (Stanley III & Benne, 1995, p. 68). By its nature, empowerment initiates conflict among people and the institutions that comprise their social environment. Empowerment education enables groups of individuals to become experts on themselves and their community.

The notion of bringing conflict into adult education is seminal to the work of Myles Horton. Horton, who founded the Highlander Folk School, established a community learning experience for adults that was rooted in the curriculum of trusting individuals to become expert at identifying and proposing solutions to their issues of social inequity and conflict. With the belief that social action could be the means to address problems of social inequity, Horton engaged his students in a dialogue that helped them define their social reality. His basic belief in adult education was that the oppressed are able to free themselves not through an in-depth study of their individual problems, but as a socially active group--a community of informed people (Horton, 1990). Highlander Folk School, the rural settlement house, was and is a place where
adults engage in the practice of understanding their political situation and learning to take social action. The curriculum is designed by participants to reflect the interests they would like to pursue based upon their need to learn about what is meaningful in life. Highlander’s residential program allows students to fully participate in their learning, with the teachers also learning with the pupils (Adams, 1975).

Social Change

There are pressures to conform to a socially approved system without examining whether one is unhappy with the direction people have made for others. However, when people begin to think about the system, judging if their experience in it is either good or bad, that is when real learning begins. It is this belief of Horton’s, along with the conviction that people should participate in the democratic process of sharing and reflecting on their experience with others (Conti & Fellenz, 1986) that forms the basis of community empowerment.

Horton and Freire shared the view that an obstacle in developing a good quality of life for people was their lack of conscious awareness of the restrictions their environment placed on them. Freire felt that by discouraging people from critically examining their environment coupled with a belief that one is unable to transform society, is the myth that society uses to oppress people. The silence of oppression from dehumanizing socialization can be broken by dialoguing about the social reality, codifying problems
into meaningful themes, and encouraging action and reflection are a means for people to
come become humanized (Conti, 1977).

Perhaps the largest group of individuals who could benefit from empowerment are
from the lower socioeconomic classes. Since ESRD recipients are considered to be
disabled by the federal government, most recipients have substantial financial trouble.
Langton (1987) believes that there is no true democracy unless citizens from lower
socioeconomic classes are able to fully participate in their community. He feels that the
means of creating participation is by empowering the poor, minorities, and disabled.
Langton asserts that organizations within the community should become organized to
establish a balance in participation. Just as Freire was concerned about literacy to
economically and politically disenfranchised adults in Brazil, so too are there adults in
America who are removed from affecting their community because of a lack of
knowledge and skills to muster in fully participating in society. Addressing this issue in
the context of literacy in America, Fingeret (1983) explored the social networking of
illiterate adults to see how they were connected to their community. She found an often
reciprocal relationship between illiterate adults and "readers" who are the individuals
from their network entrusted to read for them.

Most of the people Fingeret studied appeared to be fully contributing members of
their network, exchanging useful services to their readers. However, she noted that these
people lived in an area of their community that was associated with little mobility,
poverty, high unemployment and crime. In the case of one of her interviewee’s, Fingeret
said that, “For Margaret and others like her, it is not their illiteracy that places them on the dependent end of the continuum, but rather their inability to engage the social world. Dependent illiterate adults often do not believe they are capable of intentional action, and they do not recognize their withdrawal as an action in its own right. Their extreme pessimism and fatalism appears to be informed by their experience of the social world; their inability or unwillingness to develop a more positive framework is more deeply rooted than their inability to read and write” (p. 141). The goal of empowerment in community education is to engage individuals such as Margaret in meaningful dialogue about her reality so that she can experience her own sense of power over her life. If indeed America is a society of learning, then all Americans are affected by empowerment in community education. Concepts of empowerment can have an impact on all segments of the population.

The need for all adults to feel empowered in their environment can be addressed by community education that seeks to remedy problems through the full participation of all its members. Empowerment in community education seems to abide by Knowles’ outline for achieving an educational environment for adult learners based on democratic ideals. Knowles believes that organizations attempting to teach the adult learner should respect the personality of the adult. Organizations need to allow adults to set their own goals and participate in making decisions about their learning. Organizations should also permit adults to express themselves freely, make information available to them, and
respect adult’s ability to conduct and evaluate their learning activities (cited in Merriam & Caffarella, 1991, p. 31).

The strength of empowerment in community education is that it focuses on an awareness of self and others. Empowerment at the community level does not seek to find blame within individuals or communities; rather, it recognizes their power to solve problems while it increases their sense of dignity and self-worth. The sociocultural environment is an emerging area for understanding how empowerment aids people to become conscious of their social reality. With the current emphasis in cognitive acquisition and evaluation of competency, learning cannot be adequately assessed as it impacts the individual’s role within a community. The focus today is not so much on how much information a person is able to attain, but how the learning contributes to a social awareness within an individual. Understanding learning from a meaningful dialogue with the learner is the appropriate context to develop a knowledge of empowerment as it relates the individual to his community (Fellenz & Conti, 1989).

“Empowerment outcomes include a strong sense of community identity, an open decision-making structure, many people with recognized leadership skills, increased sensitivity toward gender and social equality, heightened self-confidence in dealing with local issues, and better two-way awareness of (and interaction with) resource agencies” (Purdey, Adhikari, Robinson & Cox, 1994). Community is forged from the struggle of the oppressed to liberate themselves from the darkness and myth that was their world to one where they have a newly developed social awareness of the community in which they
belong (Freire, 1995). "Unity and organization can enable them to change their weakness into a transforming force with which they can re-create the world and make it more human" (p. 126). Dialogue is the essential ingredient to communication, which is fundamental to cooperation in a community. As the oppressed recognize their adhesion with one another through the process of communication, they become powerful. This sense of empowerment enables them to transform their world from a community of oppressed individuals into one that allows them to take their place with the entire community as fully participating human beings.
CHAPTER III

PROCEDURES

General Design of the Study

The purpose for conducting this study was to relate the literature on the theoretical basis for empowerment with a focus on community awareness with the experience of hemodialysis recipients at a kidney center. It was therefore necessary to gather information from recipients in such a way as to elicit their own unique perspectives on their experience. The method for conducting this research project was the qualitative approach.

I realize that the value of the naturalistic, or qualitative research study, depends on my ability as an investigator to enter the setting in which the behaviors, attitudes, and beliefs of participants are developed and enacted where they occur naturally. Patton (1990) sums the essential elements necessary for conducting a qualitative study in three parts:
(1) rigorous techniques and methods for gathering and analyzing qualitative data, including attention to validity, reliability, and triangulation; (2) the credibility, competence, and perceived trustworthiness of the qualitative researcher; and (3) the philosophical beliefs of evaluation users about such paradigm-based preferences as objectivity versus subjectivity, truth versus perspective, generalizations versus extrapolations, and theory versus action (p. 491).

In qualitative research, “The naturalistic investigator is a phenomenologist while the conventional inquirer is a logical positivist. The phenomenologist is concerned with describing and understanding social phenomena; the positivist with ‘scientific’ facts and their relationship to one another” (Guba, 1978, p. 12). Guba goes on to say that, conventional inquiry may actually be self defeating by artificially linking certain variables, making it inevitable that these variables will be linked in any findings. Similarly, the design may preclude the discovery of links which ought to be discovered. Tying or untying of variables cannot occur within naturalistic inquiry. When there is a risk of such tying or untying with important variables, naturalistic inquiry should be preferred. (p. 28)

In this way, I as a qualitative researcher was able to relate what I presently observed with how things became the way they were, how persons felt about the way things were, and what unique meaning they ascribed to their environment. Qualitative research is an attempt to see things as they are, rather than an effort to control factors that may contribute to the way things appear. This holistic approach to research allowed me to observe the phenomena inductively. Inductivity is the condition of not placing preexisting patterns on the phenomena under observation (Gay, 1996). The researcher is
able to recognize the patterns that emerge from the data that is collected and analyzed, without narrowly defining or delimiting the results (Patton, 1990). The phenomenon under study represents my interpretation of the multiple reality—the subjective experience, of each of the participants (Guba, 1978).

The method of qualitative study employed in this research study is called the case study method (Gay, 1996). One unit, hemodialysis recipients who met a pre-defined criterion for selection, were used in this study. An interview guide was used on this selected population for its ability to assist me in obtaining meaningful responses from selected recipients of hemodialysis treatment (Appendix A). The interview guide was used as the basis for acquiring information from treatment recipients. Hemodialysis recipient’s responses to the interview questions were compared to the research questions to address the purpose of the study. I conducted an additional set of interviews with 6 recipients so as to address the threats to empowerment that I identified in the purpose of this study.

Data Gathering

Interviews

Gay (1996) expresses the purpose of interviews as follows.

A typical qualitative interview is a one-on-one session in which the researcher asks a series of open-ended, probing questions. In addition to serving triangulation objectives, interviews have a unique purpose, namely, to acquire data
not obtainable in any other way. There are certain things which simply cannot be observed, including (but not limited to) past events, events which occur outside of the researcher’s sphere of observation, and mental processes (p. 223).

Using a semi-structured approach to gathering data provided me with a means of systematically acquiring data from the recipients of dialysis treatment. The recipients responded to my interview guide in a manner that was focused on empowerment at a community level. I guided the recipient to respond to questions with the intent of addressing the research questions of this study. Structured, yet open-ended interviews allowed me to obtain responses from the recipients that could be compared and evaluated with respect to the individual variations in responses. Although recipients addressed the question in their unique voice, the variation in responses was reduced by asking the same questions. Probing was a useful technique for encouraging recipients to elaborate on the expression of their experience at the kidney center. As Patton (1990) observed, “The interview guide provides topics or subject areas within which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject” (p. 283).

Population

The awareness of the hemodialysis community as it relates to empowerment is a mental process that is best understood from the unique perspectives of the recipients.
Therefore, interviews were conducted with 20 hemodialysis recipients using a criterion based sampling technique. The criterion based sampling technique is a method of purposeful sampling and is useful for selecting those recipients who meet the predetermined criterion (Patton, 1990) as they were the most likely recipients to provide the rich information necessary to understand empowerment and community awareness in the kidney center. I used a purposive sample in this qualitative study utilizing a small, but not necessarily representative sample based on the likelihood that these individuals would be able to provide the information sought in the study (Gay, 1996). The kidney center chosen for this study has a population of hemodialysis recipients totaling 76. Those persons who had been receiving hemodialysis for one year or longer totaled 48.

The 20 recipients I interviewed had a mean age of 64, and were mostly female (55%). The mean number of years receiving dialysis treatment was 3. The mean highest grade completed in school was 12.1 years. A little more than half of the recipients were retired, and 42% were married, 15% were never married, 15% were divorced, and 32% were widowed. Almost all were Caucasian (90%), with another 5% Native American, and 5% Hispanic American.

Treatment recipients were informed as to the intent of the research, and asked if they would consent to serve as a participant. The agreement to participate in the study was confirmed with the signing of the consent form (Appendix B). Recipients were interviewed as they were receiving hemodialysis treatment.
One kidney center was studied because it met the criteria set forth in the literature review: it was a place to find a community of potentially disenfranchised individuals (because of their disabling illness), persons who may feel oppressed by a dominant culture (the medical, paternalistic culture), and there was an assumed need to learn about their illness for the purpose of adhering to treatment guidelines and achieving a good quality of life with hemodialysis treatment. The kidney center was also a place where people who have ESRD come together 3 times a week, for at least 3 hours at a time. I considered it likely that these individuals had formed some sort of awareness of each other, and perhaps were even able to articulate an understanding of their sense of empowerment. It was the intent of this study to investigate recipient's awareness of their hemodialysis community as a process of empowerment from each of their own unique perspectives. Only those individuals who were physically and emotionally capable of responding to my questions were used in this study. For example, persons who were unconscious, profoundly demented, or suffering from other co-morbid conditions that rendered them incapable of responding to my questions were not used in this study. I approached recipients beginning at station number one, then move to the next numbered station until the selection criteria was met.
Data Compilation

I recorded the participant’s verbal responses to the interview questions by writing them down on each interview guide. As Gay (1996) observed, the primary tools of the qualitative researcher, “Are still the good old-fashioned pen or pencil and a note pad” (p. 218). I did use a hand-held tape recorder for the participant who became a Key Informant in the study. More than one interview was conducted with one recipient during the study so that the recipient’s responses to my interview questions were further probed for meaningful responses and cross-checked with regard to consistency over time. Although I found that the recipient’s responses were consistent with the previous responses given, I discovered that there was little benefit in as the recipient put it, “rehashing” the interview. I therefore selected 6 recipients who provided what I considered to be the most meaningful responses compared to the other recipients that I first interviewed. Developing another interview guide (Appendix C) to explore more specific issues related to the threats to empowerment, I again interviewed these 6 recipients.

The Interview Guide

As Bogdan and Biklen (1992) note:

In qualitative research, interviews may be used in two ways. They may be the dominant strategy for data collection, or they may be employed in conjunction with participant observation, document analysis, or other techniques. In all of these situations the interview is used to gather descriptive data in the subjects’ own words so that
the researcher can develop insights on how subjects interpret some piece of the world (p. 96).

In qualitative studies, interviews are usually conducted by using a semistructured approach. The interview guide includes some structured questions, but includes open-ended questions (Gay, 1996). The interview questions were intended to guide me in the direction of addressing the research questions:

1. How does the theoretical basis for empowerment relate to community awareness with recipients of hemodialysis treatments?

2. What factors contribute to hemodialysis recipient’s experience of empowerment or lack of empowerment?

3. How does the process of empowerment of hemodialysis treatment recipients lead to changes in the behavior of treatment recipients within the kidney center community?

The questions on the interview guide were used as a means of exploring the objectives of this study, the threats to empowerment, and finally to address the research questions.

**Observations**

I made special note of quoting important participants’ responses, and made descriptive observations in my fieldnotes to capture the nuances of participants’ different experience and perspectives as recipients of hemodialysis treatment. The fieldnotes served as a repository of thoughts and feelings that I had and were used in the process of interpreting participants’ interview responses. These recipients’ responses were reviewed
with the participants immediately following the interview as a means of verifying the researcher's accuracy in recording participants' responses. The participants' responses were synthesized, compared to the research questions, and judged on their merit of addressing the purpose of the study. Confidentiality of the participants' responses was ensured by my use of coding the identity of each participant on the interview guide. The interview guides are kept locked in a filing cabinet in my home.

**Fieldnotes**

Qualitative researchers depend on fieldnotes taken at the time of the observations, or soon after leaving the setting for their propensity to describe the context in which the participant expressed him or herself to the interviewer. Fieldnotes are both the descriptions of what the researcher observes and his reactions to what is observed. Reflective fieldnotes contain the researcher's thoughts and feelings as well as his interpretations of the situation being observed. The reflective fieldnotes are typically coded to differentiate them from the literal, descriptive data kept by the researcher (Gay, 1996).

After returning from each observation, interview, or other research session, the researcher typically writes out, preferably on a word processor or computer, what happened. He or she renders a description of people, objects, places, events, activities, and conversations. In addition, as part of such notes, the researcher will record ideas, strategies, reflections, and hunches, as well as note patterns that emerge. These are fieldnotes [original
emphasis: the written account of what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study (Bogdan and Biklen, 1992, p. 107).

Bogdan and Biklen recommend that a description of the participant be recorded so that it may serve as a “portrait of the subject.” This description may be important in discerning the particular individuals being studied apart from any other individuals. They also suggest that the dialogue be reconstructed between the interviewer and the participant so that a close approximation of what was said is captured, a description of the physical setting to provide a mental image, and the observer’s behavior. The purpose of gathering data on the latter is so that the researcher’s influence on the participant is understood and minimized throughout the study. Bogdan and Biklen place an emphasis on the researcher’s reflections of the analysis of the fieldnotes, method, ethical dilemmas and conflicts, frame of mind, and need to make points of clarification. The purpose of the researcher’s need to reflect is based on the fact that the interviewer is the instrument of data collection, analysis, and interpretation so that the researcher can provide an accurate account of the participant’s perspective.

I kept fieldnotes for the reasons cited above. My fieldnotes described what I was thinking and feeling during and after the interviews, and were useful in interpreting the data that I collected from recipients.
Guba (1978) treats reliability and replicability as the same issue, stating that the importance of capturing the multiple realities of the participants, understanding their meaning of their environment as a function of time and circumstance, and faithfully recording and interpreting the data are important concerns of the researcher. He suggests three empirical techniques to the researcher in which to strive: the audit, overlap methods, and stepwise replication. The audit is a technique employed to increase the reproducibility of a study. The researcher incorporates the use of an auditor to evaluate the methodology of the study, and judges the appropriateness of how the researcher worked the data and arranged the categories. The overlap methods are a variation of triangulation whereby the study’s reliability is increased as a result of including different methods simultaneously in the study. The stepwise replication method is employed when teams are working on a research inquiry. The teams are divided into two and function as independent researchers. They cross-check their data at crucial stages of the research so that they can judge whether the research teams are essentially replicating the study. This is a similar technique to auditing, although the auditors are not neutral “outsiders.” Patton (1992) states that a check for the consistency of using the same method, but on different sources of data, is called triangulation of sources. He states that a mixed methods approach may strengthen the reliability of a study. Combining interview data
with observations, and comparing what people say over time is a check on consistency and therefore reliability.

Validity

Bogdan and Biklen (1992) state that, "In qualitative studies, researchers are concerned with the accuracy and comprehensiveness of their data. Qualitative researchers tend to view reliability as a fit between what they record as data and what actually occurs in the setting under study rather than the literal consistency across different observations" (p. 48). The conditions for reliability to be met by the researcher leads to validity as expressed by Gay (1996), "Validity is the degree to which observations accurately reflect what was observed (and interviews accurately reflect the feelings, opinions, and so forth, of those interviewed) and, consequently, permit appropriate interpretation of narrative data" (p. 217). Guba (1978) observes that validity is met by using the technique of triangulation. Triangulation is a means of testing one source of information against another until the interpretation is considered by the researcher to be valid. Gay (1996) notes that, "If several different people have similar stories, we have more confidence in the insights we are gaining than if only one person is interviewed. Even if their perceptions of reality are not accurate, we at least have evidence that the perception is a shared one" (p. 217). Gay states further that validity and reliability are enhanced when interviewing the same person more than once. He notes
that qualitative researchers can check for consistency over time, between data collected on those interviewed, and use the researcher’s impressions as a check for consistency. With a concern also for internal validity, Guba (1978) cites invalidating threats: 1) distortions resulting from the researcher’s presence at the research site, 2) distortions resulting from the field worker’s involvement with his subjects, 3) distortions resulting in bias on the part of the field worker or his subjects, and 4) distortions resulting from the manner in which data-gathering techniques are employed. These threats to internal validity can be ameliorated by the researcher who can react to the collected data by challenging his pre-conceived notions, maintaining his involvement with the participants while keeping objective, and recording data consistently and with scrutiny.

Generalizability refers to the external validity of the study, and according to Guba (1978), external validity to a great extent depends on the internal validity of the study’s design. Guba sums generalizability as such:

Whether or not certain information is generalizable is a function of the degree to which the situation being investigated is a representative “slice of life,” as well as a function of the isomorphism between the situation in which it was generated and the situation to which it is to be generalized. But, at least the N/I [Natural Inquiry] investigator is free of one problem that continuously plagues the experimentalist: the lack of isomorphism between laboratory and real world (p. 68).
Methods used to Achieve Reliability and Validity in this Study

To strengthen the conditions for reliability and validity in this study, I used the mixed methods approach of triangulation suggested by Patton (1992). Data was collected by using more than one method: through the use of the interview guide, observations as recorded on the interview guide and in the fieldnotes, and more than one interview on selected hemodialysis recipients. Participants’ responses to my questions and observations were checked against themselves following a second interview on one of the selected participants to ensure consistency over time. Also, the conditions of reliability and validity were met by asking each participant to verify the veracity of my recordings of their responses to interview questions immediately following the interview. That satisfied the requisite check that Gay (1996) referred to for accurately reflecting the thoughts and feelings of the participants by the interviewer.

Another use of triangulation employed in this study was the discovery of a Key Informant. Describing the use of key informants, Patton (1990) notes that, “Key informants are people who are particularly knowledgeable and articulate—people whose insights can prove particularly useful in helping an observer understand what is happening” (p. 263). I recognized the value of using the information that my Key Informant provided immediately on interviewing her. I was able to use her 19 years of experience as a hemodialysis recipient at the kidney center I conducted my study as a standard to compare the other interviews I conducted.
My qualifications as a researcher are relevant to the design of this study. As Gay (1996) notes, "It is obvious then that to a much greater degree than in a quantitative study, the validity and reliability of measurement in a qualitative study are highly correlated with the competence, experience and dedication of the person conducting the study" (p. 217). Gay further notes that an attribute of qualitative research is the close relationships developed between the researcher and the research participant for the purpose of attaining the most in-depth understanding of the phenomena under study. As a Licensed Clinical Social Worker with more than seven years of experience working with the hemodialysis recipients selected for this study, I am involved in aspects of their care that include psychosocial evaluation and treatment. Among performing other duties, I am the first person at the kidney center to meet the potential hemodialysis recipient and his or her family members. At this meeting, the options for treatment for ESRD are discussed and demonstrated. Potential treatment recipients and their accompanying family members tour the kidney center and meet with a person who is undergoing hemodialysis. The potential recipient receives the book that I wrote that treats in greater depth concerns about choosing a treatment option. The potential recipient also has the opportunity to express his or her reactions to what he is experiencing. I explore the potential recipient's understanding of his or her illness, psychological defense mechanisms employed, ability to adjust to changes inherent in choosing a treatment
approach, family support, and other factors uniquely affecting the recipient. The results of this meeting are written and submitted as a permanent record in the potential recipient's chart to be read by authorized kidney center staff. I discuss my findings with the Clinical Team (composed of four nephrologists, two renal social workers, a renal dietitian, administrative staff, nephrology nurse, home care nurse, chaplain, and financial counselor) at the weekly meeting held to discuss issues of recipient care. This report to the Clinical Team sensitizes kidney center staff to the characteristics and needs of the potential recipient.

This first meeting with the potential recipient and family is followed by an all-day meeting held three times a year with representatives of the Clinical Team. I facilitate the meeting for the purpose of allowing persons and their family members who have not yet started treatment with an opportunity to get to know one another and learn more about treatment in a group setting. Once a person begins hemodialysis treatment, I provide individual, marital, family, and group psychotherapy to enable treatment recipients to adjust to the rigors of hemodialysis treatment. If hemodialysis recipients are not in need of these services, I nonetheless speak with each recipient at least once every three months to assess for any difficulties they may be experiencing.

I have a desire to learn from the recipients so that I am able to understand their unique perspective on being a dialysis recipient. It is my belief that I will be a more effective clinician as a result of engaging in the study of empowerment at the community level of a kidney center. I am uniquely qualified to interview persons who are being
treated for ESRD because of my level of involvement with each hemodialysis recipient throughout the course of their treatment, the number of years working with persons with ESRD, education and experience working in health and mental health settings, and expertise in a sub-specialty in my profession. A working relationship based on trust had already been established with the persons who I interviewed in this study.

Data Analysis and Interpretation

Gay (1996) notes that, “The qualitative researcher looks for categories, patterns, and themes which will facilitate a coherent synthesis of the data. This synthesis, including relevant illustrative examples and quotations, eventually represents the researcher’s overall understanding of what the data mean” (p. 227). Gay notes that it is the qualitative researcher’s task to report on the process of how data was collected and categorized. “Aspects to be coded typically include variables such as persons, processes, and events observed, recollections, thoughts, and opinions reported, and the researcher’s reactions to same (recall PC = personal comment)” (p. 228). Concerning interpretation, Gay notes that, “The conclusions in a qualitative study are the insights the researcher believes she or he has gleaned as the result of a lengthy, intensive effort” (p. 229). Bogdan and Biklen (1992) suggest that the data first be numbered, and then divided into preliminary codes and categories numbering less than fifty. This process facilitates location of the data, and leads towards a process of reducing the amount of data to be
analyzed. The codes can be used to separate varieties of data, namely major areas and smaller areas. Bogdan and Biklen suggest going through all the data units, such as paragraphs, and marking each unit with a code. The data can then be "cut and pasted" into the appropriate categories for analysis.

The culminating activities of qualitative inquiry are analysis, interpretation, and presentation of findings. The challenge is to make sense of massive amounts of data, reduce the volume of information, identify significant patterns, and construct a framework for communicating the essence of what the data reveal (Patton, 1990, pp. 371-372).

Since the product of qualitative research is not pre-defined into categories, the results of the inquiry are interpreted following the acquisition of the data. Guba (1978) recognizes two sub-classes in which to classify and interpret the products of observation: convergence and divergence. Convergence represents the bases of inference for an underlying behavior, the prioritizing, categorizing, and unitization of information, and the criteria for determining when this process has continued amply. It is the assimilation of data into discrete entities. Divergence represents the strategies used for completely and thoroughly "fleshing out" the important data into exhaustive sets. Guba suggests that material that reoccurs with regularity, has high internal homogeneity within categories, and high heterogeneity between categories, meet the conditions for exhaustion.

The process of analyzing, interpreting, and reporting on a case study may be broken into three steps, as Patton (1990) prescribes. In step one, the raw data is collected about the persons. In step two, the data is condensed, organized, classified, and edited
into manageable data sets. Step three is the descriptive narrative that portrays a holistic view of the persons or the program under study. Patton relates that in the reporting of the findings of a qualitative study, the researcher must have a clear focus, and have a balance between description and interpretation. The report must be thick and rich in descriptions so that the reader has the supportive basis to understand how the researcher leads to interpretation of the findings.

I found Patton’s methods to be useful in analyzing the data I had collected from the 20 recipients I interviewed. I first wrote down the recipient’s responses to my questions on the interview guide, discussed the recipient’s responses with the recipient, typed each recipient’s responses, then wrote fieldnotes after each interview. I followed this procedure with all of the recipients, but included the use of a tape recorder to capture information from my Key Informant. The Key Informant’s data was later transcribed and was used as a means of checking the integrity of the other interviews I had conducted.

The second step to analyzing the data was to classify and edit the data collected from the interviews. I studied the data, created categories based on the Objectives, Threats to Empowerment, and Research Questions of this study; and cut and pasted recipient’s responses to several poster boards representing classes of data. The sub-categories that were created and retained appear in the Findings section of this study, and were useful in identifying certain aspects of the recipient’s responses. My third step involved examining the bits of data that were cut and added to other bits of data under my categories, then compare the information in these categories with copies of the complete
interview guides kept on each recipient. This step assured me that the cut and paste process preserved the flavor of each recipient’s responses, while discerning similarities in the data to allow groupings into categories. Once the data was divided and edited to be more manageable, I typed the data collected in the categories that I created and compared it to the interview transcripts of my Key Informant.

**Issues Related to the use of Qualitative Methods**

Qualitative research has been compared to quantitative research on its relative merits and shortcomings (Bogdan and Biklen, 1992; Gay, 1996; Guba, 1978; Patton, 1990). Patton (1990) notes that, “Statistical data provide a succinct and parsimonious summary of major patterns, while select case studies provide depth, detail, and individual meaning” (p. 17). Gay (1996) succinctly puts it:

> Results are difficult to analyze, conclusions are highly tentative, and generalizations are minimal or nonexistent. At a practical level, qualitative research tends to be more costly [than quantitative methods]. Thus, the good news is that qualitative research typically yields an abundance of potentially useful data and insights not obtainable using other methods, and the hypotheses generated by such research are in many cases more valid than those based on theory alone. The bad news is that collecting and analyzing such data and drawing defensible conclusions is not an easy task (p. 230).

Notwithstanding these drawbacks of qualitative research, it is important to approach hemodialysis recipients in their natural environment of the kidney center to understand
the process of empowerment as expressed by an awareness of their community. In this way, hemodialysis recipients are allowed the expression of their own unique experience and perspectives on an experience that is uniquely theirs and should be expressed as they see it.

My investigation into empowerment at a community level at the kidney center may have stimulated thought on the empowerment process. By directing questions aimed at illuminating certain aspects of their experience as dialysis recipients, recipients may have been subtly encouraged to consider their ability to be empowered on a community level. Even though I sought to control my influence on gathering information for this study, it is nonetheless likely that asking questions of recipients could have encouraged them to think about their awareness of one another in a manner different from what they might have thought for themselves.

With consideration to my possible influence on this study, it is conceivable that I was unable to detect subtle processes that kept empowerment at a certain level at the kidney center. If there is a subtle oppressive force that prevents recipients from engaging in critical reflection, then I was unable to determine what it is with the tools used in this study.
I completed a pilot study that was conducted before the dissertation research. The study was conducted so that the interview guide could be field tested for its ability to assist me in obtaining meaningful responses from selected recipients of hemodialysis treatment. Responses to the interview were compared to the research questions to verify whether the interview questions addressed the purpose of the study. The results of the pilot study was useful in modifying the interviewing tool.

I conducted interviews with 4 hemodialysis recipients using a criterion based sampling technique (Patton, 1990). Those individuals who were physically and emotionally capable of responding to my questions were used in the pilot study. For example, persons who were unconscious, profoundly demented, or suffering from other co-morbid conditions that rendered them incapable of responding to the my questions were not be used in this study. Also, these treatment recipients were selected on the basis of having received at least one year of hemodialysis treatment, signed my consent form for participation in the interview, and were available for at least one and a half hour interview session. When I conducted this pilot study I had not known that recipients could choose the station where they wanted to receive their dialysis treatment. However, recipients used in this study were given a station on the basis that they did not specify where they wanted to be in the kidney center's treatment area. I approached the
recipients beginning at station number one, then moved to the next numbered station until the selection criteria were met.

I recorded the participant’s verbal responses to the interview questions by writing them down on each interview guide. I made special notes of quoting important participant’s responses, and made descriptive observations in my field notes to capture the nuances of participant’s different experience and perspectives as recipients of hemodialysis treatment. The field notes served as a repository of my thoughts and feelings and were used in the process of interpreting participants’ interview responses. These responses were reviewed with the participants immediately following the interview as a means of verifying my accuracy in recording participants’ responses. The participant’s responses were synthesized, compared to the research questions, and judged on their merit of addressing the purpose of the study. Confidentiality of the participant’s responses was ensured by my use of coding the identity of each participant on the interview guide. The interview guides have been kept locked in a filing cabinet at my home.

As a result of conducting the pilot study, I found that recipients responded to the interview questions by articulating their own unique experience with dialysis treatment. Their unique experience formed themes that embodied their attitudes and beliefs about themselves and others in relation to receiving dialysis treatment at the kidney center. I learned that it was unnecessary to ask questions that promoted a discussion of issues that were not at the focus of my study. For example, a question such as, “What do you do in
your leisure time?" seemed to divert recipients' responses from the issues of empowerment, and ultimately fatigued them. I was therefore able to modify my questions so that they kept the recipient’s attention on topics related to empowerment.

I found that some of the questions I asked received responses that were better at allowing recipients to expand on their ideas. Questions like these furthermore addressed the research questions of the dissertation study. Finally, the experience of conducting this pilot gave me the confidence and experience with conducting qualitative research to progress with my dissertation study (see Appendices).
CHAPTER IV

FINDINGS

This chapter contains the demographic information about the recipients studied, a physical description of the kidney center in which this study was conducted, and the findings of the study. The findings are presented after each of the Objectives and Threats to Empowerment, and the conclusions are an analysis of the Research Questions of this study.

Demographics

The recipients interviewed were 45% male (N=9) and 55% female (N=11); 90% Caucasian, 5% Native American, and 5% Hispanic American; with a mean age of 64. Recipients had received dialysis treatment a mean of 3 years. The percentage of married recipients was 42%, never married was 15%, divorced was 11%, and widowed was 32%. The mean highest grade completed in school was 12.21 years. Most recipients were retired (58%), the others were disabled (20%), homemakers (17%), and unemployed (5%). There were an equal number of people who were laborers, skilled laborers, clerical
workers, and homemakers. Most recipients owned the home in which they were residing (68%), and there was a mean of 1.5 persons living in the household.

The range of income was from $310 to $3500 a month with a mean of $1156 a month. Most recipients paid for dialysis treatment with insurance and Medicare (70%), and the others by Medicare alone (15%), and both Medicaid and Medicare (15%). The range in number of years receiving dialysis treatment was 1 to 19 years with a median of 2 years.

Description of the Physical Setting and Operation of the Kidney Center

The kidney center in which I conducted my study is a division of large health care delivery system. The kidney center had been remodeled on the site of the old kidney center, and had been completed several months ago. For the eight months that it took to remodel the old kidney center, hemodialysis recipients had received their treatment in a converted snack-bar in the basement of the old part of the hospital. The old kidney center was a converted surgical suite that occupied an area of its own. Before then, the kidney center had been located at various places in the hospital. The use of hemodialysis to treat people with End-Stage Renal disease became a vital part of the overall hospital mission within the past decade, when a large number of persons seeking dialysis treatment made it necessary to expand and update the kidney center service.
The recent transformation that the kidney center had undergone over the years is noted in the hemodialysis recipients' responses to my interviews with them. The recipients did not note that the temporary unit was a noisy, poorly ventilated, congested, out-of-the-way, and ugly place that I felt it to be. I looked forward to the completion of the newly remodeled kidney center that promised to be well designed, capacious, and a clean and modern haven for both recipients and staff. Yet the data I collected from the recipients in my study suggests that recipients felt that the old kidney center was a more intimate setting in which they could feel closer to one another and staff. I found that recipients liked the old kidney center because of its open design, allowing both recipients and staff to view each other easily.

The high ceilings with the skylight, a row of windows on the west side, the ramp leading to the hospital corridor remains, but all else is new. There is a new use of the space: offices on the main floor, an elevator to the lower level of the kidney center (which was previously a loading dock), new furniture everywhere, and new chairs for dialysis recipients to sit while they are receiving their hemodialysis treatment.

The old kidney center was difficult to gain access to for recipients. They would have to walk through the hospital corridors, hike up stairs, or take an elevator and walk some more. It was very difficult to navigate through the hospital for many persons who were feeling tired or woozy after their dialysis treatment. It could be an ordeal to get to and from the kidney center for persons in wheelchairs or walkers since they would have to bypass stairs in favor of using elevators located at various places in the hospital. These
persons would have family members drop them off at an entrance in the hospital, wait for their transportation to find a place to park, then receive the assistance they needed to get up the ramp of the kidney center. If recipients used community transportation services they would be dropped-off by a main door of the hospital and wait to be taken to the kidney center by a volunteer. This sequence of events would probably not seem consequential to them if this was not a routine in which dialysis recipients re-enacted three times a week. The remodeled kidney center now features an elevator that takes treatment recipients directly to the upper level where they receive dialysis treatment. For those in wheelchairs or walkers, their transportation can either drop them off at the elevator (that is accessed from the street level) or park in the exclusive parking lot directly next to the kidney center.

Each recipient enacts the same ritual three times a week on arrival at the kidney center. Coats and jackets are hung on racks by the washroom where recipients are expected to wash their hands after treatment. Valuables are placed in lockers provided to each recipient, and a bench lines one wall of the locker room so that recipients can take off their shoes. It is unusual to see a recipient who is wearing shoes during dialysis treatment. Next to the bench is an ice machine where recipients sometimes get a cup of ice before coming into the treatment area. Recipients go into the waiting room until a nurse appears informing the recipient that she or he is ready to, “Put you on now.” The nurse helps recipients wash the arm in which the access is placed, and the recipients take their temperature, weigh themselves, and go to their dialysis station.
The way that the kidney center operates is different now than it was in its pre-remodeled state. Much of the change is due to the way that the space is allocated by the designers. They attempted to embody a philosophy of patient care that maximized the space for the comfort and convenience of treatment users. For example, treatment recipients now have an enlarged waiting room, two sets of restrooms, a locker room, refrigerator and ice machine, and a washroom. Before the remodel, they had a waiting room and one set of bathrooms. The kidney center used to have recipients lined-up against the walls and the dialysis area was divided by a long white table placed in the middle of the room used as the nurse's station. Nurses, as well as treatment recipients could see everyone else at a glance, and hear everyone easily. Even though nurses were assigned to work with certain dialysis recipients each time they came to work, they may not have worked with some recipients for some time depending on the nurse's schedule. This situation led to both nurses and recipients feeling uncomfortable about working with each other. The discomfort was more than a social awkwardness. It is well know among all recipients and staff that providing hemodialysis treatment varies according not only to the medical needs of the recipients, but mostly because of the intricacies of placing needles into the recipient's access for the purpose of initiating treatment. The art of nephrology nursing is what is called “cannulating the fistula,” or putting the two needles into the artificial access recipients have underneath the skin of one of their forearms. The procedure is delicate, as each recipient’s fistula (or another similarly functioning access called a gortex graft) is different. Some recipients will not allow certain nurses to initiate
their treatment because of the difficulty they might have with the recipient’s access. This sometimes causes some hurt feelings and additional pressure on the nurses to perform well. The treatment procedure is almost painless. Recipients feel a stinging sensation when the nurse injects xylocaine into the recipient’s access, but xylocaine numbs the two places the nurse uses for cannulating the fistula.

The remodel of the kidney center makes it possible to divide the treatment space into two “pods,” or independently functioning sections. Each pod is assigned nurses who regularly work with the same dialysis recipients. Six dialysis machines are set up on each side of the kidney center, and each one is called a “station.” Recipients are assigned a single station for the three times each week they have treatment, and the station is separated from each other by a waist high island. The islands are composed of a counter top with shelves along either side. The island contains everything that recipients may need throughout the course of the three to four hour long treatment sessions. Needles, gauze, clamps, tape, gels, and other medical supplies are neatly stocked for each recipient. Each station also has a television set connected to the wall by a large swing-arm. Recipients typically watch cable television throughout their treatment, and wear headsets so as to not bother others. Some recipients sleep the majority of their treatment (a remarkable feat considering the noise of staff calling-out to one another, dialysis machines sounding beeps, and recipients visiting with staff and other recipients).

There are three shifts of recipients coming to the kidney center a day—a daily total of thirty-seven recipients. For each shift, there are three Registered Nurses (RN’s), and
two Licensed Practical Nurses (LPN’s). There is an additional LPN who comes later in the day to assist with, “Put-ons and take-offs.” Putting-on and taking-off is kidney center vernacular for initiating treatment and ending dialysis treatment for each recipient who is “running.” A “run” at the kidney center is one session of dialysis treatment. The RN’s monitor the process of hemodialysis treatment, and assess each recipient’s health throughout treatment. The LPN’s participate in the care of each recipient by responding to the RN’s directives. There is typically one Patient Care Technician who works in the re-use area. Re-use refers to both the area and the process of cleaning artificial kidneys so that recipients can use them again a number of times. Because the kidney center functions as two independent units, each shift of staff is divided into teams of RN’s and LPN’s. The third RN is the charge nurse, taking care of any problems that arise during a shift. She or he is able to coordinate treatment between the two independently functioning pods. These pod teams are predetermined groups that come to work knowing who will be on their team and which recipients they will be working with on their shift.

There is a nurse’s station in the middle of the room as before, but it is no longer one large table. Now the nurse’s station is two tables that allow nurses from each pod to monitor the recipients while doing paper work, making phone calls, and other duties nurses perform while recipients have their treatment. There is an administrative staff of three nurses; however, all but the director of the kidney center provides clinical nursing service in support of the pod teams.
During any given shift a number of family members and friends visit recipients. The kidney center rules allow recipients to have visitors accompany them while they are receiving treatment. Also, a variety of other professionals work with recipients while they are having their treatment. Since recipients resist coming-in on a non-dialysis day for other appointments, professionals tend to meet with recipients while they are receiving their treatment. Since recipients are at the kidney center for at least three to four hours three times a week—not including travel time to the kidney center, it is not surprising that recipients resist additional appointments. Nephrologists (internal medicine physicians who specialize in the treatment of kidney disease), renal social workers, and renal dietitians are employed by the kidney center to be present throughout the shifts. Other professionals such as medical specialists, chaplains, and financial counselors routinely “make rounds” to recipients throughout a typical day at the kidney center.

The kidney center has undergone many changes through the remodel, and it is noteworthy that recipients and staff had a significant influence in creating changes at the kidney center. From the development of the pod system to the selection of wall coverings, recipients and staff who wanted to participate in the creation of the new kidney center were invited to do so. Surveys were taken as to the color scheme of the new kidney center and recipients tried various types and styles of chairs. What art work to put on the walls as well as other issues that affect the recipients and staff of the kidney center
are debated by Patient and Staff Representatives who sit on the kidney center Advisory Board.

Although the kidney center is a part of the hospital, staff and recipients tend to perceive themselves as having a separate identity apart from the hospital. Each year there is a recipient recognition ceremony, a Christmas Party, Summer Picnic, a Crafts Show, and various other activities in which recipients and staff participate that are unique to the kidney center. There are also learning events that take place throughout the year designed to provide new dialysis recipients with opportunities to get to know other recipients and staff members.

**Synthesis of Data**

One point mentioned in the section above suggested that recipients seemed to prefer what they described to me as being the more intimate setting of the old kidney center and the temporary kidney center. They preferred the physical closeness that brought them together, and seemed to associate that with the feeling that everyone was friendlier in the old kidney center. This was a viewpoint held by many of the recipients I interviewed. In the following data, I will specify whether the one or more recipients gave me the information cited. I will use the recipients’ words as much as possible to provide descriptions of their experiences at the kidney center distinct from my own.

The findings are presented by relating the data to the objectives of this study. The objectives are the key theoretical points made in the literature pertaining to
empowerment, and the findings are the data that I collected that addresses the theoretical key points.

Objective 1

Through dialogue with other hemodialysis recipients, how do hemodialysis treatment recipients name the elements of their world (the kidney center) to give these objects a subjective meaning?

Dialysis treatment recipients seem to name their world by speaking with each other particularly in the waiting room of the kidney center. The waiting room is where recipients establish relationships with one another, and informally discuss what it is like to be a recipient of dialysis treatment. It is by sharing their experience that a culture of communication with each other is developed. Those recipients who were limited by physical deficits such as poor hearing or vision, indirectly related factors such as receiving transportation to the kidney center for meetings, or having difficulty initiating conversations expressed difficulty engaging their social world. Their inability to interact with other recipients principally by verbal communication made it difficult for these recipients to name the elements of their world and feel a sense of camaraderie with others.
Relationships Among Recipients

Recipients are given a choice of which station they would prefer to use at the kidney center. Conflicts seldom emerge regarding where in the kidney center recipients would like to sit in relation to others. The selection is typically made by recipients on the basis of noise. The recipients who choose the stations on the far end of the kidney center have done so to avoid the traffic of other recipients coming in and going out of the kidney center. Their selection is based on a need for privacy, and they usually sleep their entire dialysis run. Others prefer to have contact with the other recipients as much as possible, and it is unavoidable to enter or leave the kidney center without acknowledging these recipients with greetings and small talk.

Only two stations are not separated by the island storing supplies needed during recipient's treatment. The two dialysis chairs are about six feet apart. Otherwise, each station is demarcated by an island. With the separation that recipients experience from one another during the dialysis treatment, it is not surprising that most conversations occur in the waiting room. The waiting room is long and narrow. In the middle of the waiting room, between the elevator and the area that contains the waiting room chairs, is an area where wheelchairs are stored for recipients while they are receiving treatment. The wheelchair area is usually full in the morning and afternoon. The recipients needing to use wheelchairs bring their own to the kidney center, and the wheelchairs can number around eight in the area.

The morning and afternoon shifts have mostly the recipients who live in retirement and nursing homes. They run on this shift because they are dependent on
community transportation that only operates during business hours. The late afternoon shift that extends into the evening hours typically treats recipients who have day jobs, and the recipients come to have their treatment at the kidney center after work. There is a long brick shelf on one end of the waiting room used mostly to put large potted plants on, and the other two walls have chairs separated from each other by arms, yet linked together at the hip. The television set was removed at the time of the remodel because recipients and staff felt that it brought much unwanted noise to the kidney center and prevented recipients from speaking to each other.

I asked recipients about what it is they talk to each other about while they await their treatment. Even though some recipients come anywhere from a half-hour to an hour early for their treatment, most recipients described the waiting room conversations as casual, comfortable, and polite. The content of the conversations did not seem to get very in-depth as demonstrated in the following example. “We just talk to each other. Sometimes they talk about their troubles and I talk about mine. Dialysis is what you have in common, so we compare ourselves with each other. If you have the same affliction you’re bound to compare. Sometimes you have a good run, and sometimes you don’t.” Other recipients said, “We more or less chit-chat. I introduce myself and visit. Sometimes you feel that you connect with people,” and, “I’m a nosy guy, I like to find out about people. You compare things like how much time you have to run on the machine, and you ask how they are feeling today.” Although, “I’ve never invited anyone to my place and they haven’t invited me to theirs,” most recipients described, “A friendly
atmosphere,” in the waiting room. Recipients noted that they felt friendship towards each other immediately because they felt that, “We’re all in the same boat.” Some recipients said that the waiting room had become about the only place for recipients to speak with one another because the physical setting of the dialysis treatment area did not allow recipients to talk. “Before I knew the lady who sat next to me pretty well, but now I feel like I don’t know anybody real well.”

The quality of the relationships that recipients have with each other varies by the individual. Recipients mostly seemed to agree that they view most of the other recipients as just acquaintances. “I don’t know too many of them. Once in a while I see guys to talk to, but I don’t know their names. I only talk to them once in a while.” Some recipients said that they simply have a difficult time getting to know other people regardless of the circumstances, “It’s too hard for me to get to know people. All of my friends became friends to me because they came up to me and started talking. If I see someone I greet them and at least tell them that I hope they have a good run.” The kidney center environment and the need for recipients to receive treatment for renal failure didn’t seem to be enough of a basis to form deep relationships among dialysis recipients. It seems that even the more outgoing recipients strive for making good acquaintances rather than good friendships, “I just take the opportunity to talk to them. I say hello and good-bye to them, and you get to know people because of conversations that you overhear.”

Some recipients report that they take the opportunity to help others who are curious about them. “I explain my treatment to everyone who asks about it. I try not to
get too gloomy, because it doesn’t hurt now that they aren’t poking into my arm [referring to having gotten a better hemodialysis access]. I don’t think I’ve read in articles where it says that it doesn’t hurt, but it doesn’t.” Recipients also seem to be able to share problems with each other regarding treatment such as how much fluid they can consume between dialysis runs. The difficulty keeping within the safe limits of consumption is a topic about which almost every recipient can strike-up a conversation regarding, “We could have a real gripe fest.” Although one recipient said that he assumed that, “Other people are just like me; I suppose they read, sleep and probably watch TV” while receiving dialysis treatment; the desire seems to be present in most to get to know other recipients on a friendly basis. Even though friendship may not be the goal, most recipients cited benefits in at least getting to know other recipients better. “I get encouragement from other people, but no one person in particular. When you get acquainted with people you get to understand your own risks on dialysis better,” and simply, “It increases your knowledge about other people. If you’re here long enough, you get to know them. I’ve met a lot of patient’s wives by being here.”

A compelling reason for wanting to get to know other recipients was expressed as, “None of us want to be alone in this so we talk about it a little bit. We talk about the little incidents in our life. You ask what problems they’ve had and how they dealt with them. Some people are asking why they have to be the one to have kidney problems and not someone else.” New recipients seem able to get some information and support from recipients who have been receiving dialysis for a long time.
They ask me about dialysis treatment and I tell them I didn’t like the alternative. I tell them that I wanted to live, and thought that there was no other choice than to take dialysis. I give them information so that they can decide what to do on their own. I tell them that they can eat and sleep, and pretty much do whatever they want to do while they’re on dialysis. It is always their own decision.

It is noteworthy that those recipients who reported that they wanted to give some support and assurance to new recipients doubted their helpfulness to them. One recipient who had received dialysis treatment at the kidney center for several years talked about how eager she is to help others. Though she lives quite a distance from the kidney center, she offers to be available to talk to new recipients and to answer their questions and concerns about treatment. Yet she states, “I don’t know what I really have that’s worth telling new people.”

There are other acts of expressing support by dialysis recipients to one another. One elderly recipient who is confined to a wheelchair said that,

“Joe looks after me. He tells everyone that he hates dialysis, but I tell him that if the machines weren’t here we wouldn’t be either. He talks of dying. He checks on me every time I’m here. When he is finished with his treatment he comes over to me to see how I’m doing. He helps me get down to the elevator. He asks me if I’ve had a good run. One time I said I was dry after my run, but he thought I said die. That concerned him quite a bit.”

It is particularly interesting that the person this recipient is referring to is also confined to a wheelchair and is mentally retarded.
Not everyone, however, feels that they have developed nurturing relationships with other recipients. Some people come to the kidney center with characteristics they say make it difficult for them to communicate with other recipients. “I was always kind of a loner. I’d rather be left alone. If they don’t want to talk I leave them alone,” and “I’m not one to go to social functions.” “After treatment you don’t want to talk to anyone. You just want to go home.” Some recipients blame other recipients for not wanting to communicate.

If people would talk to each other and visit it would be nice, but they don’t want to. You try to make it interesting for yourself while you’re here, and that’s all you can do. Each individual has their own ideas about things. Even doctors have a hard time getting into people. People are afraid to do that. They have a wall. You try to pry into their business or try to let them get to know you, and they just won’t. People just don’t try. I visit with some of them waiting to get on. They answer questions, but they don’t socialize. A lot of people are not too well educated and they’re afraid of themselves. It all boils down to their personality. They don’t say anything. I must be the only one who has problems around here. I have a bad attitude, didn’t you know that? I don’t know anybody, no one wants to talk to nobody. You’re here to get dialysis and then leave.

Not all recipients who have tried to establish positive relationships with other dialysis recipients feel so injured. Many could sum their experience as one recipient did by saying, “The people are nice here. I feel like we’re all one big family. No family is happy all the time. I haven’t met anyone that I couldn’t get along with.” A couple of recipients even desired spending more time with other recipients, but “I’m limited as to how much I can be away from home because Medicaid doesn’t allow you unlimited
transportation—so this is where I do my visiting. I suppose I could call people on the phone, but what would I say?” Another used to go to meetings that were held at the kidney center for recipients, but said that the meeting times proved difficult for her to find transportation to attend. “I would love to go to the meetings again. I liked being with people and hearing what they go through. I’m in bad shape, but not that bad. Why would you feel sorry for yourself when someone else is worse off than you?”

Some recipients feel hesitant to get to know anyone, particularly since recipients are aware of their own and other’s mortality. “The risk of getting to know people is that one day they won’t be here. In talking to people here, I think, maybe this will be the last time to talk to them.” Another recipient said, “I get acquainted with someone and then they pass away. What’s the use?” One recipient addressed the issue of mortality this way:

You don’t think so much about yourself as you do others. If they get worse, you wonder how they are doing and if they are getting better. You care. When I first came here I felt there were risks of getting to know other people. I got to know people like Bill real well—the one without the legs, and then there is another one, you forget the names. You get acquainted with people and they die. That’s why I don’t care to get acquainted with people anymore.

A recipient who had received dialysis treatment at the kidney center for several years talked about getting to know another recipient well, “Then he died. Most of the others have died-off. After that I said I wouldn’t get tangled-up with anybody else.” The heightened sense of mortality may be a reason why recipients prefer to make good acquaintances rather than good friends with other recipients. “We always have a little
conversation when we get ready to go. It seems that they all feel the same way that I do. You just rather not make too close a friend.”

The attitude about mortality is naturally perceived differently by each individual. One recipient interviewed wore a jacket that pictured a skeleton and carried a written message emblazoned on the backside: “Don’t fear the Reaper.” He said of it, “When I had my jacket done the guy who did it said, ‘Are you nuts?’ I said no—I’m not afraid of death. I’ve been dead clinically four times. When you’re a dialysis patient you’ve got a 50-50 chance of being the next to die.” The theme of mortality was pervasive in the interviews—it seemed to at least color the perceptions that recipients had about making good friends with other recipients, “I know several in here and most of them are very friendly. You meet them, then one day they don’t show up. It’s kind of, well, I guess that’s all that I can say about it.”

One recipient spoke of the relationship she has with another:

We clicked right away and I get along with his wife. When he first came on he was hypertensive and didn’t know if he wanted to do this. After talking to him he saw that he can live for a long time pretty well. When I started, they gave me five years and now I’m going on ten. Some patients are standoffish, others you can talk over certain problems that you’re having and they understand. I joke around especially with Carl. Carl is always trying to tickle my feet. I got him back and tickled his feet even though he had thick socks on and could barely feel it.

Limitations made on Recipients by the Physical Structure of the Kidney Center

There was a common occurrence of participant’s perceptions concerning the
distance from each other they experience at the kidney center. “I think that when we were downstairs you got to know people better by being closer together. Now we’re so isolated from each other.” Another recipient observed that, “The only thing is that you’re not close together here like we were downstairs. Also, people come in for treatment at different times. That makes it hard to get to know them. You spend a lot of time here, but you don’t want to yell out at them from across the room.” Other recipients described the new setting as, “I feel segregated. Down in the basement we were close and we talked to each other.” “You look at them from across the way, that’s all. I don’t know anybody in here really except Mike, and he sleeps most of the time.” A recipient noted that the distance prevented her from hearing what other recipients had to say because of her hearing deficit, thereby preventing her from knowing other recipients. One recipient who has been receiving dialysis treatment at the kidney center for several years suggested the value of being closer together.

It’s kind of hard now with the way we’re setup. We used to be able to talk with each other better. There are a lot of neat people on [receiving dialysis treatment] right now. I’ve seen them come and I’ve seen them go. If I didn’t live so far out of town I would spend time working with the patients. We need to have monthly meetings again. But I’ll never refuse to see someone who needs guidance and direction to make decisions.

An extreme example of what it is like to have limited contact with people is described by a recipient who traveled to a major city recently to visit relatives. While he was there he required dialysis treatment. He reports his experience as, “You walked into dialysis in the morning, washed your hands, took your temperature and weight, then sat
down. You don’t see anybody during your treatment. You have a call button on your chair. It was clean, but I wasn’t impressed with their operation. The staff acted like it was just a job, and they really didn’t want to be there.”

It seems that recipients are resigned to certain forces acting on them, preventing them from fully naming the elements of their world. They seemed to be unable to overcome the barriers of separateness from one another at the kidney center, and had difficulty accepting the death of someone they knew as a member of the kidney center. There too is a sense of frustration at not being able to develop a friendlier environment at the kidney center. Yet recipients were able to identify these forces, and seemed perplexed about overcoming the difficulties as individuals and as a community. Hemodialysis recipients did not seem to have any special abilities over anyone else to resolve such difficult problems as death among its membership. They did not express any desire to memorialize those who had expired, but instead seemed to place more distance between themselves and other recipients. Being awakened to the reality of death is a force that is acknowledged by all recipients.

Objective 2

How is critical reflection necessary to develop an understanding of the reality of one’s world (the kidney center) and envision change?
The theoretical viewpoint on empowerment suggests that persons must engage in critical reflection in order to envision change in one's world. At the kidney center, I found that recipients could not express by my questioning the process in which they engaged to challenge their presuppositions when confronted with their need to accept dialysis treatment. Either my questions did not address the process of critical reflection, or critical reflection does not occur in the absence of oppression in a kidney center. I did find, however, that recipients spoke of a mutuality they experienced with both other recipients and staff members. The sense of give and take in relationships was evident to them in adjusting their expectations to living with chronic dialysis treatment. Recognizing the value of other recipients and staff, asking questions, and trying to understand the motivations of others seemed to play a role in changing how recipients learned to view their life and other's lives with dialysis treatment.

Recipient Viewpoints of other Recipients

"If you have dialysis, then we all have something in common" is a sentiment that seemed to be shared by most recipients. Recipients assumed that other recipients, "probably have the same ways that I do. You have to come here and there are things that you have to do." Some recipients seem to feel that there is an unspoken commonality between all recipients, "We're all kind of quiet, we all know what each other is going through." One recipient contrasted his experience at the kidney center with having cancer treatment,
You don’t want to be alone. It’s like anything else, you get to know people at work or in illness. Maybe someone is having a problem that you have. This is different than with the people at the cancer center. They don’t talk to you, even if they know you. It helps to talk to other people. The ones who talk the most are the ones who have been around the longest.

This recipient notes the universality of having a desire to join with others in a similar situation as one’s own to avoid the sense of separateness from others. He states that longevity in receiving treatment is attributable to talking with others, and suggests that the kidney center is more conducive to speaking with others. Treatment for renal failure necessitates a routine of three times a week visits lasting for up to four hours each treatment. Cancer treatment, on the other hand, varies in length and duration without the structure that the kidney center demands.

It is not easy for recipients to acclimate themselves to having to be at the kidney center, “I think a lot of them have trouble getting used to being here. Especially the new ones who are too shy to ask questions. That’s what I liked about the bull-sessions, you can draw out new people. They don’t understand yet that you’re here to help them.” Dealing with the feelings that emerge with the rigors of dialysis treatment can also be challenging.

I wasn’t depressed right away like the other patients, it took me a couple of years to feel it. Until they realize they can live with it, and it won’t hurt them. So many people have so much negativity about it. I am commended by my friends and family for doing this, but I tell them that you don’t know what you can do until you’re forced into it.
Recipients do notice what is going on around them, particularly when something is happening to another recipient. “This guy next to me clotted his graft and was upset and threatened to leave and drink a bottle of Rye. I told him he needed to stay—that those things happen. You have to have a sense of humor to get through all of this.” Recipients acknowledged that they have spoken to one another about the necessity of remaining on dialysis for without it they would die. “I talk to Dan about it and he feels the same way as I do—if you don’t have the treatment, you’re not here.” I found it interesting, but not too surprising that the recipients who had been on for more than a few years tended to say that they speak with other recipients more often than do the newer recipients. They tend to offer advice to the newer recipients, and seem to be more patient and understanding of the way that other recipients feel about the inconveniences of having to receive dialysis treatment. Perhaps the more noticeable traits that some people have noticed of other hemodialysis recipients are that they, “Squawk when they don’t get on time. But I don’t hear about that too much. The biggest problem for people has to do with getting their rides. They’re old and they have to wait to get home. You can’t mobilize and you feel tied down. You can’t blame them—I’d hate to be like that.”

One recipient who has received dialysis treatment for more than ten years did find it hard to believe that newer recipients had such a hard time talking to one another.

Put it this way, it’s hard to talk to these people. They don’t want to socialize. I don’t know what it is, if they’re afraid because they’re on dialysis, but most don’t want to talk. They’ve been more or less that way all their life. They may think you’re interfering in their life. They won’t let themselves loose. I’m different, because I talk to everyone.
Most of the observations that recipients make of each other have to do with brief conversations on such topics as what food they crave since starting dialysis treatment, concerns about their access clotting, feeling tired, and low blood pressure. The advice given by one recipient who has received dialysis for more than a few years is, “Some, when they’re new they get scared easily. They itch a lot and get fidgety. They have to learn to calm down.” A re-occurring bit of advice given is, “you go and you try to get along—that’s all there is to it.”

Although the physical limitations are often cited by recipients as preventing their access to other recipients, “I haven’t met anyone since we’ve been setup like this,” or emotional distance, “You do become attached to somebody and loose the connection with them, then you feel sad;” most recipients report friendly gestures such as, “I just say hi.” I found one exception to this, and the viewpoint was made by a younger recipient, “Most of them [recipients] are old. I know one other kid on the other shift who is younger than me, and he’s been on dialysis a lot longer than me. He’s sleeping all the time. I stick to my own business. I don’t like to meddle in other people’s business. I’m fine with them as long as they don’t tell me their problems.” Typically, recipients want to know each other at least on the acquaintance level. One recipient suggested that pictures of each recipient be displayed in a showcase in the waiting room along with featuring a recipient in each kidney center newsletter.
Recipient’s Relationships with Staff Members

Recipients generally expressed a warm relationship with staff members. They stated that they felt the staff wanted to see them do well, and were readily available to help them if they were experiencing any difficulties. Recipients seemed eager to discuss their perceptions of how they interact with staff. “I do what I’m supposed to do—what is necessary to get this done in four hours without difficulty. If you get obnoxious, you can get the nurses upset and that makes them anxious. They’ve got feelings too.” Typically, recipients are able to identify at least one staff member they know and trust beyond the others. I found it interesting that recipients were able to see staff members as having different personalities, rather than grouping them into one large assumption of what a staff member is like. I suspect that this prevents over-valuation of staff, as well as demonstrating recipients’ ability to see staff members as having individual characteristics that are either perceived as being helpful or of no help to the recipient. This appears to be a trait that serves to humanize staff and enable recipients to appreciate the qualities or the deficits of each staff member.

“They’re all real good, especially Lori—she has me on in 5 minutes. They’re all real good people. Except Sam, he’d start putting me on and then walk off and talk to someone else. Last time he put me on I was 20 minutes late.” Recipients expressed feeling very strongly about the time in which they are started on dialysis each session they appear for their treatment. Some recipients are baffled that their treatment is not started before their neighbor’s treatment, no matter what the reason. Once started, they notice particular characteristics about each nurse.
There are some I like to work on me better than others. Some of them seem to make every move count for something, and others seem to flutter around. I like the ones who accomplish something in a shorter time. They know what makes you hurt, and if they hurt you they apologize. But some make you hurt more than others.

I did not find in the participants’ reporting that there was any deep-seated dislike for any particular staff or other patients. I did find, however, that recipients stated that while they were receiving dialysis treatment they did feel somewhat vulnerable or at least unable to do much. “The other day we had an emergency alert and I thought ‘oh no’ I don’t remember what to do. But I knew that the staff would help me.” “You’re stuck in a chair—what can you do? I think you have a real nice staff. With all the problems and things that could go wrong, you’d think that they would be upset, but they’re not.” One other recipient notes that, “the staff does everything that you ask them to do.”

There are some complaints that recipients have about the staff, such as, “I would like them to not forget me when I come off dialysis,” and, “The nurses seem so cross with each other,” and even, “One nurse walked away from me to help another nurse when I felt that I needed her more.” One recipient felt that he should have his dialysis treatment started before anyone else because he comes in the earliest rather than at his scheduled time, “I have to be here for four hours. They should put the ones who have to be on the longest first. I don’t have a choice, I have to be here. If you don’t like this, then get another job.” Even the recipients who had these complaints, however, countered that they felt the staff was mostly working for rather than against them.
Only once was there a time I felt that I wasn’t being treated with respect, but I talked to them and it never happened again. It’s nice to be polite. I always thank the nurses for putting me on or taking me off even though it’s their job—you always get a smile that way. And when I’ve had problems, they always listen to me and help me out.

Recipients who observe others who in their viewpoint are unnecessarily demanding with the staff note that, “They’re old and it’s hard for them to get here and have dialysis,” or that, “Most of their trouble is that they can’t accept that the problem is theirs and not someone else’s.” Most recipients seem to have adopted an attitude that helps them deal with inconveniences associated with receiving dialysis treatment as, “It does no one any good if you bitch about it, it just upsets everyone.” One recipient said,

I mainly just be patient. I talk to other people, try to be sociable, and have them relax. I don’t go into the foyer and bitch. Sometimes you have little problems that should go no further than this chair. Everybody’s got different feelings about things. Some people, if they feel just a little bit neglected complain. But you’ve got to show some kindness.

There was an expression of nostalgia by one recipient who had been receiving treatment for several years. She recalled when there was a nurse who insisted on staff and recipient participation at the kidney center, “Back then it was mandatory. You used to know that everyone cared for you here, and that made it special.” Recipients seemed to have a high positive regard for the nurses, “I’ve made friends with all of them,” and “The people down here are one hundred percent, even the young ones. It’s nice to know
that you have someone who cares.” One recipient expressed that she had a dream about one of the nurses and in her dream, “I was showing her my photo album.”

Recipients didn’t seem to express much desire to change their relationship with staff members. “I don’t know what it would be. I told the staff I wanted to move to another spot, and they moved me about a week later.” Also the staff, “Ask questions to see how you’re doing. They get concerned about some things. This is a good place. Dialysis is something you have to do and make the best of it. I would like to travel to other dialysis places and see what they are like.” “I think the staff treats me exceptionally.” “The staff wants to see me do well. When they talk to me about the water, they’re nice about it. They do scold somewhat, but I know that my fluid gains are a problem. They’ve done things to help me.” Recipients also expressed that they, “Try not to give them [staff] any problems.” The relationship with staff is not without some problems, “I have differences of opinions with a couple of the nurses. It doesn’t happen all the time, it just comes up every so often. Some problems have to do with policies and procedures.” In one example, a recipient who transferred to this kidney center stated that, “I wanted to be here. I heard this was a better facility. You hear this kind of stuff by listening. My mom did some research into this place before I came here.”
Objective 3

How is awareness of self within a community of other hemodialysis recipients necessary to experience empowerment?

An element to awareness of oneself is the capacity to do for oneself at the kidney center. In part, it is the recognition of personal responsibility, but it too is a recognition of what others are responsible for at the kidney center. I did not find any evidence of recipients feeling that they were unable to participate in their treatment at the kidney center in the manner in which seemed most appropriate to them.

Participation at the Kidney Center

The level of recipient participation at the kidney center differed quite a bit among recipients. Some participated by, “coming in here and helping to setup my station if it isn’t completely setup,” and others by, “Just observing and watching.” There also is a certain identity with other recipients that is experienced by recipients, “You’re not the only one who is living with this. You can live with the pain because you learn they have as much pain as you do--the cramps in the legs.” And some recipients are able to participate by, “reading the book that I got when I first got on dialysis. I look around and I watch. I ask a lot of questions and I’ve always gotten answers that made sense. Anybody who asks me a question, of course I talk to them.”

Some recipients would like to participate more in their care if they were able to, “I wish I could see better, then I’d do more with the machine. Like Sarah, she takes the
blood pressure and is able to check the kidney for herself. But this is nothing that staff prevents me from doing.” Another recipient expressed her desire to, “know more about how the machine works. I asked the nurse, but she told me she didn’t know either because it’s all computerized.”

Some recipients seemed to have attitudes or problems that affected them, but were not directly related to their care at the kidney center. For example, one recipient said, “It’s the administration around here worried about their dollar. They’ve tried to get me and I’ve called them on it. They try to get all that you have. You work all your life and they want to take it away.” Another recipient said, “They [nurses] even forget to call for our rides. When I called for myself, they come right away.” I found that recipients did not express difficulties with participating in their care while at the kidney center.

Many recipients stated that they did not think of themselves as being very sociable, but liked going to the kidney center because the environment is comfortable, “It is nice to know people you see three times a week. There is a common ground to get to know them.” Many people seem to experience a comfortable sense of being with others vicariously, “I just observe and watch. I like people and it’s easy for me to talk to them, but I like sticking to myself mostly. I’m here for four hours, go home and rest, then I go to school. This is just a part of my day.” Only one recipient noted that she did not like to, “Interfere with others. I know that the doctors or nurses will help them out. I’m not a doctor or nurse.” Most recipients, however, described a situation where they felt that they would help out another recipient without hesitation, “I saw a guy trying to get his
coat on and I told my wife to help him, but she said no. I couldn’t get to him because I was on the machine. She said that she was afraid she would get some disease from him. I’m not that way any more, I’ll help anybody.” Another recipient stated that she had lost contact with her sister because her sister was afraid that she would contract kidney disease from making contact with her. The recipient said that she felt sad that her sister was not able to be helpful to her by showing her support.

It appears that dialysis recipients are eager to demonstrate a small kindness towards each other if they can, and appreciate the quality of their relationships with each other. “They’ve been good helping me out. They haven’t been rude to me or anything. You have to come up here and do this, so I make the best of it.” Some want to help other recipients when they are making a transition such as relocating to be closer to the kidney center, “You feel pretty isolated when you are from far away.” It is the common ground, the “We’re all in the same boat” attitude that recipients cite as being comforting to them. “They’re all friends. That one fellow who went to California is a good friend. I think that everyone here tries to be a friend. We’re all in the same predicament. It just gets you upset if you act unfriendly.” This attitude seems to extend beyond the kidney center, “I come in, get my things, do what I have to do, and try to be happy. I go home, and I try to help and be happy there too. I’ve even gotten to the point where I like the dog.”
Objective 4

How is praxis necessary to experience empowerment within a community of hemodialysis recipients?

Recipients seemed to be able to take into consideration what they were thinking and feeling about their situation, and modify their actions as a result. The repetitive nature of dialysis treatment gives recipients the continuous opportunity to put into practice their reflections. Recipients demonstrated some type of action, even if the choice of action was to behave passively or become dependent on others.

What Recipients Learn

Hemodialysis recipients express learning the essentials of living with dialysis treatment in their lives, about themselves, and about each other.

I think that life is a funny thing. What is dealt to you, you have to take. You look around and see other people who are worse than you. Like that young fellow over there—he’s on for four hours. The thing that I’m glad about is that I don’t have to work. I’m financially secure.

Recipients seem to recognize the sacrifices that others have to make because they are all renal patients, such as the amount of time spent on the machine, how others fit their treatment into their work schedule, their financial well-being, and how dialysis affects their family.

You have to think about how it will affect your family. You can’t be sneaky. My son knows the routine: what type of medications I take, what I should be eating, and the like. I still like cashews. My husband and son look in all
of my hiding places and find them—they always know when I'm eating them. I stopped drinking coke a couple of years ago—it was too high in phosphorous. I just quit; it wasn't doing me any good.

“Most things about dialysis I learned by myself. I don’t talk to anyone else,” and “I’ve listened very well up here about what they’ve told me and I’ve read a couple of papers that they gave me.” There appeared to be no consensus on how and what recipients learn by attending the kidney center. “I found out that the fellow over there is in for four hours. I guess it depends on how much kidney functions you have left.” “I haven’t learned a hell of a lot. I know it’s a machine that takes off the fluid and purifies the blood. The machine is amazing to me to be able to do what it does.” Another person said that he, “Realized that this is the only way that I can stay alive. I’m too old to have a kidney transplant, and I have a lot of other things wrong with me so I have to put up with it [hemodialysis treatment]. It makes you realize that you’re not far from the end of your life.” Some recipients said that they have subscribed to journals about kidney disease and treatment, read the books, magazines, pamphlets, and newsletters in the kidney center waiting room. A couple of people said that they knew other people who received dialysis treatment, and it helped to talk to those persons before starting dialysis themselves.

Making Decisions as a Dialysis Recipient

Most recipients stated that they make their own decisions that affect their dialysis treatment. Some said that the decision to go on dialysis to begin with was heavily influenced by their doctor’s explanation of the options and concluded that, “You either go
on and live, or not and be dead—that was my choice. It’s not much to choose from.”

Another recipient said that, “the doctor was very up front about it—start dialysis or die. I was grateful to him for being straight forward with me.” One young recipient described his relationships with his doctor’s as improving over the years,

I’ve been brought up in it. I started when I was 15 years old. The doctor’s always put limitations on me. The surgeons always talked to my folks, not to me. The doctor in the other kidney center always talked down to me, but not these doctors, they talk to me like I know what I’m talking about. They’re letting me have my own diet as long as I keep my tests where they need to be so that I can do whatever I want.

Another decision that recipients make is one that determines the mode of dialysis treatment they choose to receive. “I explored the different methods of dialyzing and I thought this [hemodialysis] is the best way. I couldn’t be successful with the home methods because I’d skip treatments. I know that about myself.”

Some recipients seem to understand the impact of making decisions in their behalf and the consequences that result, “You always have it in the back of your mind that one major mess-up and you could be dead. I go on with my life and I don’t blame anyone for what might go wrong.” A decision that is known to all dialysis recipients is, “Whether to continue dialysis or stop it. The decision was made to continue because I have a 13 year old son I want to see grow up. We made the decision as a family.”
Another recipient said, “I don’t think that I could make the decision to quit it [stop dialysis treatment] because I love the world so much and everything in it. Just so it could be so that it doesn’t feel bad, although I don’t know what you would do to make it better. Sometimes I feel better after dialysis than before.” In a way, knowing that dialysis treatment can be stopped at the recipient’s request is a huge decision that the recipients I spoke with had thought about but, “I can’t take that step. Something else is going to have to get me.”

One recipient said the decision to go on dialysis was difficult because he didn’t want to believe that he had kidney failure.

I guess it would be making a decision that I was sick. I didn’t believe that I was sick until I was put into the hospital. More or less the doctors would make decisions, but I made the decision to follow their advice or not. It’s like getting a prescription filled and taking it; you don’t have to—it’s your choice.

What Interferes with the Quality of Dialysis Treatment

Other health problems were frequently cited as being a greater concern to many of the recipients than was dialysis treatment. Diabetes, heart disease, and cancer were often cited as being health problems that interfered with dialysis treatment. There are other problems, “I think the biggest is probably the arthritis and back problems, and then I had a stroke. I’m very weak on my left side. Getting around is difficult.” Recipients reported a number of problems with their health that they acknowledged may or may not be directly related to dialysis treatment, but nonetheless make their life a little more uncomfortable. “I used to have a lot of cramps in my legs, but not anymore. I started
taking quinine, and that helped. Now I’m having problems with my blood pressure.”

“Itching and vomiting but basically, I have pretty good runs.” “I had a heart attack then I had my gallbladder out 6 months later. They told me I had a heart attack before, but I thought it was trouble with by lungs. I thought I’d be the last one to have a heart attack.”

Naturally, recipients brought up the problems of their diet and fluid restrictions, taking medications, having to be on time for dialysis treatment, the long time it took to receive dialysis treatment each session, and the frequency of the treatments interfering with work, family, and recreation. When asked if they could change anything about their treatment, one of those topics would readily emerge such as, “Shorten my run time,” “What’s the use? I can’t travel,” “Just let us have dialysis once a week, and “let me have oranges and bananas.”

**Objective 5**

How do hemodialysis recipients experience changes in their behavior, attitude, and perspective on life resulting from empowerment as they develop an awareness of the experience of other hemodialysis recipients in the kidney center community?

Dialysis recipients note experiencing the most difficulty in their adjustment to dialysis treatment when they initiated dialysis treatment. Over time, they report that they perceive the changes as not significantly changing their view of themselves or others.
This is not to say that there are no important changes that recipients experience. From an empowerment standpoint, it is notable that recipients did not report believing that there were changes that they were not allowed to make if they so desired.

Changes in Life

Hemodialysis recipients seem to feel that although they have had to make a number of changes in their life to accommodate dialysis treatment, they are essentially the same person as before they started treatment. "I’ve still got the same thoughts, the same things that I do. It takes up time, but what the heck?" “I really haven’t changed on my attitude. The reports I’ve seen from the doctors say that I’m a pleasant lady to be around—and I don’t think I’ll change.” Mostly, participants of my study spoke of their general sense of physical discomfort associated with dialysis treatment.

A lot of changes like leaving work, for instance. It took me a long time to get used to changes. It slows me down. I used to work a lot faster than I’ve been able to. I would get tired from just pounding nails. The worst thing is that I’d lose my confidence. I used to be afraid of going up the stairs, now I can run up them.

One of the changes this participant made was to initiate a supervised exercise program, thus diminishing some of the physical problems he had experienced at first with treatment.

Some recipients have relocated to the community in which dialysis treatment is offered, or have changed their residences, "I moved into a smaller house so that I can do my chores and rest. I don’t feel as exhausted as I used to.” Participants almost
unanimously stated that they don’t have the energy that they used to have prior to having kidney failure. One recipient summed the changes that she experienced this way:

We used to travel all the time. When we got tired of living someplace, we would just pack up and go somewhere else. You can’t travel like we used to. I feel more irritable with other people, because people don’t understand why I can’t just come and visit them. I’m active, but there are days when I just want to stay home. My eating habits have changed, my smoking habit, and my home life has changed. Basically, I can’t work anymore—I had to quit working because I would feel too tired after dialysis treatment.

A loss of spontaneity in life was a common theme,

Not being able to just leave town. Trips need to be planned ahead. Just having to be here on a regular basis; I just can’t up and decide when I’ll have dialysis. Drinking less water—I thought it would be harder, but it isn’t. The dietary restrictions are a little harder than the fluid restrictions. I think that if you can control the sodium you can prevent a lot of trouble from happening.

I found it remarkable how many times not being able to travel emerged as an issue with being a recipient of dialysis treatment.

I haven’t been able to travel very much. My older son and his wife moved. They insist that I come and visit them for Christmas, but I’m so fearful about flying with the crowds. And I’m worried about the expense of flying, too. Anything could go wrong, then what would I do? My son worries about it. If everything goes well I’ll go in the Spring.

And, “You can’t do the things you really want to. You can take trips, but there are drawbacks. If you take a trip, you have to try to get into the unit. Like Steve who has a cabin up at Kalispell. He has to get up a 5 am to get to the unit.”
Recipients are mindful of the changes that their spouses and family members have to make also,

My house doesn’t get clean like it should because I can’t see. I do the laundry. Now Bill helps me around the house a lot more than he used to. Bill helps me make the bed, he does the cooking, and sometimes he helps with the laundry, but he’s not much help. He drives because I can’t. But what am I supposed to do? My husband cares, but he’s not able to show it very well. Bill has helped me with not drinking so much fluid. I don’t know how to tell how much weight that you have on when you come into dialysis—I’m just not good with mathematics.

Another recipient felt his spouse was more helpful, “You’ve got to take what comes up. You can go out to eat, the movies—you can get around. Your lifestyle does change though—you can’t take long trips, you have to go local. My wife and her friends from the town we used to live in stay with me. I’m lucky to have a wife who has stayed with me through all of this.”

Being a dialysis recipient is stressful to both the recipient and the spouse.

I’ve thought about not going to dialysis—just quit. But one of the waitresses at the cafe we go to tells me not to give up. But it’s hard. There are so many problems with my graft that it gets me discouraged [she begins to cry]. The last time it clotted my husband and I started arguing. We never argued before about anything. We even argue about the dog now. I can’t do anything anymore, and it’s hard to get my husband to do anything. It’s things like that that makes me upset. He doesn’t like to talk about it, death and the like. Maybe I ought to just stop and die.

But another recipient felt differently about continuing with dialysis treatment. “When life doesn’t have any meaning for you, you should go. I’m already dead anyway, I mean;
I’ve been able to postpone death because of dialysis. Without it I would have been dead. I have no moral issues about stopping.”

Related to the physical problems associated with dialysis treatment is the change in diet. “I used to do an awful lot of cooking. Since I’ve been on dialysis, I don’t seem to have the strength that I used to. I still do a lot of cooking, but not as much as I used to. Of course, when you’re on dialysis you have to change your whole diet. I’ve lost a lot of weight—from 150 to 108 pounds. I can’t seem to get the food seasoned to make it taste good.” One recipient reported that her husband lost a great deal of weight trying to live off her dialysis diet.

One recipient acknowledged feeling as if he was restricted from some activities like hunting and horseback riding because he used to go out for a week or so at a time. He quipped that he probably could engage in these activities in a limited manner but, “The good Lord blessed me in the wrong way, he made me lazy.” Despite saying that they did not make significant changes in their life because of dialysis treatment, I nevertheless found that some recipients noted differences in how they perceived their life as a dialysis recipient. “I guess I feel a little happier to be alive. Little things don’t bother me too much.” And, “It makes you more appreciative of what’s going on around you. I’ve always been patient, but now I’m probably more patient.” “I don’t know about other people, but I’ve turned to God and I encourage other people when I see them.” “I eat better than I used to.” “If there is something that needs to change with me, I accept it—I go with it. My life is in the hands of my doctors, and I completely trust them.” “I
don’t work anymore. In a way you wish you could do more things. I’d go back to work. I just take it easy. I’ve gotten lazy.” And finally, “I was scared to start with, but I knew I had to go on dialysis—I couldn’t breath. I made up my own mind about going on dialysis. I knew that I couldn’t go on the way I was. I was always well protected by my husband and brothers, and they would make decisions for me. But I decided about going on dialysis myself. It was scary, but I’ve adjusted well.”

Key Informant

The information that I was able to obtain from my Key Informant in this study corroborates with the data collected from the other 19 recipients I interviewed. The edited transcript of the interview with her is presented here because it portrays much of what I learned from the other interviews. It differs from the others because this recipient was able to describe a process of development that she undertook to arrive at her perspectives on having dialysis treatment at the kidney center.

My doctor acted like he had all the time in the world to listen to me. He was also concerned with my whole family, not just with me. I was the kind of person who asked 9 million questions, and he answered every one of them. I read books about dialysis, and my doctor always encouraged me to get information. I asked the social worker if I could see the dialysis unit. He was floored, he never had anyone ask before then. My dad said it was too windy to go see it (he didn’t want to deal with it), and my mother almost passed-out in the nurse’s arms.

I have always made my own decisions about my health. To go off the machine is my choice, and my children have always known it. I told them I wouldn't until there was no quality in my life. It's hard to make some of the decisions about your health, but once you do you feel better about it, and I have made lots. I have refused to take
medications after finding out about the side-effects, like morphine; I'd rather deal with the pain. I always make educated decisions. I'm not obstinate just because I don't want to do something, or that it just doesn't work into my schedule. I can sound like a broken record, "What are the side-affects?" They know me at the drug store like their best friend. I ask the pharmacist about side-effects. I always seek out the information.

I talked to patients, and I talked to nurses. I bought cookbooks that were salt-free. I always enjoyed reading them, but I wanted to find information. I used to have a problem with potassium, but I think the dialyzers today are better and have largely solved that problem. I look at the blood work, and feel that the more I know the better I can juggle my diet. I still ask questions--I'm always learning. You learn so much as you go that I will never stop asking questions and learning. What have I taught others? I have always spoken to patients before they started because I've never forgotten that fear of when you first started. Now that we have the seminars, people don't seem to have that fear, they get to relate to each other before they start treatment. When I went on, I talked to an elderly lady. Her son took care of everything for her. I talked to another older lady who said, "You're so lucky to be young and going through this." I thought to myself, you have already lived your life. I talked to another woman who was my age and had two children. I got a more accurate picture of what it would be like for me to be on dialysis. I feel privileged to be a part of the seminars. I couldn't relate to these older women. I am sitting there with a three year old and a six year old. I didn't know if I would be alive a year from now. I didn't know if I could take care of my children, and be a good wife too. Dialysis is my lifeline. You have some bad days, but mostly good ones. I think the seminar is one of the most important things that have come in the 19 years I've been on dialysis. Education is very important.

I can't say that there's really anything that I would change about my dialysis treatment. I am constantly very conscious of doing things that won't clot my graft. For example, I think that I clotted my graft last week from cleaning my garage and lifting planters. I have always been very clean, and have not worn elastic around my access.
You become more aware of things that can go wrong, and try to do what is right so they won't go wrong. I don't take my health and life for granted.

I thank God for every day I have. I think that I appreciate people more. I was probably more materialistic before I started dialysis. I still like nice things, but what's really important here? Being with your family, and enjoying each other. Through the years of having dialysis I changed the way I think and feel. I have always had compassion for others, because I was raised with a brother who had polio. He taught me to love others despite the adversity in one's life. When I went on dialysis I wanted to be a supermom, and I struggled to keep everything perfect. It's my personality—I'm a bit compulsive still. Dialysis has changed the way that I feel in that I don't have the energy that I used to have. It's been so long ago that I wasn't on dialysis that I consider the way I am now as what is healthy for me. I obviously have times that I feel better than other times. I always felt like I pushed myself along, but I think that you become more aware of your shortcomings. I used to get so frustrated about obstacles in my life, but now I go with flow; I think that I behave better as a result. I used to get crabby, but now I am better at letting go.

I have gone through a lot of changes. I possibly could have held my marriage together better if I could have let go of some of the little things instead of being this do all person; it may have made the situation better. I didn't drive because I was afraid of having a seizure with my kids in the car, but when I became divorced I had to drive. If I didn't have dialysis things may have been different. I think that I have grown a lot because of the experience. I used to be very independent, but then I slipped into some dependency on others. I was so proud of myself to get some of my independence back after my divorce. I have always been a Christian, but I think that my faith has become much stronger since starting dialysis. Sometimes that's all you can turn to. I think that most of the patients go through a period of frustration because so much changes in their lives. You have to accept dialysis daily as a way of life. I don't have enough energy, my diet is so restrictive, and I don't think that I laugh as easily as I used to since I have been on dialysis. I do think of myself as a happy
person, but I'm not as spontaneous as I used to be. My mother has said that since I quit working I'm happier.

It's very easy to become self-absorbed with stress of everything else. Working, raising teenagers--it was easier to deal with the stress of dialysis in comparison. I guess I would have to say that since I became a dialysis patient that I've had to work at being happy. I am a much happier person now, since starting dialysis than at other periods in my life. Not just true of dialysis itself, but everything else in my life has taken more work since I've been on dialysis. I like to think that maybe I'm a better person since dialysis, because I feel that I'm a stronger person. You have to work at being happy, because there are so many negatives out there. Life is an attitude, and attitude is a choice. With dialysis patients, it is their attitude that makes them go on or give up. Some people don't have the strength of others because their personality can be so different. Like I told the new patients at the last seminar, we want to say, "Why me?" and not, "Thank God there is a machine." My brother died of uremic poisoning because there wasn't the machine. I think that attitude really does affect your health. I didn't think that I would have been here 19 years later from the time I started, but God knows I'm not a martyr--I've had my times over the years.

At first it seems that there are many obstacles to living with dialysis, but you go with it day by day. One of the big changes is diet. I like to cook, so I read a lot of cookbooks. I learned to read labels, and I've noticed that everything that is fat-free they take out the fat and put in the sodium. The obstacles and changes were more difficult when I started as compared to now. Now there are a lot of salt-free products since I started dialysis treatment.

As far as who has helped me to cope with dialysis, I would say that it was the doctors, nurses, or anyone who could help me. It was a smaller unit back then and you got to know people and share more with each other. Now the unit is so big that you don't have the opportunity to talk. No one can fully understand what it is like better than another patient. Dialysis is a very isolating experience. For instance, I've been thirsty for 19 years. No one but a dialysis patient could fully appreciate being thirsty like that. We even got to know the staff well because the
dialysis unit was smaller. The nurses used to teach us crafts while we were having dialysis treatment. I learned cake decorating. Mary and I were close. It was real hard when she died. She was someone I could share my experiences with. When Edith died it was very hard for me too—it's always hard. There are many obstacles to coping with dialysis, but you just get through them as they come. It can feel like a rigid life, but I try not to make it be that way. I can't have this, I can't have that. There are obstacles in your personal and family life, also. I just can't take a week off and go when the kids are off—it limits you. And clotted grafts are an on-going problem too. You have to take problems day by day and try to grow with them and don't let them become a burden. Dialysis is such a big part of your life, and it's hard not to let it become your life. I have limitations, but I'm not sick. Sometimes I feel sick like when I broke my pelvic bone, But I've tried not to think of myself as being sick. I do think other dialysis patients think of themselves as being sick.

I was raised with religion, and I know that I have to let my worries go. I think that my faith has helped me a lot. I started going to church when my brothers died. When something tragic happens in your life, you need that. The patients who do the best have a faith. I don't feel like, “Why me?” I feel like, “Thank God the machine is here.” I get up each day and I'm thankful I have another day. I never expected to live very long with kidney failure. When people used to talk about the future, I would block it off. Ten years seemed to be the longest people lived. How would I be different from them? Maybe I'm here so that my mother doesn't have to bury another child. My mother is the end of my original family. She's my best friend. Dialysis is very lonely. Especially if you are in a “poor me” attitude. I can see where it causes difficulty with spouses. All the learning is stressful. I don't think men do as well on dialysis as the women. On the whole, men have been the least accepting of it, and they've had to stop working. They become totally dependent on their wives. Some of that is just characteristic of their generation. I didn't want dialysis to be all consuming, but it is at first. Perhaps others lose their desire to want to try—it's just easier to give up. I feel that I have a good quality of life.
I've taken actions such as being educated about dialysis, to take responsibility for my health and diet, and I never miss my medications. It isn't though I don't ever cheat on my diet, everyone does. I cheat in a way that I know from experience will be safe for me. I keep an eye on my blood work, I scrub my arm, and take care of my graft. With other patients I educate them. When I sit next to other people I take the opportunity to talk to them. I've made friendships because I always try to speak to others. Some speak back and some don't. I've always tried to be helpful to other people.

Some patients are very friendly and kind of make an effort. Some are more quiet and laid back. I guess the ones I feel that try to get to know you are the ones who you happen to be sitting next to, and they are friendly and strike up a conversation with you. When you come in you've got things to do to get ready so there isn't a lot of time to sit around and chit-chat. By the same token when you're done you get ready to leave and get out of here. But when you hang around you get to know other patients like David. David called me at my home the other day and brought me some vegetables. I got to know him and his wife just by making a little effort to do so after treatment. This isn't just like any other social setting. Sometimes it “clicks” between you and someone else and sometimes it doesn't. But most people you don't end up getting to know because you don't sit next to them or they come at a different time than you do.

Sometimes I feel that we had a better support system at the dialysis unit in the past. They used to have support groups, but I never went to them. I felt that I got what I needed at the dialysis unit when I had my treatment and didn't need to come in at other times for more. Not that I would be opposed to offering my help or coming in myself if I needed it, but the support group isn't what I felt like I needed at that time. Maybe because I had been on so long could be a factor in my decision not to attend. There probably was a time when I would have gone religiously; perhaps when I needed to experience the hope of friend. I'm sure if they would have had something like that when I started I would have made more friends than I have now. But many other patients didn't have small children or were
dealing with some of the things I had to deal with that were relevant to my life. I'm sure I would have taken part in the support groups if they were relevant to me, and that probably would have been a great help to me. So I'm not saying that it's a negative at all, I think it is like I said before that dialysis is kind of a lonely thing for me and for some people, it's even more so because they find they can't talk to their friends about it apart from the dialysis unit. My friends would pick me up from dialysis and they could tell when I walked out of the dialysis unit if I had a bad time with treatment that day. My mouth would get too dry to talk and my blood pressure would drop—it could be any number of things.

There are times in your life when you have more of a need for something like a support group than at other times. I think the support group probably was good for people to help them deal with their denial. You know, you just don't absorb fluid from the atmosphere. From the thank you that I received in the mail from one of the patients who attended the seminar, she said that because of my experience with dialysis she came to believe that her life could go on. I know that when I started dialysis I was concerned with how long I was going to live. My goal at that time was to see my kids graduate from high school, and to see that they were raised well, but I never really expected to live that long. There was a time that I wouldn't allow myself to think about dying, and hoped that I would still be here the next year.

I tell the new people about the history of the unit. I think it's very important for them to know the history so that they realize the improvements that have been made. I believe that we are going to see even more improvements in the upcoming years, and God the things I've seen. When I started dialysis, people who would go for a kidney transplant would get so much anti-rejection drugs (cortisone type of stuff), that their immune system was knocked out of order. They would come home appearing huge because of the medication's side effects, and their immune systems would be shot and they would die. That was the sort of thing that happened to people and it would prevent others from wanting a transplant. You don't see that sort of thing anymore, thank God. Dialysis is just a
hard thing to do, but I'm in the phone book and feel happy to help anyone discuss the decisions they need to make about treatment. Some have called on me, and I felt that I was able to tell them not only about my experience with dialysis and transplantation, but also about other people's experience. I relay information to new people, and in the worse case scenario I tell them to give treatment 6 months, what do you have to lose?

As for my lifestyle on dialysis, I may have become more regimented and I have to work at doing ordinary things a little harder than others. It hasn't been easier for me to be on the machine than anyone else. I've had to raise my children as a single mom after my divorce, I've had financial worries, and I've had a number of complex medical problems since I've started dialysis treatment. Some patients don't do so well here as others, and I think that it is regardless of whether they have family or not, they continue to feel very much alone.

I think that it is important to continue to do things and have fun. The Christmas party is one of the enjoyable events of the year. It is a good opportunity to see patients and staff socially. I even take my mother to the party. Some of the patients just sit with their family and expect that everyone else will come around to them to be introduced. If you don't get up and introduce yourself to anybody, what's the use of going? I think that the parties that we used to have were more relaxed because they weren't held at the hospital; that's why I always suggest that we have our parties elsewhere. Some of the patients feel very lonely because not all of them have a church or other things that they belong to. Some people, like Edith, consider dialysis to be a way to socialize a little. She enjoyed coming in here and bobbing around watering the plants and so forth. The way the dialysis unit used to be set up allowed for more homey activities, but as for myself, I like the new unit where I can sit in my little corner by myself. I'm not suggesting that I want to be antisocial—I like people, but the privacy is a nice change.

I got to know Edith very well having sat next to her in the old unit. She worried about everything so I encouraged her to enjoy life a little. I told her that no one was watching her to see her do poorly, so not to worry
about what other people thought. I also told her that she didn’t have to worry about her diet so much because there are a lot of different foods she could eat and enjoy. I shared my recipes with her, and even introduced her to salt-free pickles. I think that she became grateful to me for helping her and needed to reciprocate. She began to buy or make me gifts for Christmas, my birthday, and other events. I felt uncomfortable about that, especially because I knew that she didn’t have the money to be giving me things. It also put me in an uncomfortable spot because I felt that I needed to give her things in return. Another thing that was a little uncomfortable about the gift giving is that we had such different tastes. I wanted to be nice, because the thought of giving things to me was nice, but I didn’t have any practical use for the gifts. Another situation I fell into was with my dear friend Mary. Mary and I had become such good friends while we were on dialysis that we used to do things outside of the dialysis unit. Mary was blind, and her husband wasn’t very considerate of me. He would invite himself to our family meals for instance, without consideration for our need for some privacy. I got to the point where I felt a little used and unappreciated. Now I don’t do anything socially with any of the patients. I consider Sue a friend, but not a friend to do something with. I’m not opposed to making friends with other patients, but I like to spend time with the other friends I have.

I typically get along with the other patient at the dialysis unit. I had one situation recently where one of the men would throw his locker door in my face every time I bent down to get into my locker. I would be putting things away in my locker, and it seemed like he would come out of nowhere just to use his locker the same time as I. I said, “Excuse me, but do you have to hit me with your locker every time I come in?” He played dumb, so I told him that I thought he was a very rude man and that he could wait until I was finished using my locker. Sometimes he gives me dirty looks, but overall he has been pleasant towards me since I told him off. Maybe he’s afraid the old bat will lay into him again.

My on-going problem with the kidney center is that there never seems to be enough help in the summer time
when people want to take a vacation. I think that it’s important that the staff take a vacation, but each summer those who don’t vacation look overworked. You would think that they would be able to anticipate this problem, but it occurs every summer that I’ve been here. I have addressed this problem with the manager. I told her that people should not have to be so exhausted from working here. I think all the staff is wonderful, but they simply can’t work 12 hour days and feel refreshed. I think the manager cares, but she is unable to solve the problem. I think that we’ve lost some good staff as a result of this problem. They go elsewhere to places that don’t put so much pressure on them to perform. I can’t say specifically that anything bad has happened to me as a result of this problem, but I can’t help feel that it affects patient care. I don’t think the staff would make a mistake that would be injurious to me; the only time I kind of feel that way is sometimes when you get a nurse who is new. Years ago I refused to have a couple of nurses get near me. Maybe it was because of the terrible needle sticks they would inflict on me and I would infiltrate every time. They just didn't have the competency level yet, and I would turn away other nurses who I felt didn’t have the skill to work with me. I figure it is my body, my graft, and you're not going to mess with me if you aren’t capable of helping me. It is a big hassle to have trouble with your graft. Overall I think the staff here is outstanding, and I have always felt this way. The new nurses are slower and make me nervous, but you have to expect that—it's my hang up, not theirs. Everyone has always been friendly and caring and I feel they take an interest in me.

I can’t imagine how I would change things around the kidney center. I feel that anything the staff prevents you from doing is for your own well being. Oh yeah, I think not coming in on time is totally irresponsible of patients, and it is totally irresponsible if the patients get angry at the staff when their times would change. That’s hard to deal with, I mean, I wouldn’t like it if my time was changed either. You get your schedule setup and you get used to a routine that in my case, I’ve been doing for 19 years. If I had to suddenly come in the middle of the afternoon, I wouldn’t be a very happy camper. I probably would let the
staff know and pretty directly, but not angrily. I think that my seniority should pull some weight here, but I can't think of anything I would like to do that the staff wouldn't let me do or has told me I can't do. I felt it was more efficient when we would wash our arm in the sink and then put alcohol on it, but now I can see why the nurses won't let patients continue doing it. Edith was a perfect example. She would clean her arm and then she was all over the unit watering plants and the like. By the time Edith sat down in her chair her arm was not sterile.

Some of the new people can feel very intimidated and not be willing to speak up. I think I drove the staff nuts when I started on the machine because I asked 40 million questions, "What is this?" "Why are you doing this?" "What happens if this or that happens?" The staff was so good about it, but I'm sure there were times they just wanted to say, "Oh give it up!" But I learned by feeling free to ask questions, so that's why I encourage the others to speak up also. I think that speaking up is a generational thing too. I notice it is the older patients who are afraid to ask questions. My mother is the same way. They put doctors up on a pedestal so they don't ask questions. I have to tell my mother that she is paying the doctor to work for her. For example, she went in for a physical and when she got home she called me and said that something was wrong with the doctor. I ask her what he did, and she said that he had done nothing. She said that he didn't give her the physical exam she expected to get. I asked her why she didn't say to him, "Do you want to reschedule this at your expense or do you want to do the physical now." After all, she is the one who is paying the bill. She said that she didn't know why she didn't say something like that, and said that she's not an assertive person. Here on dialysis I see the nurses informing the older patients about dialysis, but they just don't ask questions; they wait to be told what they think they need to hear.

The nurses here are great and they do their job quickly. I have dialyzed in other units and their nurses are not looking at how they can please you. You see how austere and clinical it is at other units, instead of being friendly and having the staff be willing to visit with you. The doctors and the nurses know their jobs, and they know
me well too. I've had some weird things happen in dialysis, and I'll never forget that time that I was out of it for about 12 hours. I had come off the machine and one of the nurses asked me how I was doing. Even though I told her I was fine, she could tell I wasn't doing well. I couldn't even tell her my name. I ended up in ICU that day. The others can tell how I am doing also, and I find it very reassuring to be among people who know me so well. That is why I feel badly when any of the staff leaves to get a job elsewhere.

Threats to Empowerment

Data acquired from the follow-up questions comprise this section of the study. The intent of this section is to bring the obstacles to empowerment found in the theoretical body of literature to the kidney center to ascertain the influence of these threats to recipient’s of dialysis treatment.

Threat 1

How does the dominant medical culture bestow power to individuals receiving hemodialysis treatment as charity?

I did not find that recipients were coerced or otherwise compelled to accept the values or attitudes of the medical profession. Further, I did not find that recipients viewed the medical professionals who cared for them as having too much power over them. Recipients did not perceive that medical professionals could prevent them from participating in their own treatment or their efforts to affect change at the kidney center.
Improving Relationships with other Recipients and Staff

I asked what recipients would like their relationships to be like with both other recipients and staff members. With staff, recipients said that they would like to have more time to get to know them better. "Like any establishment that pays their employees, they expect eight hours of work out of the staff. Everything is timed to the minute."

Another recipient said, "I like the personal interaction with staff. I miss some of them who have left, especially the ones with a sense of humor." The barriers cited for getting to know staff better was noted to be, "When the staff isn't running short and when they aren't working under stress."

A recipient wanted other recipients to be a little more friendly, but said that it was she who had trouble making friends, "I'm just not a very assertive person—that's what makes it difficult for other's to get acquainted with me." Another recipient said that she too would like,

Everyone here to be more friendly. The people who have been here longer are friendlier than the new ones. I think that the new ones are traumatized by the experience of dialysis at first. That's that value of having a group to support the new ones; it gets them to open up and ask questions. We learned that we weren't the only ones on this and that if you watched things like your diet you could live a long time.

One recipient noted that she too wanted to not feel alone in her experience with treatment, "It's nice to know that you're not the only one who has problems." However, she went on to say that relationships between recipients can get too intense to be comfortable. "If
they begin to tell you too many of their problems you feel that you can’t handle it. You know that they need an ear to listen to them, but their problems can seem overwhelming.”

**Awareness of the Rules of the Kidney Center**

I asked recipients if there were rules that governed their behavior at the kidney center, who make them, and if they thought the rules were fair. Recipients identified the, “Management and the staff,” as being the rule makers. However, one recipient noted that OSHA probably had something to do with the rules, and another said that there was a, “Patient Board that adds input.” The only rule that came to mind with most of the recipients was,

The one that you have to wash your hands after treatment. I thought that was a crazy rule until I asked my nurse why we had it. She told me that we could be carrying germs to everyone outside of the kidney center. It made sense to me when I understood it could place other people at risk.

Another recipient acknowledged that the rule about hand washing existed and that she obeyed it without understanding why, “I do it anyway to make everyone happy.” A recipient said, “What rules? That you have to wash your hands and arm? I’ve always done that anyway. You do it for everyone’s safety.”

One recipient said that,

I heard a nurse tell a women in here that she couldn’t bring her children into the unit while she was dialyzing. The kids were little and were crawling on the floor and were hanging on things--they were unruly. I don’t know if there is a rule about this, but it seems that if there was the nurse took care of the situation fairly.
A recipient said of rules in general, “What’s the use of trying to change rules anyway. There’s no use in trying to cause confusion. They had good reason for making the rules that they did. If I knew other people who had the same problem with a rule that I did maybe I would do something about it.” Finally, one recipient said, “No, I don’t even think about the rules. I don’t feel oppressed by them or by the staff in any way.”

**Threat 2**

How do hemodialysis recipients become accustomed to the stability and comfort of the kidney center so that they become oppressed?

Much of the stability and comfort experienced by the hemodialysis recipients was expressed in the relationships they had with one another as well as the community outside of the kidney center. There was no expression of recipient’s feeling that they were being oppressed at the kidney center.

**Recipients Perceptions of being Different than Others not Receiving Dialysis**

A recipient said that she felt, “Just as good a person as someone who isn’t on dialysis.” Others said that they felt fatigued, couldn’t do as much around the house as before, couldn’t travel easily, and had to plan activities more so than people who weren’t receiving dialysis treatment. One recipient said, “There are days when I’m feeling down in the dumps.” Another recipient said that,
From what I understand, a long time ago you could only have dialysis if you had a lot of money or were young. If my being on dialysis meant that someone else couldn't have it, then let me off. Especially if I was preventing a child from getting dialysis. I feel the same way about getting a transplant. I'm not doing so much in my life that I would prevent others from getting dialysis.

A recipient describes that some recipients,

Don't feel that they're a very valuable person to themselves, their families, or to society. We all go through that. I think, "What do I contribute to society?" I just stopped working, but I don't volunteer. I need a vacation from work right now--I'm so tired. It was different when I was raising my kids, because I was needed. These other patients feel that they're not worthwhile because so much is taken care of for them. I don't have anyone else to do things for me such as making my meals, cleaning my house, and mowing my lawn. I have chosen not to become dependent on other people. I do it myself, I allow it to happen. But I am proud and happy that I got my act together. I also think it comes with getting older. You become a more sensitive person--your feelings get hurt easily. Kids are grown and you always hope that they visit because they've moved away. My social life has become my 73 year old mother. I became friends with Maria, but that's the only patient I got that close to. Our relationship developed because we sat next to each other. But I'm not opposed to making friends with other patients. I participate in the seminars we have. I received a lovely thank you card from one of the new patients who heard me talk there--she even remembered the things that I had said. She said that it helped her quite a bit when she got started on dialysis. Participating in that program makes me feel useful.

What Recipients Learn from Each Other Vicariously

I asked recipients what they had learned from watching other recipients and overhearing their conversations in an effort to see if information gleaned in this way was helpful to them. "I heard Bob talk about his bursitis. I have bursitis also, and he was talking about going to the doctor. The doctor put a needle into his shoulder and rotated it."
He didn't know why and I did, but I couldn't talk to him from across the room.” Another recipient said that she was able to learn a valuable piece of information by, “Watching other people mostly. Some of them are coming and going like I am--in a wheelchair or a walker. They go very slowly, but I didn’t know why when I first got started. I do now; it’s because they are of afraid of loosing their balance when they come off the machine.”

A recipient felt that, “A lot of patients don’t take dialysis seriously enough. There are a lot who haven’t conformed to the diet. Like when the staff was looking for one guy and he’d snuck out to the local bar.” Another recipient said, “John was having problems this morning next to me. I was getting concerned about that. I don’t know if I should be as concerned as I am, but it really does bother me when something goes wrong. Especially when people die. I don’t really know if I should get involved with other patients because of that.”

“I’ve learned a lot from eavesdropping. In this new unit, you’re separated and you can’t see or hear other people easily. I’ve been on dialysis for so many years, and I know that there is a lot more still to be learned. I feel that I am free to ask direct questions. I’m even able to argue with staff at times, even the doctor.” A recipient said that he overhears some recipients treat staff poorly.

I think that the staff should be treated better by the patients. I've seen it a few times in here. The staff isn't getting rich taking care of these people. They should be more grateful and tell them that they appreciate them--I do. This is my
world in here, and I don't appreciate it when the staff are treated badly. You hear some patients talk bad to them—the language is very foul. I've talked to the patients who do this—I have a way of getting my point across to them. I think it has helped.

He went on to say, “I didn't know anything about the catheter and when I got the fistula, I needed to learn about it. I also learned about peritoneal dialysis from listening to other people. I talk to other people in the waiting room and I learn a lot. I've gotten advice from other patients about the do's and don'ts of catheters.”

**Threat 3**

How do hemodialysis recipients accept the meaning, values, and beliefs of the dominant medical culture without reflection?

It appears that recipients are aware of their surroundings to the extent that they do not uncritically accept their environment as static. The symbols of the medical culture are not distracting nor do they seem destructive to recipients in their own construction of what is of meaning and value at the kidney center.

**Expectations made on Recipients by Staff**

I asked the question of recipients if the staff expected them to do more than they felt able. The responses were all, “No.” One recipient said, “No, they’re very good to me. If I feel that I can’t walk out, they get me a wheelchair.” Another recipient said that staff didn’t need to expect more of her because, “I push myself along. I’ve seen the
nurses helping to get older patients out of wheelchairs. They get so weak just sitting around.”

Confidentiality

Since a re-occurring theme expressed by recipients seemed to be that they missed not being closer to one another, I asked if they ever felt a loss of confidentiality when they had dialysis treatment closer to one another. “I haven’t been concerned about confidentiality because the doctor doesn’t have to tell me anything personal while I’m here,” said a recipient. Another recipient said,

I felt that at times there wasn’t much confidentiality, but when we were close together we were all friendly. Now there is no chance to visit. There isn’t a friendly and supportive feeling in the place like there was before it was remodeled. Even family members who came in with other patients asked us how we were feeling.

This was repeated by another recipient, “Not having confidentiality has never been a fear. In fact, we were quite close to each other and we cared about each other before we were remodeled. Now I’ve lost contact with them because of the counters between us. I understand why they’re there; they’re going to put computers on them and the nurses don’t need to run around getting things from the carts.” One other recipient said, “You don’t get to visit with your neighbors, but that’s the only thing I see. The barriers are convenient for the nurses because everything they need is right there, they don’t have to go running about like they used to do.” One recipient did envision where a lack of confidentiality could be a problem, “It would be awful if you had the flu or something and you couldn’t get away from the person next to you. You could also be in
a situation where you had to talk about your bowel problems and then everyone would know."

Steps Taken to Create Change

I asked recipients if they had taken any steps to creating change at the kidney center. "It seems all I have to do is talk to the secretary at the front desk or whoever is the charge nurse the time and that solves the problem. The staff always does something about it." And, "When they were remodeling dialysis you couldn’t see a clock. I told the nurse several times about it, and then they got a clock." Another recipient said of her experience with change that, "I insisted that for this new unit we had a smoking and a no smoking rack to put our coats on so that my coat wouldn’t wreak of cigarettes when I left after treatment. I also had them put up signs to designate the areas."

One recipient said that she tried to change the way another recipient was behaving while she was receiving her dialysis treatment:

I can only take so much belly-aching. I let Bonnie have it—I gave her both barrels. She felt that everyone was picking on her, but it was her own stupidity that caused her problems. She was always fluid over-loaded and didn’t take any responsibility about it. She would complain because she got cramps while she was on dialysis. I let her have it a few more times and it didn’t seem to help too much. I told her it was her own fault. She was a little different at the Christmas Party. One of the nurses told her that she should watch how much coffee she was drinking, and she seemed to take heed. Sometimes they just need to hear it from the other patients and not just the nursing staff for it to make sense to them.
How do hemodialysis recipients become dependent on the rewards that the dominant medical culture provides?

Becoming dependent on the rewards of the dominant medical culture requires the recipients to acknowledge that the only worthwhile rewards are given by the medical culture. If recipients had become dependent on the rewards given to them then they would certainly not challenge the system with the threat of change. I found that the recipients were not opposed to making changes at the kidney center.

Who is Threatened by Change

I thought it was important to know if any recipients were afraid to ask for a change if they thought that someone might be threatened by the proposal. I found that none of the recipients said that they felt afraid to propose a change in the way that the kidney center operated, or to correct the behavior of staff or other recipients. A couple of recipients offered explanations as to why it is difficult to change, such as, “People are pretty set in their ways.” Another said that, “The most sacred thing for every patient is the amount of time of their treatment and when the treatment is scheduled. If you wanted to change that then I could get angry.”
“I think that anything could be changed. The people around here are very good to be around. I’ve felt that the staff here always try to lift your spirits. They never keep you down. I’ve never felt pressure from any of them.”

Fieldnotes

Following each interview that I conducted with recipients I wrote my impressions of what I experienced during and directly after each interview. My thoughts, feelings, and observations about each interview went into each fieldnote. I felt that it was important to write information for which I was not directly asking recipients, but information that one naturally acquires during the interview process. For example, I found that recipients seemed eager to engage me and wanted to tell me about their experience with dialysis treatment. I was impressed at how recipients did not seem to hesitate to recognize themselves as being the experts on their own experience with treatment. They spoke with authority about their knowledge of themselves and their treatment. I too found that my fieldnotes became an opportunity for me to express my concerns about the productivity of the interviews, my style in asking questions and probing for more in-depth responses from the recipients, and how I felt that my relationship may be changing with the recipients in the process of interviewing them.

Thus, I faithfully recorded information recipients gave me as accurately as possible on my interview guide, then I used my fieldnotes to reflect on each interview as
well as make observations about how the study was progressing as a whole. I found that almost without exception recipients wanted to be interviewed. Since my relationship with each recipient was already rooted in trust, I found that I did not need to go into any extensive explanation as to why I wanted to gather information about their experience as a hemodialysis recipient. With the exception of one recipient who said that he would agree to be interviewed if I would let him return to sleeping as soon as possible, I was pleased by the response from recipients to wanting to participate in the study. Aside from recipients interrupting the interview to get a sip of water or a moment or two of being distracted by a noise or someone walking by, recipients seemed to be as engrossed in the interviews as was I.

Another plus with having prior knowledge of the recipients was not only that a trusting relationship with each recipient had already been established, but I felt more comfortable about getting into the interview questions right away without having to sacrifice any of the warmth and ease of our relationship with each other. As I reflected on the information I had gathered following each interview, I thought about how consistent was the information they gave me with what I had already known or what I had suspected of them. There were no surprises here; I felt that the recipients’ responded accurately and genuinely portrayed their thoughts and feelings in a manner I have always known them to be. What I did not know, of course, was their responses to specific questions regarding their sense of empowerment at the kidney center.
After I conducted the first few interviews I became concerned that I was not getting the data I sought from the recipients. This suspicion crept into my notes when I observed that recipients weren’t being as witty, informative, and insightful as I had hoped they would be. I wondered if the questions I was asking got at the heart of the issues for them, if I was probing deeply enough into their thoughts and feelings about their experience, and finally if I was not expecting too much from them and myself. On reflection, however, I discovered that I had determined a useful dynamic to my understanding of their experience as hemodialysis recipients. I establish that the recipients I interviewed viewed dialysis treatment as an ordinary experience. I began to suspect this when I heard from all of the recipients a contrast between their reactions to first needing dialysis treatment to the time that they had become settled into the routine of receiving dialysis treatment. I reasoned that the recipients were giving me the data that I sought--the perceptions of a routine, perhaps even mundane activity that they must perform three times a week for possibly the rest of their lives.

I noticed that patterns of communication between recipient and nurse had been established and were functioning smoothly each time the nurse made a routine stop at the machine for an adjustment or to take the recipient’s blood pressure. The recipient would ask, “What’s my blood pressure?” And if it was low, the nurse would ask, “Would you like a mannitol [a medication that raises the blood pressure]?” Patterns of communication with other recipients had been established and questions such as, “How was your run?” or “Staying warm today?” would be exchanged between recipients as they
were walking by the dialysis station while I was interviewing. It was these little interactions that caused me to consider the dialysis community not so much as a setting that relationships needed to be consciously negotiated each session a recipient attended, but more a setting that seemed quite ordinary and comfortable to recipients.

If recipients were not consciously grappling with issues such as how they could use each other as a resource to cope with a chronic disease, whether there are greater rewards in being friendly with the staff as opposed to other recipients and the like, then it was because the kidney center rapidly became a place where attitudes and behaviors were unconsciously formed in the process of adjusting to the routine world of the kidney center. I found that most recipients had not asked themselves these type of questions as such, but they had for the most part made some observations about what it meant for them to be a dialysis recipient at the kidney center. I think that my questions and interview techniques were equal to the task of learning about empowerment at a kidney center as seen by hemodialysis recipients.
SUMMARY, CONCLUSIONS, DISCUSSION AND RECOMMENDATIONS

Summary of the Study and its Findings

The data I collected from the hemodialysis recipients I interviewed was obtained to address the purpose of this study. Specifically, the purpose of the study was to delineate a process of empowerment that recipients undergo that acknowledges an awareness of the community of the kidney center; and to determine if recipients experience empowerment as described in the pertinent literature. As a result of interviewing recipients, I found that they seemed to experience a process of empowerment in the absence of an oppressive medical system. Although their reflections on themselves and their situation at the kidney center did not necessitate actions towards humanizing the medical profession (as it was unnecessary), recipients did alter their perceptions about the quality of life they experience as influenced by an awareness of other recipients at the kidney center. I will address the purpose of the study by answering the three Research Questions posed in the Purpose of the Study section.
Research Question 1

How does the theoretical basis for empowerment relate to community awareness with recipients of hemodialysis treatments?

The theoretical basis for empowerment emphasizes the need for persons to achieve an awareness of their needs and the needs of others to enjoy full participation in their community. The data collected in this study indicates that hemodialysis recipients engage in a natural process of empowerment without the constraints placed on them by a dominant medical culture. To be unempowered on a community basis would mean that hemodialysis recipients would be unable to have the opportunity to learn from other recipients, express dissent with the medical culture, envision change, as well as feel that they were oppressed by the medical culture.

Recipients did not indicate that the medical profession had been paternalistic to the extent that they were unable to embrace their social reality as hemodialysis recipients. They acknowledged the role of the medical professionals to establish the guidelines for recipients to receive dialysis treatment, but did not feel that the quality of their dialysis treatment would be jeopardized if they were to confront the medical professionals with their objections. A couple of the recipients I interviewed did state their value of wanting to get along and be liked by the medical professionals overrode their need to complain, however, even these recipients stated that they did not feel that the medical professionals
were a force that prevented them from complaining. Recipients indicated that groups of recipients sharing their experiences with one another was a method of learning that has been in place at the kidney center, and that those who participate in the experience benefited. This is particularly true of those who are able to give back what they learn to others. The kidney center has a structure that allows recipients to give of themselves to the new recipients so that they feel a greater sense of self-esteem. The self-esteem that they obtain from their experience through participation at the kidney center makes them feel as though they are also competent people outside of the kidney center. Almost half of the recipients interviewed take part in kidney center activities that are designed to orient new recipients to dialysis treatment. The remaining half spoke of sharing their experience with other recipients informally. Even though most recipients reported that they were disappointed with the responses they sometimes received for their efforts to be pleasant with other recipients, they were nonetheless hopeful of establishing friendlier relationships with other recipients and staff.

The learning that dialysis recipients are able to articulate is strengthened by the routine practice of implementing the information they have obtained from staff, other recipients, and what they have reasoned for themselves. I saw little practice of obeying instructions by rote. Recipients were eager to share whatever information that they had gained with other recipients; the purpose for which seemed to be to improve the quality of life of their membership. When the opportunity to give to others was present, recipients benefited by developing a deeper awareness of themselves and other members
of the kidney center community. The longer a recipient had received treatment the more willing they were to share in their experience with other recipients.

Longevity may be necessary for the process of establishing empowerment on a community level. As all the recipients noted, it took quite a while for them to feel that they could grapple with the many changes necessary to adjust to the dialysis regime before they felt confident to share their experiences from receiving dialysis treatment with others. Sharing of themselves through dialogue with other recipients required time to develop. There may also be a relationship between longevity and the ability to verbally communicate with other recipients. Since empowerment on a community level encourages communication with other recipients, it is possible that empowerment improves longevity. All but 4 recipients expressed the need to communicate with one another as being important for their adjustment to dialysis treatment.

The disorienting experience of beginning dialysis treatment causes recipients to question what they believed was true about their health, their future, and interpreting events that occur daily. There is a rationality through consensus experienced in areas such as the waiting room of the kidney center where recipients are able to test their perceptions with those of other recipient’s. The need to search for information involves self-appraisal at times when recipients experience strong emotions such as depressions, isolation, and denial. Without exception, the recipients I interviewed expressed an awareness of other recipients’ experience with a problem they were experiencing. Either by identifying with another recipient or by finding that they were an exception to what
another recipient was experiencing, all recipients were aware of others in the kidney center community. As a result of this awareness of others, some critical adjustments had been made by recipients to learn more useful skills, and recipients indicated that many of those skills are learned because they themselves have deemed them important.

Internalizing the experiences of other recipients to some extent was present in all the recipients interviewed. The kidney center is a place where recipients feel that they are respected and able to judge what is useful information for them to know without fear of being harshly treated if they do not conform to other’s evaluation of them.

Research Question 2

What factors contribute to hemodialysis recipient’s experience of empowerment or lack of empowerment?

All hemodialysis recipients shared some common characteristics that led them towards an experience with empowerment at the kidney center. They are able to recognize the suffering and the achievements of one another, they are able to engage in satisfying relationships with other recipients and staff members, they acknowledge a universality in their physical and emotional condition, and they feel that they are accomplished learners in regard to what is important for them to know as a dialysis recipient.

Other characteristics of recipients are their ability to define the extent to which they want to be affiliated with one another and staff members, they report taking
ownership for the decisions they make on their behalf, and they recognize the mortality of others. The recognition of other’s mortality is what prevents recipients from developing bonds beyond the level of acquaintances and casual friendships. As permanent as is their need for dialysis treatment, recipients experience their relationships with one another as temporal. This creates a friendly and even generative spirit among the recipients, but not one of deeply felt affiliations or dependency. Perhaps being friendly in the setting of a kidney center helps recipients to focus on a more constructive element of health, rather than attention to the morbid.

The recipients are interested in others for the purpose of learning by observation, and gathering bits of advice gleaned from brief conversations with other recipients. The physical structure of the kidney center, however, can be limiting to the development of friendly relationships with other recipients. It is clear from the data collected from this study that dialysis recipients would like to avoid a sense of aloneness. Physical barriers prevent recipients from seeing one another, speaking to one another, and enjoying a feeling that a group exists in the kidney center. The sense of aloneness that segregation into individual stations creates is commonly experienced by the dialysis recipients who participated in this study.
Research Question 3

Does the process of empowerment of hemodialysis treatment recipients lead to changes in the behavior of the treatment recipient’s within the kidney center community?

Recipients felt that they were not greatly different as a hemodialysis recipient than before they initiated dialysis treatment. They indicated that they were able to make changes if they felt them necessary, but sought to acclimate themselves to a comfortable routine quickly. On the surface, the level of interaction between recipients at the kidney center rarely seemed to go beyond making comments to one another to pass the time. Yet I summarize that most conversations people have with one another in any other situation might also appear to lack depth. The seemingly casual comments made about dialysis treatment to one another unites recipients with a vocabulary and an experience that served to set a standard for membership within the group. The informality of the waiting room conversations strengthen the affiliations that recipients have towards the group rather than the individual. There is some comfort taken in the universality of having to receive dialysis treatment with others, and the language of dialysis recipients reflects efforts made by recipients to change their orientation from being someone who is not experienced with dialysis treatment to one who is experienced with treatment. The change is too subtle for most recipients to acknowledge, but subtly is the route of empowerment on a community level in a kidney center.

Change was not recognized immediately by recipients because of the momentum achieved by quickly adapting their life to dialysis treatment. The changes they made at
the beginning of their treatment tended to be understated over time by the need to form a sense of group affiliation. It is clear from the data collected in this study however, that recipients felt unimpeded to make changes that would benefit them and others. Although the kidney center does present certain limitations to empowerment such as its compartmentalized physical structure, it nonetheless creates opportunities for recipients to challenge their naive understanding of the kidney center they first experience, to perceiving the possibilities and the limitations of their new world as a dialysis recipient.

Recipients experienced an evolution in their identity as a hemodialysis recipient in relation to what they observed, communicated, and overheard from other recipients’ conversations. The kidney center as a whole reflected the force of recipients becoming more invested in their identity as recipients of hemodialysis treatment through the casual conversations and the concern that developed between recipients. They were able to suggest change at the kidney center without experiencing a deleterious consequence for having proposed a change. It must be therefore concluded that the kidney center under study is not a place where hemodialysis recipients feel oppressed by a dominant medical culture. Additionally, the kidney center is a place where empowerment occurs because recipients are able to engage each other openly, share vital information about treatment with one another, and avoid morbidity among its members. All of these factors contribute to recipients feeling empowered to make changes at the kidney center.
Discussion

Social interaction is vital to the development of empowerment on a community level at the kidney center in which this study was conducted. This finding suggests that a kidney center must allow recipients the opportunity to develop relationships that encourages unhampered contact with each other. Although certain configurations at a kidney center may be more practical from the standpoint of convenience for medical staff to have supplies at hand, kidney center designers need to be cognizant of the impact that it has on recipients. Treatment recipients feel comforted by being able to see one another in an open treatment area so as to decrease their sense of isolation from one another. I suspect, however, that empowerment on a community level exists at the kidney center studied because of the need that recipients have to form relationships with others despite the obstacles placed before them.

Empowerment occurred at this kidney center because recipients were able to share their unique experience as a hemodialysis recipient with other recipients who did not feel oppressed by the medical profession. All of the recipients studied indicated that they had learned from one another in the waiting room or by what was observed and overheard in the treatment area of the kidney center. Recipients were able to form an identity as a hemodialysis recipient in relation to what they learned from other recipients. With the treatment outlined by the medical professionals, recipients develop their style of accepting the treatment guidelines based on what they had learned from other recipients.
and what made sense for them. Although the on-going relationships with medical professionals was reported as being important to recipients, they nonetheless indicated that their adjustment to dialysis treatment developed over time in relation to other’s experience with treatment. Further, recipients who had gained experience with dialysis treatment were eager to share what they knew with other recipients.

This finding has important ramifications for the success of recipient education programs. Medical professionals can encourage recipients to participate in formal efforts to introduce new recipients to dialysis treatment. Not only will these efforts serve to guide new recipients in the way of adjusting their lives to dialysis treatment, but it will also increase the self-worth of those recipients who have experience to share with new recipients. This could be a means to help all recipients develop a deeper awareness of themselves and others at the kidney center, create a dialogue between themselves, name their world with subjective meaning, and generate significant changes at the kidney center through their participation.

Compliance with the dialysis regimen is a process of learning, and recipients were forgiving of themselves for not adhering to it strictly. A couple of recipients indicated that the medical staff was somewhat patronizing in their attempt to encourage the recipients to better adhere to the treatment regimen, but the rest of the recipients interviewed indicated that the medical staff’s behavior was more like a partnership in which they felt accepted despite having problems following the regimen. The ability to make the decision to comply or not to comply with the regimen gave recipients the
control they desired over their own bodies. The recipients who were able to see themselves working in partnership with the medical professionals were more satisfied with the quality of their life and better able to share what they knew about dialysis treatment with other recipients.

Although hemodialysis recipients noted that theirs was a unique experience from persons who do not receive dialysis treatment, they portrayed no sense of being inferior to a person without kidney failure. The recipients did note many inconveniences entailed in receiving dialysis treatment such as keeping their treatment appointments and fatiguing easily, they nevertheless felt entitled to participate in society. This finding suggests that hemodialysis recipients are able to actively participate in society fully. Being a dialysis recipient does not necessarily engender a pathological dependence on the medical system, nor did the medical professionals who treated the recipients studied seem to keep recipients from participating in their own treatment. Hemodialysis recipients did not feel disenfranchised from society.

This study demonstrates that empowerment on a community level occurred because recipients needed an awareness of each other to adjust to the rigors of dialysis treatment. The recipients confronted the crisis of needing dialysis treatment, sought one another with a desire to affiliate and express common concerns, communicated to decrease a sense of isolation from other recipients, felt generative towards each other, and achieved their dialysis treatment goals within the structure of the kidney center. This study indicates that empowerment occurred in the absence of oppression.
The literature search used in this study indicated that oppression under the form of paternalism could be a factor that prevents empowerment from developing. Paternalism could be a force that does not allow empowerment to fully reach its potential to change the lives of those who belong to a community of dialysis recipients. This study, however, did not find that paternalism prevented empowerment at a community level. It is possible that other medical settings where long-term relationships develop between medical professionals and the recipients of their care that paternalism is observed. Cancer treatment might be an area where recipients of medical care are unable to recognize other recipients as being important to their adjustment to their illness. Further, it may be an area where medical professionals have not recognized their tendency towards paternalism where there is no strong sense of community affiliation between recipients of care and staff.

Recommendations

The following areas of interest for further study have emerged as a result of conducting this study.

1. The results of this study make it is unclear if empowerment is a process that could be expected to develop in other medical settings. It would be useful to study other areas where recipients of treatment other than hemodialysis experience empowerment or a lack of empowerment in their setting. The kidney center may be a unique medical
setting where recipients come together often for a similar treatment. In areas such as oncology, treatment may be varied and recipient contact with one another may be more limited thus preventing a sense of a community with other recipients.

2. Longitudinal studies need to be initiated on recipients as they enter hemodialysis treatment so as to determine the affect of empowerment over time. It is important to ascertain if empowerment is a process that occurs similarly in each recipient's experience at a kidney center. Understanding the role that critical reflection has on empowerment could also be better studied in another qualitative research study. It would be important to know if recipients bring with them certain characteristics favorable to empowerment, and to determine how much change in their perceptions that has occurred as a result of the process of empowerment they experience.

3. Qualitative research into the unique perspectives that medical staff members have in empowerment needs to be conducted. Attitudes and beliefs that engender medical professionals to create an atmosphere where recipients can develop a sense of empowerment on a community level should be a focus of further research.

4. Further study should be conducted in the area of empowerment where medical treatment is more controversial than is providing hemodialysis treatment. Other factors that can play a role in recipients' of medical treatment experience with unempowerment needs to be examined. Such forces as economic, social and political realities may cause groups of treatment recipients to succumb to these factors and not have the opportunity to develop community empowerment.
5. Medical professionals who work with hemodialysis recipients need to develop opportunities for recipients to share their experience with one another. Medical professionals too have the opportunity to learn about the unique world in which dialysis recipients construct by participating with them in this endeavor. Participation in joint efforts to unite kidney center staff with hemodialysis recipients could be an excellent starting place to develop an empowered community. Working together on a council that addresses concerns shared by members of the kidney center community and developing a newsletter that involves the efforts of recipients and staff can establish the opportunities to develop empowerment. Staff members can also create a special role for recipients who have experience with treatment to share their knowledge with new recipients.

6. Kidney centers need to be designed so as to allow recipients the chance to interact with one another in the treatment area. Efforts need to be made to construct areas in which recipients are able to join with one another to decrease their sense of isolation from one another.
REFERENCES


The Life Options Rehabilitation Advisory Council (1994). *Renal Rehabilitation: Bridging the Barriers*. Medical Education Institute, Inc.


APPENDICES
APPENDIX A

INITIAL INTERVIEW GUIDE USED TO QUERY 20 RECIPIENTS
I. Demographic Information.

1. Gender: Male Female

2. Age: _____________

3. Years and months on dialysis: ____________

4. Marital Status: Never Married Married Remarried Divorced

5. Race: White Native American Afro-American

Hispanic American Asian American

6. Highest grade completed: ____________

7. Employment status: Full-time Part-time Unemployed Disabled

Retired Homemaker Self-Employed

8. Occupation: Doesn’t Apply Labor Skilled Labor

Clerical/Office Managerial Professional Homemaker

9. Living Arrangements: Own property living in Renting

Long-term care facility Temporary/Transitional housing

Subsidized housing

10. How many live in household: ____________

11. Estimated household income: ____________

12. How is hemodialysis treatment paid: Self-Pay Insurance Medicaid

Medicare Medicaid\Medicare Insurance\Medicare Self-Pay\Insurance

Other
QUESTIONNAIRE

Code:

1. Give me an example of a problem that you had regarding your health. (Who did you talk to about it? How satisfied were you with their response?)

2. Tell me a time when you had to make an important decision regarding your health care. (Who made the decisions?)

3. What have you done to learn more about dialysis treatment? (What have you taught others?)

4. How would you change your hemodialysis treatment if you could? (What keeps you from changing? Give an example of how you have made changes in your dialysis treatment.)

5. In what way are you different since you have been a hemodialysis recipient? (How has dialysis changed the way you think, feel, and behave?)

6. Name the changes that you have made to adjust to dialysis treatment. (Who helped you? What were the obstacles?)

7. What actions have you taken to make things better for yourself and other persons who receive hemodialysis treatment?

8. What have you done to get to know other recipients?

9. What have other recipients done to get to know you?

10. What are the benefits and risks of getting to know other recipients better?

11. Is there any recipient you consider a friend of your? (Why?)
12. What are your on-going problems at the kidney center?

13. What are the on-going problems of other recipients?

14. Give examples of how staff treats you.

15. Is there anything that you would like to do that staff won’t let you?

16. Do staff members do anything to “keep you in your place?”
APPENDIX B

CONSENT FORM USED FOR OBTAINING RECIPIENTS PERMISSION TO PARTICIPATE IN THIS STUDY
INFORMED CONSENT

IRB #96.07 Date of Review: _________________

I, ___________________________ grant permission to Thomas D. Bordelon, a doctoral student of the Adult, Community, and Higher Education Program at Montana State University-Bozeman, to use information obtained from me by interview and observation for the purpose of submitting a research project as a dissertation and publication.

The following terms of this agreement apply:

Confidentiality:
My identity as a participant in this study will be protected so that I will not be harmed or embarrassed by any disclosure of information. All written documentation pertaining to the information I provide the interviewer in this study will be coded so as to conceal my identity, and will be kept in a secured location.

Procedures:
I will not be subjected to any procedures in this study. I understand that I will be orally interviewed one or more times.

Rights of Subject:
I have the right to refuse participation at anytime during the study, or may refuse to answer any of the questions without jeopardizing my future medical care.

I understand that my rights as a human subject are protected by the Department of Health and Human Services, 46 FR 8386, January 26, 1981, 48 FR 9269, March 4, 1983.

The Inter-Institutional Review Board is a volunteer group acting under Federal guidelines as a participant advocate, who have reviewed this consent for clarity and of information. If you have any questions, comments or concerns about this study, or your rights as a research subject, you may call the IRB at 245-8528.

Participant's Signature ___________________________ Date _________________

Thomas D. Bordelon, Researcher ___________________________ Date _________________

Copy: Participant
APPENDIX C

FOLLOW-UP INTERVIEW GUIDE USED TO QUERY 6 RECIPIENTS
Follow-up Questions

1. What would you like your relationship to be like with the other recipients and staff? What prevents you from having a relationship you would like?

2. What are the rules at the kidney center, and who makes them? How fair are they?

3. How are you different now than before you became a dialysis recipient in terms of how others treat you? Can you hold down a job and enjoy life like anyone else?

4. What have you learned from other recipients by watching them and overhearing their conversations?

5. Does the staff expect you to do more than what you want to do?

6. When you were dialyzing closer to one another, were you afraid of losing confidentiality?

7. What were the steps you made to create a change at the kidney center?

8. Do you think that anyone would become threatened if you were to propose a change at the kidney center?
APPENDIX D

PILOT STUDY:

A PILOT STUDY TO DETERMINE THE EFFECTIVENESS OF AN INTERVIEW GUIDE USED TO ELICIT RESPONSES PERTAINING TO EMPOWERMENT ON A COMMUNITY LEVEL AT A KIDNEY CENTER
Purpose of the Pilot Study

The purpose of this pilot study was to ask hemodialysis recipients the questions from the Interview Guide (addendum) that will address the Research Questions listed in my doctoral dissertation proposal. This pilot study field tested the Interview Guide for its ability to assist me in obtaining meaningful responses from hemodialysis recipients. The results of this pilot study will be used to modify the questions that I will use in the Interview Guide for my dissertation. The following are research questions derived from the theoretical basis of empowerment selected from the literature review of my dissertation proposal. The answers to these questions will describe to what degree the theoretical basis of empowerment are present in the hemodialysis community, and to what degree they affect participant’s perception of their own empowerment.

Research Questions:

1. Through dialogue with other hemodialysis recipients, do hemodialysis treatment recipients name the elements of their world (the kidney center) to give these objects a subjective meaning?

2. Is critical reflection necessary to develop an understanding of the reality of one’s world (the kidney center) and envision change?

3. Is awareness of self within a community of other hemodialysis recipients necessary to experience empowerment?

4. Is praxis necessary to experience empowerment within a community of hemodialysis recipients?
5. Do hemodialysis recipients experience changes in their behavior, attitude, and perspective on life resulting from empowerment as they develop an awareness of the experience of other hemodialysis recipients in the kidney center community?

    Threats to empowerment:
1. Does the dominant medical culture bestow power to individuals receiving hemodialysis treatment as charity?
2. Do hemodialysis recipients become accustomed to the stability and comfort of the kidney center so that they become oppressed?
3. Do hemodialysis recipients accept the meaning, values, and beliefs of the dominant medical culture without reflection?
4. Do hemodialysis recipients become dependent on the rewards that the dominant medical culture provides?

    Literature Review

    There is a preponderance of research dealing with patient education in the renal literature. This focus on patient education largely deals with programmatic issues relating to dispersing information that is important for persons with End Stage Renal Disease (ESRD) to know so that they successfully comply with the regime of hemodialysis treatment (Brantly, Mosley, Jr., McKnight & Jones, 1990; Szczepanik, 1995; Brundage, Swearengen, 1994). Patient education literature does not, however, discuss the ESRD population in terms of a community, nor does it suggest that empowerment is or should be a focus of learning. An empowered community of persons
being treated for ESRD may be able to attain a greater understanding of their treatment, be more compliant with their treatment regime, have a greater participation in their treatment, and be better satisfied with their lives. Community empowerment encourages social change that leads to greater participation in society (Horton, 1990; Freire, 1995). Empowerment may also help renal health care providers recognize an important and useful dynamic that may lead to greater participation from renal health care recipients.

It is unknown if hemodialysis recipients develop a sense of community as a result of being treated at a kidney center for ESRD. If community awareness is achieved as a result of empowerment, then issues such as compliance and a good quality of life become a community issue rather than just an individual issue. This awareness of self and other treatment recipients may lead to change in the kidney center community that encourages recipients to fully participate as partners in the hemodialysis treatment. Empowerment, then, may be viewed as the path to a good quality of life and fuller participation in the community for which one belongs.

Methods

Interviews were conducted with 4 hemodialysis recipients using a criterion based sampling technique (Patton, 1990). Those individuals who were physically and emotionally capable of responding to my questions were used in this study. For example, persons who were unconscious, profoundly demented, or suffering from other co-morbid conditions that rendered them incapable of responding to my questions were not used in this study. Also, I selected the recipients on the basis that they had received at least one
year of hemodialysis treatment, signed my consent form for participation in the interview, and were available for at least one and a half hour to complete the interview. Since hemodialysis recipients are randomly provided with a treatment station, I approached recipients beginning at station number one, then moved to the next numbered station until the selection criteria were met.

I recorded the participant’s verbal responses to the interview questions by writing them down on each interview guide. As Gay (1996) observed, the primary tools of the qualitative researcher, “Are still the good old-fashioned pen or pencil and a note pad” (p. 218). I made special notes of quoting important participant’s responses, and made descriptive observations in my field notes so as to capture the nuances of participant’s different experience and perspectives as recipients of hemodialysis treatment. The field notes served as a repository of my thoughts and feelings and were used in the process of interpreting participant’s interview responses. The recipient’s responses were reviewed with the participants immediately following the interview as a means of verifying my accuracy in recording participant’s responses as a means of ensuring the validity of the data I collected (Bogdan and Biklen, 1992). Confidentiality of the participant’s responses was ensured by my use of coding the identity of each participant on the interview guide. The interview guides are kept locked in my home office.

Data Analysis

The responses given by hemodialysis recipients on each Interview Guide were first viewed individually as a check for individual consistency. In other words, I wanted
to be certain that all recipients interviewed were able to represent their perceptions in their voice. Responses to the Interview Guide questions were compared to the Research Questions to verify whether the interview questions addressed the purpose of the study. This process required that I rate each response on a 4 point scale (4 x’s represents the highest rating) as a judgment of how well I thought that the recipient addressed the question on the Interview Guide. The scale system seemed to be an effective means of not only contrasting the individual responses to the others, but also caused me to consider the question itself and why a certain recipient had difficulty in answering the question, or did not answer the question at all. The best of the participant’s responses to the Interview Guide questions were compared once again to the Research Questions, and used to examine the quality of the other questions on the Interview Guide.

Results

Demographic Information:

The Interview Guide had 12 demographic questions that pertained to needed data for my dissertation. The results of the Demographic Information show that the 4 hemodialysis recipients interviewed were equally distributed in gender, had a mean and median age of 56.5, and had been receiving dialysis treatment for a mean of 21 months. Two (2) of the recipients were married, and 2 were never married. Three (3) of the recipients interviewed were white, and 1 was Asian-American. The mean number of years in school was 14.5. Two (2) of the recipients were disabled, 1 retired, and 1 recipient said that he was self-employed. One (1) identified his occupation as skilled
labor, 1 as clerical/office, 1 managerial, and 1 professional. An equal number owned the property they were living in, and the other 2 were renting. The mean number of persons in a household was 1.75. The median income was $11,800. Two (2) of the recipients paid for their dialysis treatment with Medicaid/Medicare, and the other 2 had Insurance/Medicare.

Interview Guide:

After analyzing all the data as a whole, I found that each recipient maintained a theme throughout the entirety of the interview. Each recipient seemed to articulate their unique perceptions of being a hemodialysis recipient in their own voice. They returned to the theme as though I had tapped a belief system that they wanted to articulate. One recipient expressed his self-reliance on an inherent distrust of other people. This belief seemed to extended to the other hemodialysis recipients, as well as the doctors. “Doctors never get to be friends with you. If you had one who could really talk to you, that you could trust, not just the ones who are looking to put money into their pockets. I guess you get this way living lonely and depending on yourself.” This recipient seemed to recognize others, but stated succinctly, “You feel sorry for a lot of people [who are receiving dialysis],” he looked about the kidney center and indicated that he was pointing-out a couple of other recipients with a nod of his head, “I’m more concerned about myself than any of them.” He felt that he had a right to be receiving dialysis because he was eligible to get a kidney transplant, whereas he did not see why the others (particularly older recipients), remained on dialysis, “What can he do?” Another
recipient interviewed expressed a theme of how much better his life could be if he was not restricted by his hemodialysis treatment to get a job. He even described his relationships with other recipients as, “Casual, like co-workers. I say hello and visit a little in the waiting room.” Another recipient’s theme appeared to be a pre-occupation with fear of death. “It [dialysis treatment] makes you feel mortal,” and “The thing that bothers me so much is death and complications. It seems to be so much worse on the families.” She was clearly struggling with trying to adjust with the demands inherent in hemodialysis treatment in addition to wanting to look as if she was adjusting well, “Sue [a renal social worker] brings people to me to tell the about dialysis. I try to be honest, but not about the bad things that may not happen to them.” Another recipient interviewed seemed most concerned about the limitation that hemodialysis treatment places on her ability to travel. She felt that this impediment is probably not one that is not shared by other recipients, “If their health is better than ours [including her arthritic husband], they could get out more. They could get to an airport, for instance.”

Those questions that are retained for the dissertation study (6-18) seemed to address the purpose of the study, address the research questions, and elicited relevant information from hemodialysis recipients. Questions numbered 1, 2, 3, 4, 5, and 19 were eliminated as a result of conducting this pilot study because they were superfluous to the purpose of exploring the concepts of empowerment in a community of hemodialysis recipients. These questions did not address the Research Questions, nor did they elicit
any relevant information from hemodialysis recipient's perceptions of their experience with empowerment or lack of empowerment at the kidney center.

The retained Research Questions may be summarized with the corresponding Interview Guide questions asked of hemodialysis recipients in the chart that follows.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Interview Guide Question Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dialogue with other recipients.</td>
<td>6, 15</td>
</tr>
<tr>
<td>Critical Reflection.</td>
<td>9, 10, 11, 18</td>
</tr>
<tr>
<td>Awareness of self and others.</td>
<td>6, 8, 14, 16, 17</td>
</tr>
<tr>
<td>Praxis.</td>
<td>12, 13</td>
</tr>
<tr>
<td>Change to empowering behavior.</td>
<td>7</td>
</tr>
</tbody>
</table>

The degree to which the retained questions were judged according to the quality of response on my rating scale was developed during the data analysis phase of my study and is demonstrated in the table below. The legend is:

- \( x \) = the response to the Interview Question addressed the Research Question
- \( xx \) = the response to the Interview Question addressed the Research Question and allowed hemodialysis recipients to elaborate.
- \( xxx \) = the response to the Interview Question addressed the Research Question, allowed hemodialysis recipients to elaborate, and obtained detailed information about the recipient's experience.
- \( xxxx \) = the response to the Interview Question addressed the Research Question, allowed hemodialysis recipients to elaborate, obtained detailed information about the recipient's experience, and yielded thick and rich data about recipient's perceptions of their experience.

**Dialogue with other recipients.**

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Response</th>
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<tbody>
<tr>
<td>6</td>
<td>x</td>
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<tr>
<td>15</td>
<td>x</td>
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**Critical Reflection.**

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Response</th>
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<tbody>
<tr>
<td>9</td>
<td>x</td>
</tr>
<tr>
<td>10</td>
<td>x</td>
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</table>
Since Interview Guide question numbered 13 achieved the highest rating, it is important to examine the Question and sample responses so that it can be a model for constructing more effective questions in my dissertation study. The question, “What actions have you taken to make things better for yourself and other persons who receive hemodialysis treatment?” yielded detailed responses from all the hemodialysis recipients interviewed. One recipient stated, “I've talked to a lot of people on dialysis and told them about dialysis. I feel like I've helped them.” Another recipient took the view that he really couldn’t do anything to alter the quality of his or any other person’s life, “There’s nothing you can do to make it better. I've tried watching TV, but it's boring. If you had lots of money, you could get a [dialysis] machine, buy enough tapes [a reference to audio books he enjoys], and spend all this money to make it nice. Wish they could give you
more to do while you're having treatment. Seems like no one on dialysis has enough money” ‘poor people, poor ways.’ Always been that way, always will be.” This response demonstrated the recipient's inability to grasp the opportunities to take charge of his treatment with a realistic plan. This response could also indicate that he does grasp the hopelessness of his situation to make effective changes in his treatment and others. It also indicates a belief system that he developed before his need for hemodialysis treatment, and maintains as a hemodialysis recipient. His response suggests that an aspect of the quality of the question is that it treats recipients as historical—not only dealing with the here and now of their experience. The question has the power to inquire about the depth of a person’s experience and attitudes.

**Discussion and Recommendations**

The length of each interview was between 1 to 1 1/2 hours. Although recipients are being treated for about three hours each session, my fieldnotes indicated that the interviews seemed to be tiring for each of the recipients interviewed. One took a break by locating a piece of gum on himself and chewing it throughout the last 45 minutes of the interview. Another needed to get a cup of ice to soothe her dry throat. The other two recipients said that the interview helped them pass the time, yet they seemed to show their fatigue by looking about the kidney center. I do not think that these behaviors demonstrated resistance to answering the interview questions, as each recipient seemed to want to return to the question in search of a response. I suspect that the superfluous questions detracted from a central focus of the interview, and made it seem like I was
shifting the focus of the interview too often. I think that the recipients wanted to answer the questions, but needed to narrow the focus so that they could sense a structure and logic in the interview. A narrower focus will probably be less fatiguing for the recipients in my dissertation study.

The questions that are retained for the dissertation study will be modified as a result of the data collected in this pilot study. Question numbered 13 is a model question that yielded the best results because it was concrete and asked for recipients to name their experience. The question also had a clear focus. It appears that the more concrete, specific, and focused on their experience is the question, the better recipients were able to provide me with a response. The recommendations for modifying the Interview Guide are, starting with the Demographic Information: The Demographic Information form needs to be modified as it did not contain the category, “Never Married,” under Marital Status; “Self-employed,” under Employment status; and “Homemaker,” under Occupation. Further refinements include asking the recipient to state his or her age, rather than asking for their date of birth. Otherwise, the necessary data was collected for the dissertation study.

The Interview Guide needs to be modified so that the attitudes and beliefs that recipients maintain are explained by their examples. Probes will be identified in the question in parentheses so as to keep the direct focus of the question. The questions on the Interview Guide will be changed to the following (and renumbered 1-16 in the dissertation Interview Guide):
6. Give me an example of a problem that you had regarding your health. (Who did you talk to about it? How satisfied were you with their response?)

7. Tell me a time when you had to make an important decision regarding your healthcare (who made the decisions)?

8. What have you done to learn more about dialysis treatment? (What have you taught others?)

9. How would you change your hemodialysis treatment if you could? (What keeps you from changing? Give an example of how you have made changes in your dialysis treatment).

10 & 11. In what way are you different since you have been a hemodialysis recipient? (How has dialysis changed the way you think, feel, and behave?)

12. Name the changes that you have made to adjust to dialysis treatment. (Who helped you? What were the obstacles?)

13. What actions have you taken to make things better for yourself and other persons who receive hemodialysis treatment?

14. What have you done to get to know other recipients? What have other recipients done to get to know you? What are the benefits and risks of getting to know other recipients better? Is there any recipient you consider a friend of yours? (Why?)

16. What are your on-going problems at the kidney center? What are the on-going problems of other recipients?
Give examples of how staff treats you.
Is there anything that you would like to do that staff won’t let you?
Do staff members do anything to “keep you in your place?”

Other questions have been added so as to keep the focus on the issues related to empowerment and community awareness at the kidney center.

**Conclusions**

This study was an effective means of field testing the Interview Guide that will be used in my dissertation research. The pilot test assisted me in modifying the Interview Guide so that it will be a more effective tool in gathering data about how hemodialysis recipients experience empowerment at the kidney center. The study also allowed me to gain some experience as a qualitative researcher. My experience as a researcher will give me more confidence to probe for meaningful responses from the recipients as I conduct my dissertation study.
References


**I. Demographic Information.**

1. Gender: Male    Female

2. Age: _____________

3. Years and months on dialysis: _____________

4. Marital Status: Never Married  Married  Remarried  Divorced

5. Race: White  Native American  Afro-American

   Hispanic American  Asian American

6. Highest grade completed: _____________

7. Employment status: Full-time  Part-time  Unemployed  Disabled

   Retired  Homemaker  Self-Employed

8. Occupation: Doesn’t Apply  Labor  Skilled Labor

   Clerical/Office  Managerial  Professional  Homemaker

9. Living Arrangements: Own property living in  Renting

   Long-term care facility  Temporary/Transitional housing

   Subsidized housing

10. How many live in household: ___________

11. Estimated household income: ___________

12. How is hemodialysis treatment paid: Self-Pay  Insurance  Medicaid

   Medicare  Medicaid\Medicare  Insurance\Medicare  Self-Pay\Insurance

   Other
II. Interview Questions

1. Describe your typical activities on the days you receive dialysis treatment, and on the days you do not receive dialysis treatment.

2. Describe what dietary and fluid restrictions you have as a hemodialysis recipient. What other restrictions are placed on you as a treatment regimen? Describe your treatment regimen.

3. What do you do in your leisure time?

4. What are the constraints placed on you because of hemodialysis treatment?

5. Describe the condition of your health.

6. When you need to know something about your health and health care, who do you speak with? (What is your level of satisfaction with their response?)

7. How are decisions made in regard to your health care? Who makes the decisions?

8. What information sources do you use to learn about your health and health care? How do you best learn? (Are these sources adequate? What more do you need to know? Are there topics that are difficult to find information on?)

9. What would you like to change about your hemodialysis treatment? What would you like to change about your health care in general? (Do you feel that you can influence these changes? How? Give examples.)

10. What did you feel when you were first getting started with dialysis treatment? What are your thoughts at this time?
11. In what way are your feelings and thoughts different now as compared to when you first started hemodialysis treatment? In what way are they the same?

12. What changes did you have to make to adjust to dialysis treatment? Who supported the changes you had to make? What were the obstacles to making changes?

13. What actions have you taken to make things better for yourself and other persons who receive hemodialysis treatment?

14. Describe your relationship with other recipients of hemodialysis treatment. What efforts have you made to get to know other recipients? What efforts have other treatment recipients made to get to know you?

15. What might the benefits and the risks be of getting to know other hemodialysis recipients better?

16. What are the on-going problems you face as a dialysis recipient? What are the on-going problems of other dialysis recipients?

17. How do you see yourself in the future? How would you like to see other hemodialysis recipients in the future? How would you like to see the kidney center change in the future? (How likely do you see changes occurring?)

18. What have you learned about yourself and other recipients of hemodialysis through your course of treatment?

19. What more would you like to share about your experience as a hemodialysis recipient?