



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.

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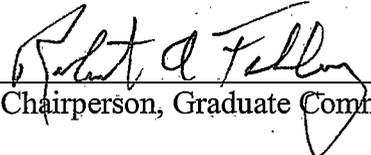
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ABSTRACT

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, Swearingen, 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, Vacc, 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 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.

