WOMEN'S PERCEPTIONS OF FACTORS THAT ENHANCE AND INHIBIT
ADAPTATION TO CHRONIC HEMODIALYSIS
WHEN RENAL TRANSPLANTATION IS NOT AN OPTION

by

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People are much greater and much stronger than we imagine, and when unexpected tragedy comes...we see them so often grow to a stature that is far beyond anything we imagined. We must remember that people are capable of greatness, of courage, but not in isolation...They need the conditions of a solidly linked human unit in which everyone is prepared to bear the burden of others.

Archbishop Anthony Bloom
Factors Influencing Women's Adaptation to Hemodialysis When Renal Transplantation is not an Option

The intent of this study was to explore and describe factors that influence adaptation from the perspective of women on hemodialysis for whom renal transplantation is not an option. Phenomenology was the research design selected for this study in order to understand the experience of these women clients. Data were collected during audio-taped interviews of eight women and were analyzed concurrently with data collection to identify common themes.

Two central themes emerged: the adaptation process and the theme of connectedness. The adaptation process was described as a six-phase process. Connectedness was defined as being connected to others and/or sources of life's energy.

Several key factors that either facilitated or interfered with adaptation were identified for each of these two themes. Key factors that facilitated adaptation throughout the adaptation process included a first run on dialysis, experience with adversity, emotional and instrumental support, coping behaviors such as asserting control and reframing the situation,
diversions, adequate rest and confidence in health-care professionals. Factors interfering with adaptation to hemodialysis throughout the adaptation process included the gradual and ambiguous nature of renal disease, increasing dependence, reduced energy, transportation to dialysis, compromised somatic health, difficulty with assertiveness, prolonged stressors and lack of confidence in health-care professionals.

Specific factors that influenced connectedness were identified. The facilitating factors identified were satisfactory relationships, nurturing others, normalizing, a harmonious atmosphere on the hemodialysis unit and pleasurable activities. Key factors interfering with adaptation related to the connectedness theme were isolation from others, unsympathetic others, ineffective communication with health-care professionals, and exclusion from activities.

The findings relative to the adaptation process were discussed in the light of the literature on adapting to illness and stress. Connectedness was discussed primarily in relation to the literature exploring the socialization of women. Implications for nursing practice, education and research arising from these findings were outlined.
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CHAPTER ONE
Introduction

Background to the Problem

As I look back now, it hardly seems possible that nearly ten years have gone by since I became a dialysis patient. The steps I have taken to reach where I am today have covered a long road, one which at times has been uplifting, at others disappointing, but with every bend that road took I became a stronger person for the experience. (Olsson, Marlene, 1982, p.4)

Since the 1940's, the life expectancy of the average individual in North America has increased significantly. Advances in scientific knowledge and the subsequent development of medical technology and improved medical treatment have influenced this upward trend in life expectancy. Nevertheless, along with these advances in medical treatment and the subsequent increased longevity, there has also been an increase in the number and type of chronic illnesses in today's society (Benoliel, 1983; Burish & Bradley, 1983). Chronic illnesses, in which life is supported by technology, have emerged as illnesses unique to this new era of technology in medicine (Burish & Bradley, 1983). Special problems, such as change in body image, family role disruptions, and issues related to survival and quality of life have emerged in response to the increased use of technology to
support life (O'Brien, 1983). Yet, the professionals responsible for health-care delivery have been slow to recognize distinct problems and issues of adaptation that affect those who must live with illnesses maintained by technology (Benoliel, 1983).

End-stage renal disease is one specific chronic illness in which life is supported by technology. This condition currently affects over 8,000 people in Canada, of whom about forty percent are women. There has been a steady increase in the number of individuals accepted into renal programs in Canada in recent years and it is anticipated that this number will continue to increase well into the future (Kidney Foundation of Canada, 1986). There are three therapeutic modalities for end-stage renal disease: hemodialysis, peritoneal dialysis or renal transplantation. Each of these intervention modes requires that the individual depend on advanced technology for survival (Abram, 1977). It is important for health-care professionals to recognize that the benefits of medical technology are accompanied by major psycho-social difficulties related to the process of adapting to a life supported by technology (Anderton, Parsons & Jones, 1977; DeNour, 1981; Gathercole, 1987).
Hemodialysis is a highly technical, life-saving measure for individuals with end-stage renal disease. Individuals on hemodialysis must manage distinct physical, psychological and social stressors (Parker, 1981). These stressors include dietary restrictions, dependency on machines and caregivers, family role disruptions, devalued social status, physiological and psychological fatigue, peripheral neuropathy, uncertainty about the future, and an awareness that the disease is incurable (Baldree, Murphy & Powers, 1982; Eichel, 1986; Friedrich, 1980; O'Brien, 1983; Stark, 1985; Ulrich, 1980).

The literature on adaptation to hemodialysis suggests that there are factors both within the person and within the environment that correlate with adaptational outcomes. These factors include social support, religiosity, compliance with therapeutic regimen and perceived control (Czaczkes & DeNour, 1978; Heinze & Mitra, 1986; Devins, Hollomby, Barre & Guttman, 1981). Inability to manage the stressors of hemodialysis leads to negative adaptational outcomes: a reduced quality of life, depression, suicide or premature death (Devins, Hollomby, Barre & Guttman, 1981; Harris, Hyman & Woog, 1982; Parker, 1981).
Although the literature has not identified gender as a personal characteristic that correlates with adaptation to hemodialysis, women on hemodialysis must not only adapt to the stressors specific to hemodialysis but must manage the additional stressors experienced specifically by disabled women. Fine and Asch (1981) state "disability is a more severely handicapping condition for women than for men" (p. 233). These authors identify that role loss is particularly more problematic for disabled women than for disabled men. Stressors specific to women on hemodialysis have been overlooked in the literature.

Successful renal transplantation offers the client on hemodialysis the opportunity to lead a more self-reliant life (Evans et al, 1985). Since the early 1970's, renal transplantation has developed into a therapeutic modality for end-stage renal disease that is superior to hemodialysis. The recipient of a successful renal transplant can return to a 'normal' life-style (Benvenisty, Cianci, Hardy, 1986; Buszta, 1981; Evans et al, 1985).

For some on hemodialysis, renal transplantation is not an option. Some live with conditions that are incompatible with successful renal transplantation such
as advanced age, severe cardiac disease, cirrhosis, uncontrolled infections and malignancies (Benevisty, Clanci & Hardy, 1986). Some clients on hemodialysis choose not to undergo renal transplantation for complex personal reasons such as fear of the medications, uncertainties about the transplant procedures and beliefs about personal physical integrity (O'Brien, 1983). In addition, there is evidence that proportionally fewer women than men are recipients of renal transplantation (Evans et al, 1985). Clients for whom renal transplantation is not an option live without the hope of returning to an independent life in a situation in which many of their peers have been given this hope. And, little is known about adapting to a lifetime of hemodialysis when renal transplantation is not an option.

Personal anecdotal descriptions of the experience of living with hemodialysis commonly appear in books and journals. These anecdotal records provide rich accounts of this experience and enable greater insight into the factors that impact on adaptation to chronic hemodialysis. While the anecdotal accounts bear out many of the claims of the research studies, studies tend to present the client's problems as viewed by the health-
care team and not necessarily as the client experiences them. However, since the way the client perceives his or her problems or illness likely influences the client's ability to adjust to hemodialysis, more research is needed to determine the nature of the client's perspective so that health-care professionals are able to deliver client-centered care (Stevenson, 1984).

Living with hemodialysis involves managing numerous physical and psycho-social stressors to ensure a successful adaptation (O'Brien, 1983). Lazarus and Folkman (1984) suggested that research into the phenomenon of coping should be conducted in such a way as to determine the client's appraised meaning of the situation. They further point out that by investigating coping in such a way as to determine the client's assessment of the meaning of the situation, the variability of coping in specific contexts might be determined (p.180).

Forty percent of clients on hemodialysis are women, and women, the literature suggests, may have greater difficulty adapting to a disability than men (Fine & Asch, 1981). Curiously, little is known specifically about women's perceptions of adapting to hemodialysis. Information about factors that influence adaptation to
chronic hemodialysis would assist nurses and other health-care professionals to plan more effective health-care for this particular group of clients.

**Problem Statement**

Little is known about the factors that influence the adaptation of women to chronic hemodialysis when renal transplantation is not an option. Further, published studies that do investigate aspects of coping with and adapting to hemodialysis report the client's problems from the perspective of the health-care professional. The perspective of the hemodialysis-dependent client has been largely overlooked, leaving a serious gap in knowledge available about these clients.

**Purpose**

The purpose of this study is to explore from the women clients' perspective the factors that enhance and the factors that inhibit adaptation to chronic hemodialysis when renal transplantation is not an option.

**Conceptual Framework**

The conceptual framework for this study is the Lazarus Theory of Stress and Coping (see Fig. 1). Central to this theory is the notion that a person's perception shapes the emotional and behavioral response (Lazarus and Folkman, 1984). The model proposes that,
Environmental Factors

Coping Resources
Coping Constraints

1) Primary Appraisal
   Harm • Threat • Challenge?

2) Secondary Appraisal
   Options?

Fig. 1
Lazarus Theory of Stress and Coping
through cognitive appraisal processes, the individual judges the significance of a stressful event in relation to his or her well being, selecting coping responses that influence adaptational outcomes.

A stressful situation can be evaluated in one of three ways: benign-positive, harmful or threatening. In the Lazarus model, stress arises from the relationship between person factors and environmental factors and the evaluation that a stressful event is harmful, threatening or benign is a result of cognitive appraisal.

According to this model, cognitive appraisal involves primary and secondary appraisal. Primary appraisal is the process of determining whether the situation is benign-positive, harmful or threatening. Secondary appraisal occurs simultaneously and is concerned with determining a course of action based on an evaluation of the coping resources that are available to that person. Reappraisals follow earlier appraisals and are based on new information from the person or the environment. Cognitive appraisals allow the person to elicit meaning from a situation particularly in relation to that individual's well-being.

The model identifies commitments and beliefs as the two person factors that shape cognitive appraisals.
Commitments are undertakings that are perceived as duties and as such influence the choices a person makes. Beliefs, which tend to be elusive to the observer, are important in determining how a person evaluates a situation. These personal characteristics provide a structure that guides the individual 1) to determine the significance of the event in terms of personal well-being, 2) to understand the event so that appropriate emotions and coping efforts are selected and 3) to evaluate outcomes.

In this model, situation factors that have particular relevance to appraisal are the "formal properties of encounters that create the potential for threat, harm or challenge" (Lazarus & Folkman, 1984, p. 115). It is emphasized in this model that the extent to which any event is stressful is a composite of person and situation factors. Thus, the model identifies a taxonomy of situational factors that are particularly relevant to the person factors. The formal properties of situations that are identified in this model as significant for cognitive appraisal are the novelty of the event, predictability and event uncertainty. In addition, the model states that the timing of stressful events and the
perceived ambiguity of a situation influence the appraisal and coping processes.

The model accounts for coping resources and constraints against coping. Coping resources, as suggested by this model, include health and energy, positive beliefs, problem solving skills, social support and material resources. Constraints against coping include personal constraints that result from internalized cultural values and beliefs, personality factors that interfere with effective coping, and environmental factors that thwart coping efforts. In sum, cognitive appraisals are influenced by a complex interactive process of personal and situational factors.

Coping behaviors arise from cognitive appraisals. Coping, in this model, is process-oriented, and is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of that person" (Lazarus & Folkman, 1984, p. 178). In effect, coping efforts function in two ways: problem-focused coping and emotion-focused coping. Problem-focused coping is directed toward managing the problem within the stressful environment, and emotion-
focused coping toward controlling the emotional response to the problem (Lazarus & Folkman, 1984).

The salient point of this model is that cognitive appraisal and coping efforts result in adaptational outcomes that influence an individual's health and quality of life. It is held that adaptation and adjustment are synonymous terms (Coelho, Hamburg & Adams, 1974). Coping effectiveness in a stressful situation is based on both emotion-focused coping and problem-focused coping. Simply put, coping effectiveness results from both regulating the stress in the face of the stressful encounter and managing the problem that is causing the distress. Both person factors and environmental factors influence the amount of stress perceived and the coping strategies selected.

Since the research problem for this study is concerned with a situation likely to be stressful, hemodialysis, and patients' perceptions of the factors that facilitate or interfere with their adaptation to this continuous situation, the Lazarus theory of stress and coping is an appropriate guiding framework.
Research Questions

1. From women clients' perspectives, what factors positively influence adaptation to chronic hemodialysis when renal transplantation is not an option?

2. From women clients' perspectives, what factors negatively influence adaptation to chronic hemodialysis when renal transplantation is not an option?

Definition of Terms

Adaptation:
The outcome of appraisal and coping processes. (Lazarus & Folkman, 1984).

Chronic Hemodialysis:
A type of dialysis in which the blood of a person in end-stage renal failure travels through an extracorporeal dialyzer to remove toxins, electrolytes and water. This person is dependent on regular dialysis treatments for survival (Kidney Foundation of Canada, 1986; O'Brien, 1983).

Coping:
"A process through which the individual manages the demands of the person-environment relationship that
are appraised as stressful and the emotions they generate" (Lazarus & Folkman, 1984, p. 19).

**Stress (Psychological):**

"Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19).

**Stressor:**

Environmental events or mental processes that are stress stimuli (Hutchful, 1980; Lazarus & Folkman, 1984).

**Assumptions**

The following assumptions have been made for this study:

1. Chronic hemodialysis has meaning for the adult individual.
2. Coping outcomes occur as a result of living with hemodialysis.
3. Persons undergoing chronic hemodialysis are willing and able to share in-depth descriptions of the experience with the researcher.
Limitations

The qualitative nature of the study limits the generalizability of the findings. The study will also be limited by the characteristics of the sample. In addition, only those who can and are willing to verbalize their perceptions to the researcher in English will be in the study and therefore will not reflect those whose facility in English is lacking.

Significance of the Study

The stressful nature of the experience of hemodialysis is a factor influencing the overall health and well-being of hemodialysis patients. Successful adaptation to hemodialysis determines the overall health of the hemodialysis patient. The literature review for this proposal revealed that little is known about adaptation to hemodialysis from the perspective of women clients. No studies were found that examined women's experience of adapting to hemodialysis when renal transplantation is not an option.

Nurses are the health-care professionals who spend the most time caring for these individuals. Nurses are therefore in a position to assist the client to manage this stressful life experience. For nurses to plan quality nursing care, it is essential that they
understand what factors enhance and inhibit adaptation to hemodialysis from the perspective of their women clients. The ultimate goal of undertaking such a study is that nurses and other health-care professionals could use such findings for the purpose of being more effective in their practice with these clients.

Organization of the Thesis

In this chapter, the research study has been introduced. This introduction included a discussion of the background to the problem, the proposed conceptual framework, Lazarus' Theory of Stress and Coping, the problem statement, purpose of the study, research questions, definition of terms, assumptions, limitations and the proposed significance of the study. Subsequently, in Chapter Two, the literature relevant to the proposed study is reviewed. The research method used in this study is explained in Chapter Three. The findings of the study are presented in Chapter Four. A discussion of these findings relative to pertinent literature is included in Chapter Five. Finally, Chapter Six which includes a summary of the study and conclusions that arise from the study, concludes the thesis. The implications of the study findings in relation to nursing practice, education and research complete Chapter Six.
CHAPTER TWO  
Literature Review  

In this Chapter, the literature supporting the choice of the research problem will be discussed. Since this study is based on Lazarus' Theory of Stress and Coping, the literature review will be presented in these categories: the stressors of hemodialysis, and factors that influence adaptation to hemodialysis. The literature addressing hemodialysis when renal transplantation is not an option, and the experience of women with disabilities will be reviewed since information pertaining to these topic areas contributes to an understanding of this study.  

Stressors of Hemodialysis  

It has been recognized for some time that patients on hemodialysis are faced with a variety of stressors (Abram, 1969; Anderton, Parsons & Jones, 1977; O'Brien, 1983; Plough, 1986). Lazarus and Folkman (1984) use the term stressor to describe environmental events that are stress stimuli. Hutchful (1980) defines psycho-social stressors as "conditions originating from mental processes or relationships with others that produce stress" (p. 31). For the purposes of this discussion,
the term stressor refers to situations or mental processes that are stress stimuli. The stressors of hemodialysis as described in the literature include changes in relationships, waiting for a transplant, changes in body-image, restrictions, economic pressures, dependency, decreased sense of well-being, losses and threat of death, and increased aggression (arising in clients from anger at multiple losses) (Czaczkes & DeNour, 1978; Hutchful, 1980). The stressors of hemodialysis elicit coping and influence adaptation and are therefore important to consider in the context of this study.

Several studies have investigated the stressors of hemodialysis. Friederich (1980) investigating problems of hemodialysis reported that the highest degree of distress related to hemodialysis occurred with the psycho-social problem of future uncertainty, while the most stressful physical symptoms were fatigue, muscle cramps, difficulty sleeping and sexual changes.

Baldree, Murphy and Powers (1982) measured the types and severity of stressors of hemodialysis using a tool they developed, the Hemodialysis Stressor Scale. When ranked by thirty-five patients on hemodialysis, the top ranked stressors were limitation of fluid, muscle
cramps, fatigue, uncertainty about the future and limitation of food. This study was replicated by Gurklis and Menke (1988) with sixty-eight patients. They found that the top ranked stressors were fatigue, limitation of food, limitation of fluid, limitation of physical activities and frequent hospital admissions.

The subjects in this replication study were asked to identify additional stressors and thirty more stressors were identified. Gurklis and Menke (1988) suggested that this large additional number of stressors, not included in the Hemodialysis Stressor Scale, raises questions about the degree to which this tool measures the stresses experienced by hemodialysis patients. The anecdotal literature suggests that tools to measure stress of hemodialysis capture only a narrow view of the realities. Whereas the research literature identifies "dependency on staff" as a stressor (Baldree, Murphy & Powers, 1982), in an anecdotal account, Torres (1986) suggested that a patient's objectivity becomes impaired by over-dependence on staff.

Stevenson (1984) conducted an exploratory study to discover the quantity and frequency of health problems of hemodialysis patients from the perspective of the client. The researcher used guided interviews with ten
subjects. The sample was not representative since all the subjects were black and lived in a racially mixed area. In spite of the limitations, the study was a beginning attempt to identify the stressors of hemodialysis from the perspective of the patient. The subjects most frequently identified the following problems: fistula, occupational worries, weakness/lack of energy, alterations in life style, dietary/fluid restrictions, financial concerns, and change in family relations.

Tucker (1986) developed the Dialysis Patient Concerns Inventory (DPCI) in response to the fact that previous studies had failed to identify the concerns of hemodialysis patients from the perspective of the patient. The DPCI consists of twenty-nine items that were identified by the investigators in informal group sessions with hemodialysis patients and through individual discussions with twenty-two hemodialysis patients. Reliability and validity of this tool was not reported. The five top-ranked concerns reported by hemodialysis patients were loss of energy, needle sticks, depression, special diets and loss of too much weight and transportation to dialysis treatments. The anecdotal literature describes the intensity of
feeling experienced when a client is first confronted by the stresses of end-stage renal disease and subsequent hemodialysis. Bailey (1985) wrote "I can still remember the doctor coming in and telling me my kidneys were no longer functioning...I really thought my life was going to become a waste of time" (p. 6). Olssen (1982) reflected, "I was terrified at the prospect, even more so when I saw my first dialysis machine. With all those knobs, dials and what looked like miles of red, plastic tubing" (p. 4).

Although there is some consistency as to the stressors of hemodialysis in these studies, discrepancies in the primary stressors of hemodialysis indicate that more research is needed in this area.

Factors Influencing Adaptation to Hemodialysis

Factors that influence adaptation to hemodialysis arise from both the person and the environment. Person factors include coping styles and coping strategies and environmental factors include factors that arise from the environment, such as social support, that influence coping and in turn adaptational outcomes.

Lazarus & Folkman stated "Since the 1960's there has been growing recognition that while stress is an
inevitable aspect of the human condition, it is coping that makes a big difference in adaptational outcomes" (p. 6). Commonly the term coping refers to behavioral efforts to manage stress. Early researchers into coping were grounded in the tradition of psychosomatic medicine and were primarily interested in the role of personality factors in chronic illness (Bradley & Burish, 1983). Since the 1960's, investigators into the phenomenon of coping have been looking beyond personality attributes of individuals to the nature of specific coping responses (Pearlin & Schooler, 1978). Presently, there is disagreement among clinicians and researchers as to how much coping Is linked to personality attributes and how much to contextual variables (Burckhardt, 1988). Folkman (1986) and colleagues state that research on coping is burgeoning, especially in relation to study of the actual coping processes used by individuals to manage the demands of stressful events as distinct from the trait-oriented approach which assume that coping is a property of personality attributes. These authors point out that there is currently a lack of information about contextual variables that influence coping.

Studies have investigated coping in the context of chronic hemodialysis treatment. Baldree, Murphy and
Powers (1982) identified coping styles used by hemodialysis patients in terms of problem-focused or emotion-focused coping and determined the statistical relationship between physiological or psycho-social stressor and coping style. In their study of thirty-five patients, they found that the patients used problem-focused coping efforts more often than they used emotion-focused efforts and that there was no statistically significant relationship between stressor and coping style. The most frequently used coping methods were maintaining some control over the situation and hoping things would get better. In this study, coping styles were assessed using a tool developed by Jaloweic and Powers (1981) for emergency and hypertensive patients. Psychometric analysis of this tool revealed that, while the tool is reliable, further revisions were needed to ensure construct validity for the affective domain (Jaloweic, Murphy & Powers, 1984). The study is weakened by this lack of construct validity.

Gurklis and Menke (1988) replicated the Baldree, Murphy and Powers (1982) study with sixty-eight subjects. In this study, the researchers reported the same finding that those on hemodialysis used problem-focused coping more often than emotion-focused coping. The researchers
did not report, however, the finding that there was no statistically significant relationship between stressor and coping scores. In this study, it was found that physiological stressors were related to emotion-focused coping and psycho-social stressor scores were significantly related to total coping scores. The most frequently used coping methods in this study were prayer, maintaining control, acceptance and hope. The findings of this replication study generally support the findings in the Baldree, Murphy and Powers (1982) study and contribute additional information about coping styles used in adapting to hemodialysis.

While coping has been the focus of some recent studies, adaptation has long been a concern of healthcare professionals working with renal patients (Blodgett, 1981). Adaptation refers to behaviors consistent with the broad goals of biological survival, competent behavior and responsible conduct (Blodgett, 1981; Coelho, Hamburg & Adams, 1974; Lazarus & Folkman, 1984). Factors that have been found to influence adaptation to chronic hemodialysis include pre-dialysis personality, coping and physical condition (Dimond, 1980; Harris, Hyman & Woog, 1982; Winkes, 1983).
Dimond (1980) examined the association between coping strategies and adaptation to hemodialysis. She found that the coping strategies of short-term planning and perception of progress were significantly related to physical stability and morale.

Harris, Hyman and Woog (1982) conducted a longitudinal study that investigated coping styles of hemodialysis patients in terms of survival. In this study, six members of the health-care team assigned twenty-two hemodialysis patients to one of two groups, the 'handicapped' group and the 'disabled' group (the study authors' terms) on the basis of both observation and an interview schedule completed by the patients. Essentially, the clients in the 'disabled' group were at a relatively high level of social, vocational and 'sick-role' functioning compared with those in the 'handicapped' group. The patients were evaluated for both physiological and psychological factors. Seven years later, when the survival rates of the participants were calculated, much to the surprise of the investigators, there was a trend toward higher survival rates in the 'handicapped' group, that is, those the health-care professionals evaluated as using coping styles that would likely lead to poorer adaptational
outcomes actually survived longer. The study had methodological limitations in that the staff assigned the subjects to each group according to staff perceptions of the patients' coping styles. Coping styles were not defined. The subjects were all male and a convenience sample was used. However, the study does raise questions about health-care professionals' abilities to judge client coping styles in relation to adaptational outcomes or to judge "handicapped" and "disabled".

Olsen (1983) conducted a meta-analysis of forty studies reporting variables predictive of adaptation to hemodialysis. The variables found to be significant in adapting to this situation were family relations, pre-dialysis functioning, anxiety, depression and the personality variable locus of control. The studies in the analysis spanned the period between 1972 to 1983 and the sample sizes varied from nine to 661. A concern with these studies is that adjustment was evaluated most often in relation to compliance, weight gain and vocational rehabilitation. These phenomena may be reflective of the health-care professionals' perspective on adaptation and not necessarily the patient's perspective.

Parker (1981) investigated the effect of anxiety on the occurrence of complications in hemodialysis patients.
She found that patients with higher anxiety levels had more complications than patients with low anxiety levels. While this study had some strengths, the small sample size weakened the importance of the findings. Devins (1981), a health psychologist, and his colleagues examined helplessness and depression in hemodialysis and renal transplant patients. The most significant finding of the study was that lower levels of perceived control over eight non-treatment life dimensions, for example work and recreation, were associated with greater depression.

O'Brien (1983) completed a nine-year longitudinal study of a large sample of hemodialysis patients. Adaptation was examined in this study using both qualitative and quantitative research methods. O'Brien found that long-term survivors of hemodialysis were less alienated, had more effective social support systems, were more socially active and more positive about the quality of their social interactions with family and friends than those who had expired over the course of the research project. Physical and psycho-social changes that occurred in the course of adapting to long-term hemodialysis were identified by the study subjects. The physical changes included infected grafts, calcium
problems, neuropathies, heart problems, fluid overload and fatigue. Psycho-social changes included alienation from family and friends, inability to carry out family role responsibilities and decreased quality of interactions with family and friends.

Hilbert (1985) conducted a study to examine the relationship between social support and compliance with the therapeutic regimen recommended by the health-care professionals for diet, medication and fluid intake. Compliance was measured by obtaining a total compliance score based on the results of a self-report questionnaire and the commonly accepted physiological measures for the recommendations of the therapeutic regimen, such as serum potassium levels. Social support was measured using the Inventory of Socially Supportive Behaviors, a tool with established reliability and validity. A positive relationship between these two factors was demonstrated.

Goodwin (1988) investigated the relationship between hardiness and psycho-social adaptation in the hemodialysis client. It was found that hemodialysis clients with higher levels of hardiness showed no better psycho-social adaptation than those with lower levels of hardiness. The researcher found, however, that the
client's perception of wellness was an important factor related to adaptation.

In addition to the findings of research studies, the anecdotal literature communicates a sense of the ups and downs of the experience of adapting to hemodialysis. Madden (1983) wrote "I couldn't sleep the night before my first dialysis session - so filled was I with despair over what was about to begin...[after four years on hemodialysis]...I live a better life than I ever did before" (p. 14).

The anecdotal literature suggests that effective coping styles that are gained through experience influence adaptation to hemodialysis. Simmons (1983), a dialysis patient for many years, advised his colleagues that in order to cope with a new life on hemodialysis certain rules must be adhered to, such as: developing a positive attitude, accepting support without being overly dependent, being informed and developing a sense of humor (p. 15).

These studies show that a variety of factors such as pre-dialysis functioning, locus of control, hardiness, anxiety, coping styles, perceived control, perception of wellness, social support and perceived control influence
the adaptational outcomes of hemodialysis patients such as weight gain, compliance, life satisfaction, vocational rehabilitation, depression and morbidity.

**Hemodialysis when Renal Transplantation is not an Option**

In contrast to hemodialysis, successful renal transplantation offers the client a return to a more self-reliant, normal life (Benvenisty et al, 1986; Mann, 1985; O'Brien, 1983). In a study by Evans (1985) it was found that 48 percent of renal transplant patients led a normal life compared with 8 percent of the in-center hemodialysis patients. However, not all clients on hemodialysis are eligible for or choose to undergo renal transplantation.

Contraindications to renal transplantation vary from center to center but generally include advanced age, cirrhosis, severe cardiac disease and uncontrolled infections and malignancies (Benvenisty & Hardy, 1986). Males may be slightly more likely to have a kidney transplant than females. Evans (1985) reports that 55.5 percent of all those receiving treatments for end-stage renal disease were male and 44.5 percent were women; furthermore, males received a slightly higher proportion of kidney transplants than did females. The reasons for this were not reported.
Some clients choose not to receive a kidney transplant. O'Brien (1983) examined kidney transplantation in hemodialysis patients both quantitatively and qualitatively. It was found that 55.6 percent of the subjects had negative attitudes about kidney transplantation. The qualitative aspect of this study outlined the following personal reasons for non-acceptance of the procedure: fear of the medications, uncertainties about the transplant process and beliefs about personal physical integrity.

While renal transplantation is held as the most effective treatment modality for end-stage renal disease, it appears likely that there will remain many hemodialysis clients who are either not eligible for or choose not to undergo this procedure. The review of the literature suggests that when kidney transplantation is an option, men are the primary recipients. In the next section, the literature related to women with disabilities will be examined.

**Women with Disabilities**

The term disability identifies those who have a limitation or interference with daily life activities such as hearing, seeing, speaking, moving, breathing and learning (Fine & Asch, 1981). Those on hemodialysis are
considered disabled because the treatment regimen for dialysis intrudes on the recipient ability to carry out the activities of daily living.

The literature suggests that women with disabilities have unique concerns that have only recently been recognized by health-care professionals (Sawin, 1986). Fine and Asch (1981) researched the problem of disabled women and argue that disability is a more severely handicapping condition for women than for men. They suggested that economic, social and psychological realities associated with a disability create a more significant role loss for disabled women than for disabled men.

Reviewing the USA Census Department statistics, Fine and Asch (1981) found that disabled women are less likely than disabled men to be employed, somewhat less likely to have a college education, earn substantially less and are less likely to find a job after the onset of the disability. Through a review of the literature, Fine and Asch found that the social and psychological realities that create role loss for disabled women include the following: disabled women are less likely to be married and more likely to be divorced than non-disabled women; they are discouraged from childbearing; are more likely
to be victims of hostility than are disabled men; they are perceived by others in a negative way; and report negative self-images. Fine and Asch conclude that these forces contribute to the role loss of disabled women. These authors reason that because these women lack socially sanctioned roles they are likely to experience a psychological sense of invisibility, self-estrangement and/or powerlessness. Sawin (1986) suggested that women who are disabled suffer from double discrimination: discrimination arising from disability and discrimination arising from femaleness.

No literature was found that examined the specific concerns of women on hemodialysis.

**Summary of the Literature Review**

This review examined the literature relevant to the stressors of hemodialysis, factors influencing adaptation to hemodialysis, hemodialysis when renal transplantation is not an option, and women with disabilities. There are many stressors associated with hemodialysis and the primary ones appear to be fatigue, food and fluid restrictions, depression and change in lifestyle. There are discrepancies among the primary stressors identified by research.
Factors that influence adaptation to hemodialysis reported in the literature include pre-dialysis personality, anxiety, depression, perceived control over non-treatment life dimensions such as work and recreation, social support, family relations, coping strategies, specifically, short-term planning and perception of progress and the client's perception of wellness. The adaptational outcomes influenced by these factors include physical stability, morbidity, morale, compliance, and vocational rehabilitation.

While renal transplantation is commonly portrayed as the panacea for end-stage renal disease, not all clients with this illness are eligible for or choose this therapeutic modality. Little is known about the effect of ineligibility for renal transplantation on the hemodialysis client.

Those on hemodialysis are considered by society as disabled persons since their movement throughout activities of daily living are inhibited. The literature suggests that women with disabilities suffer double discrimination. No studies were found that specifically examined women on hemodialysis.

In summary, while there has been considerable research directed toward clients on hemodialysis,
women's perceptions of adapting to hemodialysis has been to some extent ignored. Chapter Three, the next chapter will present the research methods used to answer the research questions.
CHAPTER THREE

Methods

In this chapter, the research methods selected to answer the research questions will be explained. The chapter begins with an overview of the phenomenological perspective and continues with a discussion of the selection of the participants and the characteristics of the participants. Following this description is a discussion of the data collection and data analysis process, reliability and validity of the study and ethical considerations.

The Phenomenological Perspective

According to Oiler in Munhall & Oiler (1986), "the aim of phenomenology...is to describe lived experience, and we accomplish this through attention to the perceived world, to the question of how phenomena appear to people" (p.81). Since the purpose of this study is to investigate adaptation to chronic hemodialysis by examining women's verbal accounts of their perceptions of the factors that help and hinder adaptation, phenomenology was the research method selected for this study.

The phenomenological method of inquiry is particularly suited to a study directed by the Lazarus
Theory of Stress and Coping. Central to both phenomenology and to the Lazarus framework is the importance of a person's perception of lived experience. As well, since nursing is an interactive, therapeutic discipline in which clients' perceptions of their illness experience is a primary determinant in directing the therapeutic relationship, the phenomenological approach is particularly suited to the study of nursing problems. It is suggested that research is needed to redefine and rename the experience of women so that knowledge will emerge that can stimulate effective social change and that qualitative research will generate such knowledge (Kirby & McKenna, 1989). Phenomenological enquiry, an inductive, descriptive research method, is therefore a suitable research method to examine the research questions of this study.

Selection of the Participants

A purposive sample of eight women was used for this study. Purposive sampling is referred to as judgement sampling and involves the conscious selection of subjects so that subjects that are "typical" or in typical situations compose the sample selected (Burns & Grove, 1987).
Criteria for selection

The subjects for this study were selected according to criteria that allow for both a selection of a typical sample and for effective inquiry.
1. Participants are currently in an in-center or limited-care hemodialysis program in Vancouver, and have been in the hemodialysis program for over six months.
2. Participants live in the Lower Mainland of British Columbia.
3. Participants are fluent in English.
4. Participants are knowledgeable and receptive to sharing their perceptions with the researcher.
5. Participants are age 25 or over and female.
6. Participants are not eligible for renal transplant and have never received a renal transplantation.
7. Participants do not consider renal transplantation an option.
8. Participants currently do not suffer from a life-threatening illness that supercedes the end-stage renal disease.
9. Participants do not suffer from a debilitating psychological disorder.
Selection procedure

Women who met the above criteria were identified in two acute care facilities in a metropolitan center located on the west coast of Canada. In one facility, the clinical nurse specialist approached potential subjects and in the other facility, the head nurse approached the women identified as potential subjects.

The clinical nurse specialist or head nurse explained the study to the potential subjects and asked if the investigator might discuss the study with them in more detail. The potential subjects were given an information letter (see Appendix A) and were instructed to inform the head nurse or clinical nurse specialist if they were interested in learning more about the study. The clinical nurse specialist and head nurse then provided the researcher with a list of telephone numbers of the women who had expressed interest. The researcher then contacted these potential subjects and set up an appointment to further explain the study and obtain written consent to audio-tape the interviews (see Appendix B).

Ten women agreed to participate in the study. Of the ten women, two women became ineligible for the study during the data collection phase of the study. One of
these two women began the evaluation process for the kidney transplant program following the first interview and one of the women revealed that she was possibly eligible for a kidney transplant during the second interview.

Eight women comprised the sample for this qualitative study. A guiding principle for determining the number of participants in a qualitative study is the principle of saturation. That is, when added information does not disclose further understanding about relations or abstractions saturation is said to have occurred (Kirby & McKenna, 1989). In-depth interviews with these eight women allowed for the development of a beginning framework for organizing data relevant to the research question. Additional subjects would enable saturation of the data to occur.

Characteristics of Participants

In this section, the demographic characteristics and health status of the sample will be described. (See Table 1). The eight participants in this study ranged in age from 50 to 77 years, with a mean age of 64 years. Three of these eight women were married, one woman was separated (although she continued to see her husband daily), one woman was divorced, two women had been widows
<table>
<thead>
<tr>
<th>AGE</th>
<th>LENGTH OF TIME ON DIALYSIS</th>
<th>EDUCATION</th>
<th>MARITAL STATUS</th>
<th>EMPLOYMENT</th>
<th>ADDITIONAL HEALTH PROBLEMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range: 50-77 yrs.</td>
<td>Range: 10 mo.- 22 yrs.</td>
<td>Grade 5 N=2</td>
<td>Married: 3</td>
<td>Blue collar worker: 1</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Mean: 64 yrs.</td>
<td>Mean: 8.6 yrs.</td>
<td>Grade 8 N=2</td>
<td>Divorced: 1</td>
<td>Homemaker: 3</td>
<td>Blindness</td>
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<tr>
<td></td>
<td></td>
<td>Grade 9 H N=2</td>
<td>Separated: 2</td>
<td>Housekeeper: 2</td>
<td>Bowel problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grade 12 N=2</td>
<td>Never married: 1</td>
<td>Office worker: 1</td>
<td>Cancer</td>
</tr>
</tbody>
</table>

Table 1. Characteristics of Participants
for five years and one woman had never been married. In this sample, the separation and divorce experienced by the two women occurred pre-dialysis. Six of the women had one or more grown children.

Seven of the women were caucasian and middle class and one woman had lived most of her life below the poverty line. With regard to educational status, two of the women had not been educated beyond Grade Five, two women had completed primary school, two women had some secondary school education but had not completed secondary school and two women were high school graduates. None of the women were currently employed. However, all the women had worked either within or outside the home prior to dialysis. One woman was a retired telephone company employee, one woman had worked as a machine operator, two women had worked as housekeepers, one woman managed and operated a boarding house and then a rest home and the remaining three were homemakers.

The length of time the women were on dialysis ranged from 10 months to 22 years, with a mean time of 8.6 years. Two women had been on hemodialysis less than 18 months, two between 18 months and five years, two between six and ten years and two women had been on hemodialysis
longer than ten years. One woman reported that she had been on peritoneal dialysis prior to hemodialysis. Two of the women were on hemodialysis twice a week and six of the women received dialysis treatment three times a week.

The women had other health problems as well: one woman had a hiatus hernia, diabetes, severe cardiac disease and was almost blind, two other women had diabetes, one woman had cancer, one woman had a history of substance abuse and one woman had Parkinson's disease. Over the interview period of four months, five of the women had a major health crisis which was either life threatening or severely debilitating. These specific crises included the following: for one woman both heart and bowel problems requiring emergency room intervention; for another, a broken hip requiring hospitalization; one woman experienced two falls leading to severe leg cramps and a broken arm that required hospitalization; for another, an infected foot and subsequent stroke requiring hospitalization and prolonged physiotherapy and finally, for another a transfusion reaction.

In summary, the women in this study were from a variety of situations and were presently living with numerous health problems in addition to kidney disease. However, in spite of these serious and potentially
overwhelming health problems, the women were enthusiastic about sharing their experiences with the researcher. The researcher considered the fragile health status and limited energy of the women when conducting the interviews in the data collection phase of the research study.

Data Collection Procedure

Effective data collection depends on the comfort and clarity of the interview for the participant and the ability of the researcher to accurately gather and record data relevant to the research question. In this research study, data collection occurred during in-depth, audio-taped interviews which were subsequently transcribed verbatim. In addition, the researcher made field notes during and after each interview. A semi-structured interview guide (see Appendix C) derived from the research questions was used to elicit the data from the informants during the interview.

The interviews ranged in length from 45 minutes to 75 minutes and took place in a comfortable environment. All but three of the interviews were conducted in the participants' homes. Those interviews, involving two subjects, took place in a private interviewing room in the hospital. On a few occasions, it was necessary to
gauge the length of the interview by the participant's energy level. Each woman was interviewed twice with approximately six to eight weeks between the first and second interviews. Two of the women were interviewed a third time as top informants.

The semi-structured interview guide was developed prior to each interview. The interview guide was developed to enable the participants to fully express their lived experience. The essential components of an interview that attempts to achieve this goal are that the interview questions and research approach should be clear to the participant and that there should be an egalitarian relationship between the researcher and the participant (Kirby & Mckenna, 1989).

Several actions were required on the part of the researcher to ensure that these components were part of each interview. At the beginning of each interview, the researcher clarified the purpose of the study and the purpose of the current interview. As well, the questions used in the interview were worded clearly and simply, were broadly stated and used the participants own language. To ensure an egalitarian relationship with the participants, the researcher treated the participants with the utmost respect for their unique experience,
avoided a counselling or information-giving role and the participants responses guided the direction of the interviews. In addition, it seemed important to reassure the participants at the beginning of each interview that there were no right or wrong answers but that whatever the participant said was valuable for the study. The researcher used comments such as "Could you talk more about that?" throughout the interviews to further explore and clarify information. The method described above allowed the researcher to provide a comfortable environment for the participant while gathering rich, relevant, in-depth data.

Data Analysis

As was stated above, phenomenology requires that data analysis occur concurrently with data collection. In this study, the researcher collected the data, reflected on the meaning of the data, began to identify emergent themes that generated new questions for further data collection. Thus, the researcher moved alternately between inductive and deductive logic (Glaser, 1978).

The data in this study were specifically subjected to phenomenological analysis using the method developed by Coliazzì (1978).
The following steps were used:

1. The spoken, written and visualized descriptive data (conventionally termed protocols) were considered in order to develop an overall feeling, making sense out the data;

2. The data were examined and coded to identify and capture significant statements;

3. Meanings of the statements were formulated;

4. The formulated meanings were arranged into clusters of themes;

5. The clusters of themes were referred back to the original protocols in order to validate them with discrepancies noted and considered;

6. An exhaustive description of the results of everything so far was developed;

7. An unequivocal statement of identification of the fundamental structure of the phenomenon was formulated from this exhaustive description;

8. The findings were validated by returning to the subjects and asking the subject if the findings were consistent with her experience;

9. New data that emerged from the validation interviews were integrated into the final product of the research.
Moving through the steps of the data analysis process, it seemed essential to not only identify significant statements within the data, but also to retain these statements within their complete context allowing for constant comparison of significant statements. Once the central themes and related sub-themes were identified, significant statements were removed from the complete text and categorized according to the themes and sub-themes. This allowed the researcher to collapse several categories.

An essential aspect of data analysis in a qualitative study is sharing reflections about the data with others to clarify one's thinking. Reflections on the central themes and sub-themes were shared with members of the thesis committee and with other colleagues. This facilitated refinement and labelling of the themes. The refined and re-labelled themes were then presented to the top informants and the thesis committee for further refinement. The logic for decision-making was presented to others as the data were collapsed into broader categories and left-over data was accounted for.

Within the data collection and analysis phases of this study, action was taken to ensure that the
requirements for scientific adequacy were met. These measures are discussed in the next section.

Reliability and Validity

This study meets the requirements for scientific adequacy. Sandelowski (1986) suggests that reliability and validity in qualitative research are enforced by examining the data in terms of the following criteria: 1) truth value in terms of credibility, 2) applicability in terms of fittingness of the data, 3) consistency in terms of auditability and 4) neutrality in terms of freedom from bias.

Credibility refers to determining if the findings are faithful descriptions of a human experience. The trigger question designed for the second or third interview (see Procedure) ensured that the criterion of credibility was met in that some subjects reviewed the categories arising out of the data analysis for the faithfulness of description of the experience.

Fittingness of the data refers to examining the findings to ensure that they fit the data. Re-examination of the data throughout the procedure of data analysis as described above ensured that the criterion of fittingness was met. The criterion for auditability is met when another researcher can clearly follow the decision trail
of the researcher. Members of the thesis committee for this study, including a specialist in nephrology nursing reviewed the decision trail of the researcher to determine if it was clear, and thereby ensuring that the criterion of auditability was met. The criterion of neutrality or freedom from bias was met in two ways; first by following the procedure outlined by Coliazzzi (1978) and by 'bracketing'.

Coliazzzi (1978) suggested that phenomenological research is unique in that the decisions concerning what aspect of the content the researcher chooses to investigate are inescapably linked to the researcher's approach to the subject. Coliazzzi stated that the initial step in phenomenological research is that the researcher examine the presuppositions of her approach. The researcher does this by first asking the question, why am I involved with this phenomenon? The researcher then pursues a line of questioning that will allow her to examine hidden gains in investigating the phenomenon using this particular method. Presuppositions related to personal gain and prestige, social recognition, moral, ethical, religious and economic features are examined. According to Coliazzzi, the researcher thereby disengages from the technological and pragmatic criteria defined by
the traditional researcher as the exclusive value of research. In this study, the researcher began by examining the above presuppositions related to this research study in order to approach the phenomenon with the objectivity gained by affirming the researcher's own lived experience. In addition to the above measures, the technique called 'bracketing' was used to ensure neutrality. In this technique the investigator keeps field notes of the research experience in an attempt to identify the nature of and therefore, control for the researcher's own involvement with the phenomenon under study (Munhall & Oiler, 1986).

In accordance with the phenomenological approach, the researcher transcribed the initial interviews verbatim as soon as possible following the interview so that all relevant interview data was captured without undue contamination from the passage of time. Analysis of the initial interview data was used to develop open-ended questions for the second interview. These questions were designed to clarify, validate and expand the data collected from the first interview (Omer, 1983).
Ethical Considerations

Protecting the rights of research subjects is an essential component of any research study. The following actions were taken to guard the rights of the participants in this study. The proposal for the research study was submitted for ethical review to the UBC Ethics Review Committee, the VGH Nursing Research Committee, the VGH Research Committee and the St. Paul's Committee for Human Experimentation. The data collection process did not begin until the proposal was accepted by these three committees.

Confidentiality was ensured in several ways. The subjects were identified by code numbers, that is, no names were used on the tapes or transcriptions. The researcher was the only one who had access to the master sheet on which the identities of the subjects were matched with the code numbers. This master sheet, tapes of the interviews, the transcriptions of these tapes and additional data will be kept in a locked filing cabinet in the researcher's office. The tapes were erased following data collection. In addition, patient confidentiality was initially maintained because only if the patients agreed to be approached did the investigator have contact with them.
CHAPTER FOUR

Findings

Introduction

The phenomenological research method described in Chapter Three generated the findings that are presented in this chapter. These findings represent an interpretation of the women's perceptions of factors that facilitated or interfered with adaptation to chronic hemodialysis when renal transplantation was not an option. Two central themes emerged as a result of the analysis of the women's accounts: adaptation as a process, and connectedness. The findings are presented here as two central themes in order to allow the truths presented by the eight women in the study to be used to help develop a new awareness of adaptation to chronic hemodialysis.

This presentation is organized into two sections. The first section introduces the theme of adaptation as a process and presents the factors that influence adaptation in relation to the phases of this process. The second section defines the second central theme, connectedness, and describes its influence on the adaptation process. Factors influencing adaptation to chronic hemodialysis and associated with the theme of
connectedness will be presented and discussed. Although the presentation of connectedness follows that of the adaptation process, the theme is in no way of secondary importance to or discrete from the adaptation process. In fact, connectedness has a primary effect throughout all phases of this adaptation process. Its secondary placement allows the adaptation process to be described in full and thus enhances the overall clarity of the discussion.

The women in this study spoke with tones of pride and courage. In their accounts, they discussed the factors influencing their physical and emotional status as they met the challenges and hardships of their disability. Issues specific to the technology that allowed these women to be alive rarely entered their perceptual fields; instead, the accounts focussed on the overall impact this technology had on their health status. As the data were analyzed, it became clear that the women's accounts were constructed within the context of a governing phenomenon: the response to chronic illness. The women's accounts described a chronic illness demanding not only a single response to ever-increasing disability but also a wide range of responses
to everyday difficulties. The adaptation process is described in the following section.

The Adaptation Process

The accounts of the women in this study suggested that there was a process of adapting to hemodialysis. One woman described the unending, dynamic nature of the process in these words:

Well, with renal failure...things come up all the time - it isn't that you have this whole thing - okay this is what it is, this is what you've got to deal with. You don't get it all at once. It's little bits all along.

Adapting to chronic hemodialysis required ongoing accommodation; it was not a one time adjustment to a finite situation. Another woman used an analogy to capture the struggle in this on-going process:

It's like swimming. You've got to swim above the water all the time...you have to keep above the water.

The women's accounts made it apparent that for them, adapting to chronic hemodialysis was a complex process. Six phases emerged: Resisting Dialysis, Fighting to Live, Accepting It, Facing It, Losing Hold and Giving Up (see Fig. 2). Resisting Dialysis was an early phase of the adaptation process. Taking issue with or avoiding the diagnosis of end-stage renal failure was characteristic of this phase. The phase culminated in 'bottoming out'.
a time of physical, and emotional depletion. The women's descriptions suggested movement then to a Fighting to Live phase. There appeared to be no return to the Resisting Dialysis phase.

The next four phases seemed to be experienced continually and in varying proportions (see Fig. 3). The words of the informants indicated that movement through these four phases is cyclical beginning with Fighting to Live, moving toward Accepting It, into Facing It, to Losing Hold and back to Fighting to Live. The accounts of two women indicated that there was a final phase characterized by Giving Up, a time when movement from the phase of Losing Hold back to the phase of Fighting to Live was seen as no longer possible.

The phases Fighting to Live, Accepting It, Facing It and Losing Hold could occur simultaneously and in varying proportions (see Fig. 3). [Figure 3 is included only to exemplify the concept that several phases of the adaptation can occur simultaneously, not to present important data.] One woman told me the researcher that she often experienced the Losing Hold phase early in the morning but went on to make the most of her day indicating the Facing It phase. During the interview of another woman it became apparent that much of the
Interview was constructed of comments indicative of the Accepting it phase. For example, she repeatedly said "you can always look around and see someone worse off than your self". Nonetheless, this same woman described how she faced each day extracting some pleasure from her life.

The following statement, demonstrated how phases of this adaptation process could occur simultaneously. When asked what had helped her cope with this situation, this woman responded:

I know I've got to go through it [Accepting It] that's all. And as I say, there's no use complaining. If they've got something that's going to help me I'm going to take it [Facing It]. I'm going to take that pill until I find out I have a reaction on it, well I'll quit just like that and I'll tell the doctor that I can't take it. [Fighting to Live].

Whether she carried out her good intentions or not, her comments in this monologue indicated that this woman clearly experienced thought processes characteristic of three phases.

With regard to the middle four phases, one woman pointed out the on-going adjustments this way:

You've got to learn to adjust all the time. I think there's stages of deterioration that you go through. It's a constant adjustment.

Another informant went on to say, in relation to the constant need to adjust:
Another informant went on to say, in relation to the constant need to adjust:

You put up your fighting forces...you get it up there and face the thing and try to sort it out and see, that's how you have to cope with it. But in order to face it you have to accept it first.

Data from this study therefore suggested that there was a cyclical pattern of movement among the middle four phases of this adaptation process, and that these phases occurred simultaneously and in different proportions depending on the particular stresses experienced at any give time.

In the following sections, each of the six phases of this adaptation process are described in detail. Facilitating and inhibiting factors for each phase are presented following the description of each phase, with the exception of the Giving Up phase which will only be described. Although, many factors influence each phase of this process, only the key factors that influence each phase are included in this discussion (see Table 2).
Figure 2. The Adaptation Process
Figure 3. Proportional Presence of Phases II-V
I. RESISTING DIALYSIS

Positive Factors
- Confrontation by health care professionals
- First run of dialysis

Negative Factors
- Nature of end stage renal failure
- Perceived threat to independence

II. FIGHTING-TO-LIVE

Positive Factors
- Role modelling
- Living for others
- Asserting control over the situation
- Experience with adversity
- Emotional support
  - Reassurance and reaffirms self-worth

Negative Factors
- Reduced energy
- Lack of confidence in health-care professionals

III. ACCEPTING IT

Positive Factors
- Reframing the experience
- Ignoring it
- Being a woman

Negative Factors
- Transportation to Dialysis
- Loss of independence

IV. FACING IT

Positive Factors
- Talking to others
- Assistance with tasks
- Confidence in health-care professionals
- Diversions
- Adequate rest

Negative Factors
- Reduced energy
- Somatic health
- Difficulty with assertiveness
- Lack of confidence in health-care professionals

V. LOSING HOLD

Positive Factors
- Presence of others
- Turning inward

Negative Factors
- Stressors that are lengthy
  and generate additional health problems

Table 2. Factors Influencing Adaptation in Relation to the Adaptation Process
Resisting Dialysis

From the women's accounts, Resisting Dialysis involved taking issue with or avoiding the need for hemodialysis. One woman described how and why she avoided the reality that she would eventually need to go on hemodialysis:

I continued on working and going and I didn't really want to think about it [dialysis] because I really didn't understand it.

By immersing herself in her regular routine, she temporarily avoided confronting the possibility of hemodialysis.

Lack of comprehension of the seriousness of kidney disease allowed another woman to believe that she did not need hemodialysis in spite of contradictory information from her doctor. This woman described her resisting as follows:

Well I didn't want to go on the machine at all. I didn't realize my kidneys weren't working because I still urinated a bit. And I said to the doctor, my kidneys are working. He said no they're not and I said yes they are. He said, you don't understand, they're not doing their job. So I said, well I'm not going to be tied to a machine for the rest of my life.

This statement illustrated the fact that the nature of end-stage renal disease could set up a cognitive dissonance that allowed this woman to deny the necessity of such a drastic treatment as hemodialysis.
The gradual onset of kidney disease allowed one woman to block out thoughts of dialysis:

The fact didn't really hit home until I began to feel ill because with me it was a slow process. It was for eight years. I didn't really know what was going to happen in eight years time. I just knew that - I just blocked it out of my mind.

For another, Resisting Dialysis involved attempting to live much as she did prior to dialysis:

I really didn't want a homemaker. I held out until just a few months ago and then when I went into hospital from January to March. They said, you have just got to have help because you have got to eat.

This resistance to assistance with the dialysis regimen culminated in a physical breakdown that required a three-month hospitalization. The pattern of reaching a point of emotional, physical, and spiritual exhaustion, that is, 'bottoming out', was evident in the accounts of other informants. Several women described 'bottoming out' as a "nervous breakdown". One woman described the experience in these words:

Then I was ill, as I say, I would get on the chesterfield and I couldn't get off. Someone had to pull me off. That was really bottom and I came up from there - just from that one evening. This is when Dr. X said you've got to have dialysis. I really hit rock bottom then. I had a sort of nervous breakdown.

The same woman recounting the experience in another interview recalled:
I had to get right down to the bottom. I had a sort of crisis in my life...

She had to reach a crisis before she was able to accept dialysis. Another woman also described how Resisting Dialysis culminated in emotional, physical and spiritual depletion:

I think my hardest time to accept the fact that I had renal failure was before I really went on [dialysis]. The fact didn't really hit home until I began to feel ill because with me it was a slow process. But I had to deal with it when I got sick and lost my job. I ended up in the hospital. I think I had like a breakdown, like a nervous breakdown. I didn't know where I was or what I was doing or anything, so they thought I had a nervous breakdown.

This statement described the experience of 'bottoming out' as a time during which personal resources were depleted, forcing the individual to deal with the realities of renal failure. One woman, when asked what it was like at the time dialysis began, accentuated the difficulty of this phase and how she blocked it out: "I went through so darn much that I forgot it all".

Only one woman in the sample did not experience the Resisting Dialysis phase. This was a woman for whom hemodialysis was an urgently required life-saving intervention. She was placed on hemodialysis following the removal of both kidneys for cancer treatment. Because of the urgent need for hemodialysis, this woman
stated that she had only two clear choices: hemodialysis or death. Therefore, this woman seemed to move directly in to the Accepting It phase of hemodialysis.

In summary, the informants described the Resisting Dialysis phase as a time during which they took issue with or avoided the reality of renal failure. This phase culminated in a 'bottoming out' experience: a time of physical, emotional and spiritual distress and then moved on to the Fighting to Live phase. Before describing that phase, factors that facilitated and interfered with the Resisting Dialysis phase are described.

**Facilitating Factors**

The women's accounts indicated that two key factors facilitated adaptation to hemodialysis: a well-timed and effectively presented confrontation by a health-care professional and the first run on dialysis. The importance of a nurse's input is described as follows:

I thank my stars...the nurse said well if you had your kidney problem back then, there wasn't any dialysis, you wouldn't be here. I used to think of it a lot in the early stages when I was really not doing too well. I'd think, gee whiz, in less than ten years, five years, I wouldn't have stood a chance.

This confrontation by the nurse, a reminder that hemodialysis was life-saving technology, was replayed in this woman's mind during difficult times and appeared to
assist her in coming to terms with hemodialysis. The data suggested that the good timing and appropriate wording of such a confrontation may be essential to an effective confrontation.

And Dr. X sort of sat down and said, you don't understand, you're going (referring to urinating) but your kidneys aren't functioning...and I couldn't grasp that.

The other factor that positively influenced the women's acceptance of hemodialysis was the first run on dialysis. One informant described how her physician introduced her to dialysis:

...he said he wanted me to go into hospital to have this done [referring to the arteriovenous access graft] and to have a run on dialysis. So I said, "Just one". And he didn't argue with me about it and he didn't make me have another because apparently my condition improved to the point where I was alright...and I came home, but by Easter I knew that I needed more and I was willing to go back by that time. I had accepted the situation.

The gradual introduction allowed her time to realize independently that dialysis was crucial for her well-being. Another woman explained:

...but when I got on dialysis I felt better because my system was getting cleared.

The first run on dialysis and effective confrontation by a health-care professional facilitated adaptation in this Resisting Dialysis phase.
Inhibiting Factors

The women's accounts indicated that the inability to comprehend the illness and perceived threat to independence were key factors that inhibited adaptation. In relation to the inability to comprehend the dialysis situation, the women perceived two contributing factors: lack of preparation and the nature of kidney disease.

One woman said it this way:

I didn't really want to think about it because I didn't really understand it.

This woman's comments suggested that fear of the unknown could have been a factor influencing her avoidance response to her illness in the pre-dialysis phase and that this avoidance behavior negatively influenced adaptation to hemodialysis. The gradual onset of end-stage renal failure likely contributed to her avoidance response.

Another informant described her difficulty comprehending her illness this way:

...for some time Dr. X had been telling me I would have to go on dialysis. I used to comment when he would say that, I'm not going, I won't do that, I'll beat it you know.

She pointed out that even though she had been told many times that dialysis was imminent, she ignored the information.
The threatened loss of independence was another factor that appeared to interfere with adaptation. One woman described this:

I didn't realize my kidneys weren't working because I still urinated a bit. So I said, well I'm not going to be tied to a machine for the rest of my life.

Because this woman continued to produce urine, she could not grasp the fact that her kidneys were failing. In addition, the threat of being tied to a machine contributed to her resistance to dialysis. Another informant described how the threatened loss of independence worked against her:

I really didn't want a homemaker. I held out until just a few months ago and then when I went into hospital from January to March. They said, you have just got to have help because you have got to eat.

To summarize, the data suggested that a well-timed and effectively presented confrontation by a health-care professional and the actual first run were facilitating factors. Lack of preparation for end-stage renal failure, the nature of end-stage renal failure -- its slow and symptomatically deceptive development -- and the threat to independence were key factors that had a negative influence on adaptation in this Resisting Dialysis. The phase following the Resisting Dialysis
phase is the Fighting to Live phase. The following section addresses this phase.

**Fighting to Live**

The second phase of this adaptation process is the Fighting to Live phase. The women's accounts indicate that there was a time in the adaptation process that physical and emotional resources were restored. This Fighting to Live phase was the time when there was a regaining of physical and emotional strength following a time of depleted or waning resources.

There was a strong sense in the women's words that resilience was characteristic of the Fighting to Live phase and that the will to carry on was essential for this resilience. If the will was there, the women described how they went on to accept their situations, the Accepting It phase of this adaptation process.

One informant described the Fighting to Live phase in these words:

Well, you've got to fight to live. You can't sit down and just feel sorry for yourself and get depressed and don't care. You've got to get above that.

Another woman elaborated on this phase like this:

Yeah, well, stress is like a fight actually. It is, because you're in a turmoil. And, yes you are, you are fighting. It's probably the best word I could think of. Like you're so limited. On dialysis you're limited on everything. You're limited on what you drink, you're limited on what you eat, you're
limited on what you drink, you're limited on your energy and so therefore it cuts you back in every field.

She went on to say:

I never really got down and really felt for myself so bad that I was really upset too much. I wouldn't let that happen. I tried my hardest not to let that happen.

This comment suggested that the internal struggle involved in fighting to live was fending off self-pity and excessive anxiety. Because the results of Fighting to Live could be seen as beneficial, the effort was perceived as positive. One informant explained:

...it's not fighting it in a negative way but it's more like the fighting force. And then that makes you face it.

**Facilitating Factors**

The women described a variety of factors influencing this phase. The factors identified by the women that facilitated adaptation in this phase included role modelling of others, living for others, asserting control over the illness situation, experience with adversity, and reassurance and affirmation of self-worth.

Role-modelling from parents, grandmothers and other women were identified as a factor that facilitated Fighting to Live. One informant described how she was
inspired by the courage of another female hemodialysis patient:

And one lady I know, she's been on for 22 years. She's wonderful. She gives me courage too. To think that she could go all that time. And she said, well, I saw my grandchildren grow up. She gives the rest of us courage. We think, well if she can go 22 years, maybe I can.

Another woman described how she was inspired by her grandmother:

I was sent to live with my grandmother...so I was around sick people then and I saw what my grandma had to go through and the determination in her and I thought, if she could do it, I can too.

This woman described how her grandmother's determination inspired her to believe that she could persist through difficult times.

The above accounts indicated that role-modelling of others, especially of other women, enabled these women to face their situations with a posture that allowed them to overcome the hardships and to enjoy a meaningful lifestyle: a positive adaptational outcome.

Living for others was another motivating factor. One woman described how her commitment to others influenced her to keep on Fighting to Live:

I. People trying to help you, keep you going. You don't have the right to stop and just...

R. People, meaning...
I. Meaning the nurses and the doctors and family and everybody, they've all tried their best, so why should I quit.

She felt committed to keep fighting because the doctors, nurses and her family had done their best to help her. Several women were inspired because of their spouses. One informant expressed this in particularly direct terms:

R. What do you think it is that drives you to not wanting to give up?

I. To tell you the truth, he don't want to die and leave me, the same with me. I don't want to go and leave him. So, we're together.

Another woman claimed, when asked what made it easier:

Just having someone you love. My husband and I have a very special relationship I feel and that's a great comfort. But it also makes you very vulnerable.

These women gained comfort, strength and a sense of being in relationship with another. Another woman described how her family inspired her:

They have me out to their place. I don't even think they realize they're helping me...it helps me because I know they want me out and they pick me up and include me in everything. It's nice to know you're wanted. It's nice.

In this account, the informant pointed out that simply knowing she was wanted by her family gave her the strength to carry on. Living in relationship with others so that inspiration, comfort and strength was derived
from those relationships is a positive factor in the Fighting to Live phase.

Asserting a sense of control over the illness situation appeared to be a third facilitating factor in this phase. The women achieved this in a variety of ways that included putting mind over matter, advocating for their rights and taking positive action. One woman shed some light on how she achieved a sense of control over the situation by putting mind over matter:

I really think I wouldn't have been as well as I am. I think I would have been more sick...it's lots to do with the mind. And that's what has to be brought to people, if people don't have that mind over matter then they're not going to make it. I don't think. Because your mind, your mental and your physical work together.

Another informant demonstrated taking control this way:

I had to make up my mind on that Monday I was going to have it out with him one way or the other way because I'd told him that I'd gone to my family doctor and he wanted to call a specialist. He says, you don't need a specialist, you've got me. Well, I don't like that attitude. He's only a kidney man and he's not paying attention to my other problems. And so I made up my mind that I was going to have it out with him.

Here, the informant was taking on the health-care system and confronting it. Another woman mentioned control in relation to compliance:

...the doctors, they give me that pill. I'll take it until I find out if it's got a reaction on it. Well,
I'll just quit like that and I'll tell the doctor that I can't take it.

This woman explained that if she needed to take action to improve her well being, she would, even if she had to oppose the judgement of her doctor.

Experience with adversity, another factor, provided the confidence necessary to assert control over their illness situation. One woman reflected on the possibility that women were well prepared to handle the adversities of end-stage renal failure.

Women are better than men. We're more tolerant. Men just blow their stack when they want to. You've put up with kids and that and I think it's tolerance.

Another woman, when asked what she had drawn on in herself to deal with the difficulties of her situation replied:

It was hard work and I've always been a stubborn person. I've never let things get me down too much. I've never given up. I knew I could do it you know.

The confidence that she could deal with the situation with dialysis sustained this woman through the difficulties of dialysis.

Emotional support, particularly reassurance and affirmation of self-worth were particularly sustaining for the women. One informant who had recently been
through a particularly difficult time recalled her experience in the hospital:

I. And she said, you know, I really believe you're going to get well and we will help you. We want you to come back, everyone wants you to come back. And I was so thrilled and so happy about that.

R. And what was it about that that helped?

I. Well, the assurance that I was doing well. They would give you praise about how you're doing...it was the positive attitude, that's what made the difference. There was no one that was negative. The doctors are good too...and it wasn't phoney.

In a time of crisis, this informant's spirits were lifted by the assurance and affirmation of self-worth she received from the head nurse on the dialysis unit.

Another informant, in response to the question of the most important thing that helped a person to cope with dialysis responded:

Kindness. If you're there and you say to someone we're here to help you and we'll do what we can, mean it. Not just say it, turn your back and forget it. Mean those words or don't say them. Sometimes you can be down and out and somebody comes and says one kind little word and you're a whole new person.

In this quote, the informant described the power of kindness in healing. Yet another woman described the importance of affirmation of self-worth in assisting her to deal with a very difficult time:

R. Can you think back to a time that you've been through with the hemodialysis where you really
weren't doing all that well, and you really needed help and reflect back on what helped you get through that?

I. When I first started, things were very bad and I was impressed that Dr. X was concerned about me as a person. I feel he cares about me as a person. I feel he's a good Dr. in that way. He has feeling.

This woman also focussed on the importance of a humanistic approach by professional caregivers. In these accounts, reassurance and affirmation of self-worth appeared to give the women hope.

Inhibiting Factors

Two key factors interfered with adaptation in the Fighting to Live phase: the lack of confidence in caregivers and reduced energy. With regard to lack of confidence in caregivers, one informant described the experience of being cared for by inexperienced nurses:

And when you get a fumbling gal, in my case right now and for quite some time, it's...one needle here and one needle here and now they've started to go into the elbow but the newer ones [referring to new nurses], you struggle.

This woman went on to describe how disturbing it was for her to deal with her concerns about whether or not her runs would go well.

I'm always in a stew about it [referring to the hemodialysis runs], because see, when you're going three times a week, I'm just getting over yesterday and I have to think about tomorrow. I don't have time to get over it. That's my problem.
Her constant anxiety about this aspect of her caregiving concerned her to the point that she felt it was a key negative influence on her overall health and well-being. Another informant articulated her lack of confidence in caregivers this way:

And I was so bad, I was just about screaming the hospital down with getting sick at my stomach and my cramps and I was just about passing out. I was just barely conscious and that's all. And when X [referring to a nurse], or one of those that are on like that, they would come and tip me upside down and they'd go off and leave me and never come back unless I called for them. And to me, it's their job when they've got a patient like that that's passing out and having those cramps so badly that you almost scream, I think it's their job to sort of stay around and look after them.

This woman felt secure when the nurses showed concern in a time of difficulty. Another woman offered the following reflection:

If you have to be in the hospital, it's a very pleasant place to be [the renal unit]. I was on another ward and the nurses were terrible. They weren't a bit pleasant. So when I came back to the renal unit I said [in jest], well now I've found someone worse than you guys. They said, well at least now you'll appreciate us. But they're terrific.

Reduced energy, a plague to all on chronic hemodialysis, was another factor that negatively influenced adaptation in the Fighting to Live phase. One informant suggested this energy reduction had two aspects:
There are two kinds of tired, one when you have a good reason to be tired and you're not feeling well and you're sick and the other you're tired because you're fed up with everything.

This quote identified that fatigue in women on hemodialysis arose from both physical sources and emotional sources. She went on to say:

And I don't like to go around saying I'm tired. I don't feel good and sit and mope and just sit there. When you don't feel good you don't want anybody around.

When this woman experienced overwhelming fatigue she didn't feel good about herself, and preferred being alone to joining in on social activities. Another woman described how she managed the demands of her life so that she would have enough energy to deal with unforeseen problems:

I don't undertake anything that I can't do, because it's silly to say 'yes, I can do it' and then I get worn down and if something happens, I don't have the energy to fight back. I have to reserve my energy if something does happen that I will be able to fight back.

Implicit in these quotes is the notion that reduced energy thwarted adaptation to hemodialysis.

In this Fighting to Live phase, the key facilitating factors were role modelling, living for others, asserting control over the situation, experience with adversity and emotional support, in particular reassurance and
affirmation of self-worth. The key inhibiting factors were lack of confidence in caregivers and reduced energy. If the overall result of this phase is difficulty with adaptation, the data suggested that the next phase would be Giving Up. If there were adequate factors to facilitate adaptation, the data suggested the next phase was Accepting It.

Accepting It

The Accepting It phase follows the Fighting to Live phase in this adaptation process for women who experience an overall positive adaptational outcome in the Fighting to Live phase. Women who had a negative adaptational outcome may give up, an end point of this adaptation process.

Cognitive maneuvers that changed the meaning of the situation were characteristic of this Accepting It phase. One woman articulated the nature of the Accepting It phase:

I appreciated more and more because gradually without even my realizing it my values were changing and my appreciation of life and pleasures were changing. That's what I guess I've drawn on. But it's such a slow process because you might term it as...an acceptance.

Another informant described it as an appreciation of life:
Well, when you see people complaining about a headache or a backache, sometimes I feel like shaking them. I think, if you go in the hospital and see all these people with so much trouble, you should be thankful and, like some of them have had two transplants that haven't worked and yet they keep hoping. So I think we appreciate life more than most people.

A third woman explained how she views accepting dialysis:

Well, you have to learn to live with it and the best thing you can do is to accept it as much as you can in a positive way. That's the way I look at it.

A fourth woman perceived that it was essential to make the best of it if one was to adjust to dialysis:

Your life is different and you have to adjust to that way of life. Either make a go of it or make your life miserable.

These accounts suggested that the essential aspect of accepting dialysis was to learn to approach life in a new way. Several factors influenced the adaptational outcome of this phase.

**Facilitating Factors**

Factors that facilitated adaptation to chronic hemodialysis identified by the women in this study included reframing the experience, ignoring it, and being a woman. Reframing the experience was the most frequent method used by the women to come to terms with their dialysis situation. The women reframed the experience by
making the best of it, using positive comparison, focusing on their wellness rather than illness, looking on the bright side and finding humor in the situation. One woman described how she reframed this situation as a part-time job:

The way I really dealt with dialysis was, okay, this little procedure I've got to do for the rest of my life and I try to think of it as something else other than a treatment. I thought of it in my mind as like a part time job. Okay? Just like I said, like a part-time job. And I've got to get up today and I've got to go and it's just so automatic, it just becomes like—just like you're going to work every day. I know, I've worked quite a few years. You get up every morning, five days a week, punch that clock in, be cheerful and say good morning to everybody and then when its over, wish everybody a good day.

Another informant described being on dialysis like having a "habit":

I talk to myself sometimes you know. I say, well, there's nothing I got to do. I've got a habit. So you might as well settle down and do it. So I just go in and lay there and let them put the needle in and hook up the machine and then in four hours I can walk out.

Thinking positively was an important aspect of reframing:

I have to talk to myself and say, its no use panicking about it. I've got to accept a certain amount of it and think how lucky I am.
Another woman described a similar process:

Yes, well sometimes if you feel yourself sort of slipping or getting some negative thoughts. I try to think of the positive things, be thankful for what you've got, what is good and not dwell on what is not good.

Finally, one woman was able to reframe the experience by using positive comparison:

When I'm on dialysis, I think of people...you know, it could be much worse.

A second factor that facilitated adaptation in this phase was ignoring the situation. The women reported that they ignored the situation by leaving it behind when they left the unit or pretending that none of this was happening or by ignoring the machines. One woman responded:

Well, I just sort of pretend that none of this is really happening and I try to go on with my life as best I can.

Another woman said:

I leave that hospital behind me. I should know how that machine runs inside out, but I don't and I prefer to have it that way. I don't dwell on any of it. I don't think it's healthy to do so.

Ignoring their dialysis situation allowed these women to go on with their lives free of thoughts of their dialysis treatment.

The informants reported that having traditional female values facilitated acceptance of the hemodialysis
situation since these values made it easier to adapt to the sick role and to adjust to the demands of the dietary regimen. One woman explained:

Men don't think that it's very manly to be sick. And a lot of them don't seem to be too happy on the machine whereas women seem to adjust fine.

Another informant noted:

I think it's probably a lot easier for women to accept than men because of the cooking and all of that. Yeah, the diet you see. You've got to know what to buy and how to cook it. How to cook it and how to prepare it.

These women viewed characteristics particular to holding traditional female values as enabling them to accept hemodialysis. In summary, key factors that facilitated adaptation to hemodialysis in the Accepting It phase appeared to be reframing the experience, ignoring the situation and having traditional female values.

**Inhibiting Factors**

The factors that interfered with adaptation in the Accepting It phase included additional health problems, loss of independence and problems with transportation to dialysis.

The women reported that additional health problems interfered with accepting their hemodialysis situation. These problems included diabetes, blindness, cancer,
constipation, heart failure, fractures and a stroke. The women also identified health problems related to dialysis as troublesome. These problems included itching, weak legs, pain and sleep disturbances. One woman, when asked how she was managing, replied:

Well, I find that my greatest problem is that I'm being bothered with itching. It's there at night and in the morning. I can't understand why.

Several women identified other physical problems as key factors that made living with hemodialysis difficult. One woman, reflecting on her additional health problems stated:

I'm sure when the doctor's get these problems straightened out I'll feel a whole lot better.

This woman's comment suggested that living with dialysis was perceived to be a life-style that is acceptable, but that the additional physical problems added considerable strain. The women's accounts indicated that additional health problems strained the women's energy resources, reduced mobility and interfered with acceptance of hemodialysis.

Another factor that interfered with adapting to hemodialysis in this phase was loss of independence. One woman, a relative newcomer to hemodialysis, said:

The hardest part is when you have been so active all your life and then to suddenly realize you can't do
these things. I can't garden. I can't do my housework and the things you're used to doing. If you've been a hard worker all your life and you've done a lot of these things. So I guess it's giving up independence. That's what it really is.

Another woman remarked:

I feel disgusted. I don't like to be dependent on him [referring to her husband] to do everything. I want to do it.

Another woman put it this way:

I get so frustrated at not doing things myself. I've always been independent. I've done everything myself and to have my husband do everything, I felt just terrible at first. Just terrible. But now I just let him do it whatever way he wants to do it. I could just cry at first, but I've given that up. You just have to accept it.

Another woman responded:

I think the most frustrating thing to me is that it takes me, that I can't work and earn money. I would say that's the number one thing.

The data suggested that the demands of the dialysis regimen and the physical problems accompanying dialysis resulted in increased loss of independence which was a frustration for these women.

Another area of frustration identified by the informants was transportation to and from dialysis. One woman claimed:

Having to take two rides in the morning...that's the only thing I get frustrated about.
Another woman remarked:

I think the worst part is the long time that it takes to get into town and to get home...by the time I get home I'm exhausted.

A third woman commented on the effect on her health of the conflict between her run times and transportation to dialysis:

Well, I think they should have a better system down at the hospital. Sometimes I don't get my full time and I think part of my leg cramps is nerves wondering if I'm going to get off in time to get down there because Handidart can be very nasty.

Problems related to the ride to and from dialysis strain the women's physical and emotional reserves and interfered with accepting dialysis.

In summary, key factors that facilitated adaptation in the Accepting It phase were reframing, ignoring the situation and having traditional female values. Key factors that interfered with adaptation in this phase were additional health problems, loss of independence and difficulties with transportation.

The Accepting It phase seemed to precede the Facing It phase. As one informant put it "Once you accept it then you can face it."
Facing It

Looking for solutions to constant problematic situations was characteristic of the Facing It phase.

One woman put it this way:

You've got to face the thing and try to sort it out.

She went on to say:

There's things that come up that you have to deal with in dialysis, a part of dialysis and there are conditions that creep up here...every once in a while and you've got to face it. You've already accepted the dialysis but there's little things, there might be some operation in your grafts and things like that...

Another woman suggested that the challenge in this phase was to live a meaningful life:

As soon as you're accepting it and you're beginning to feel a little better, then you begin to think... fitting this into your life and carrying on.

These statements together described the essence of the Facing It phase.

Facilitating Factors

Key factors that facilitated adaptation in this phase were talking to others, assistance with tasks, competent caregivers, diversions, and adequate rest.

The informants described situations in which it was helpful to talk with other patients, family, friends and health-care professionals. One woman spoke of the
importance of talking things over with other hemodialysis patients:

I think I learned more from other people about the hemo than I did from anyone because when I first went into the hospital I really didn't know what was happening and there was others like myself that maybe had been on hemo longer and could tell me really what I was facing and what was coming up. It didn't look good but that's what happened to them and I thought, well, the same thing is happening to me, you know.

This woman emphasized how essential it was for her in the early stages to hear what others had experienced with their dialysis situation. This woman identified this source of information as the most important source of support for her in facing dialysis. The following quote details how talking to other hemodialysis patients was a source of on-going support:

[Referring to the physical set-up]...basically there's three of us that can talk. We hear each other really well and the three of us are together because we are ones who don't qualify for a transplant so we have a few things in common. Sometimes like on a weekend you may get a little overloaded, as in too much fluid. So I'll say, okay, what did you indulge in and then we figure it out...people will say, well, I don't know how that happened. And then we start asking, well, what did you have to eat. And then we point it out - well there, you'd better not do that again, that's where your problem is.

The physical set-up in the dialysis unit allowed for the patients to talk over problems that arose for them related to managing their situation with dialysis. By
talking with the other patients, this woman reported that they were able to creatively problem solve together. Waiting for hemodialysis was another time hemodialysis patients talked to each other:

We have to wait so long for our machines, around 45 minutes which is quite a long time, there's such a load of patients, so we do get time to talk. When we talk to each other wetell each other how we feel.

The informants pointed out that talking things over with friends, nurses, the dietician and counsellors was helpful in finding solutions and venting frustrations. The time during which the nurse held the graft following the run was identified by one informant as a valuable time to talk.

You get into a conversation and if there's no-one following you in the bed, then no-one is being rushed. It might be quite social or if you have a question to ask or something strange is going on, you'll ask them. The more knowledge I think it's better, I feel better.

This woman received important information simply through talking with the nurse who was holding her graft after the dialysis run. This informant also identified a factor related to talking it over: the availability of the health-care professionals to be so engaged.

Talking things over with a significant other appeared to have special meaning for the informants. One woman explained:
I let down with my husband more than to anyone else. He's marvelously accepting and patient because you have to voice it to someone. You can't keep it to yourself all the time. But I try not to do it in a whiny fashion. I try to just talk about it because that relieves it and I think it's good to bring these things out in the open. He talks about how he feels about it too but he's a very strong person.

Talking things over with others was perceived by the women as a key factor in adapting to chronic hemodialysis. Talking things over with other patients, health-care professionals, special friends and significant others to find solutions to problems, to relieve tension and frustrations or to receive information was perceived by the women to have a positive effect on physical and mental health.

Assistance with household tasks or with financial situations was another factor identified as essential in living with hemodialysis. Family members and homemakers were the primary support identified. Three women reported that if it weren't for the care they received at home from others, they would have need of a care facility. One woman saw herself as very fortunate:

My husband is very marvelous. If it weren't for him I'd have to go into a home because I don't think I could manage by myself right now.

Another woman gave credit to her son:

If it weren't for my son, I would have quite a time. He does all the housework. And he gets the meals on and everything he can possibly do.
Assistance with financial matters was also identified as important. To the question about what helped to make it easier one woman replied:

My sons. Anything we want, they'll give us. My son he bought a walker for me. They're just wonderful.

Another informant emphasized the importance of assistance with financial matters:

Sometimes X [her husband] takes over. We had a big form to fill out and I said, I can't do this. He said, you don't have to. So he spent all Monday afternoon on it.

These woman described situations in which they counted on others to assist them in meeting the demands of daily life.

Confidence or faith in professional caregivers was a factor identified by the informants as essential in adapting to hemodialysis in this Facing It phase. When asked what helped in dealing with dialysis, several woman commented on the competent, warm presence of the physicians, nurses, technicians and aides. One woman put it this way:

If something's happened, accidental, they seem to fix it right away and everything's fine. If there's something wrong with me the doctor's been good and the nurses are attentive and the technicians are helpful. Even the girls that make the beds are very good to me.
Another woman said:

Well they'll do anything for you. Or if you need help, you just ask and they'll get it for you. Or if I need another doctor for something they have him come right away. You feel secure because everything is done right away for you. If you're cold, they bring you an extra blanket or ask you if you want a hot water bottle or if you're not feeling well, they'll wave and say are you all right, is something wrong?. They always seem to be on guard whether you're up or down. If they thought you were down, they cheer you up. They try to get at whatever it is that's bothering you, they would try to help you.

These accounts suggested that these behaviors on the part of the caregivers assisted the women by boosting morale and making the women feel secure. Overall, the women's accounts made it clear that confidence in caregivers was a powerful factor influencing adaptation to hemodialysis. One woman summarized it in these words:

You've got to have something to hang on to...faith helps. Faith in your doctor and nurses. If you haven't got faith in them you're alone.

Without faith in the competence and caring of the doctors and nurses, this woman perceived she would have felt very much alone in her illness.

Diversions were identified by the women to be important facilitating factors in this phase. Diversions appeared to alleviate the monotony of the dialysis regimen. Important diversions included hobbies, volunteer work, travel, seniors clubs, outings with friends and spouses, fun and humor on the unit and even
maintaining the daily routine. One woman explained this:

You've got to have interests. You've got to have hobbies and things. I find that is what really keeps me going. Like, there's a lot of things I like to do outside. I like gardening. I think it's good for the mind, it's good for the body. And I like sewing too.

This same woman explained that volunteer activities had helped her by making her better about herself and capable of working with others. She said:

Volunteer work has really helped me a lot because I felt better about myself, I can do this.

Diversion in the form of travel was repeatedly identified as important to the women. One woman, speaking of the dialysis treatment said:

It [hemodialysis] gets a little tiring. I'd like to chuck it...a trip...I'd be getting away from everything. I like the idea of getting away for a while, that's all. It's fun.

Another woman noted that holidays to her were a reward:

You have to reward yourself with a holiday or something like that so you've got something to look forward to.

Fun and humor on the hemodialysis unit were reported to be an attractive diversion for some. One woman described how she and another patient, with the help of the nurses, broke the monotony of a morning on dialysis.

Like, this morning, my friend and I brought in a birthday cake for one of the patients - it was her birthday. And they bring it in about half way through the morning and we all sing happy birthday and we all get a piece of the cake. It's just something that
takes away the monotony from being there all morning. So we just bring the cake and balloons usually to put over their beds.

Celebrating a birthday on the unit with cakes and balloons appeared to interrupt the monotony of the dialysis run and was perhaps also a life affirming act.

Even the daily routine was valued by the women as an important diversion. One informant put it this way when asked what kept her going:

Ordinary days. Get up, have my meals. Go out. Go for walks and go for coffee in the afternoon, come home and watch TV have supper and go to bed...walks around the park and we go down to Eaton's or the Bay and look around and window shop we call it or our wishing windows. It gives you a feeling that you just wish you had the money to but that.

The daily routine gave this woman comfort, companionship and sensual pleasure, thereby boosting morale.

Diversions appeared to keep the women going by breaking the monotony of the situation, providing companionship, sensual pleasure and an opportunity to experience a sense of accomplishment.

Finally, resting was identified by the informants as essential. One woman said:

You just couldn't keep going every day. It would be hard to be on deck every day. So I think these mornings when you slump a bit do help you keep going as well.

Another woman, when asked what has made it easier on dialysis, replied:
I do enjoy the days that I don't go in to the hospital. I look forward to that break because I can really sleep in if I want and take it a little bit easier so it does help.

Days that were designated as days of rest allowed these women to rebuild the strength needed to keep going.

In the Facing It phase, key factors that facilitated adaptation were talking to others, assistance with tasks, competent caregivers, diversions and rest periods.

Inhibiting Factors

Key factors that interfered with adaptation in this phase identified by the women were lack of confidence in caregivers, reduced energy, compromised somatic health and difficulty with assertiveness. The first three of these factors have been discussed elsewhere and will not be repeated here.

With regard to difficulty with assertiveness, one woman described her dilemma in confronting others:

I don't like fighting, I never did...I was always afraid of hurting someone...because I don't like hurting people's feelings. I hurt myself by doing it.

Although several women realized they must stand up for themselves in order to enjoy a certain level of well being, one woman pointed out that by advocating for herself, she took risks:
I've got to make a decision. There's two nurses I am not very happy with putting me on. That's all there is to it. Two out of that whole group of, what, there must be about 40 or something. But, my blood pressure goes up just trying to hold that stance.

She went on to say:

I'm not going to let a couple of young nurses upset me whole life at this stage of the game. That's all right for me to think that way, but to put something into action...is a different story.

Although this woman was determined to overcome her problem with the nurses, she lacked confidence in her ability to confront the situation effectively.

Factors facilitating adaptation in the Facing it phase were talking to others, assistance with tasks, competent caregivers, diversions and adequate rest. Inhibiting factors were lack of confidence in caregivers, reduced energy, compromised somatic health and difficulty with assertiveness.

Losing Hold

Characteristic of the Losing Hold phase is a decreasing will and strength to meet the demands of life on hemodialysis. One woman put it this way:

I'm just too tired to think. Nothing seems as important as lying down and if I don't go to sleep but I'm just resting I feel alright. You lose your capacity to keep going in life.

Another woman spoke of a weakening of her emotional reserves:
You know, you get these little depressions once in a while. This is how it starts. You might get one this week and maybe it's once a week and pretty soon you find it's coming closer and closer and you're getting them more often, like twice a week. Maybe you had dinner and you're sitting there thinking and then all of a sudden it hits you and you start crying and you feel sorry for yourself. Pretty soon it seems the time you're dealing with it is longer and more frequent and then it seems a lot easier to stay in it than it is to snap out of it.

These women described situations in which they experienced a loss of will. Losing Hold appeared to involve losing the ability to keep going.

Facilitating Factors

Two key factors facilitated adaptation in this Losing Hold phase: the positive presence of others and turning inward. One woman described what was necessary to overcome the listlessness of this phase:

Something has to happen. Something has to come along there. There might be a person that will come along and give you some enlightenment or something and it can break it.

This informant articulated how some intervening act could interrupt the enervated state experienced in this phase. Another informant shed some light on the kind of act that had the power to reverse this state in these words:

Little things count. Little things make all the difference in the world. Sometimes you can be down and out and somebody comes along and says one kind little word to you and you're a whole new person.
Another informant described a similar phenomenon when describing her listless times:

Having that thing come along and it brings you right out and right up. And it's almost pretty instant. Just everyday things that can take you right out of it. But it's having that thing come along.

The data suggested that a positive act such as a kind word could instill hope and reverse the enervated state of the Losing Hold phase.

Another factor described by the women as empowering in this phase was introspection. One woman when asked what she did when she felt herself losing hold, replied:

Well, I can't cope with anything else. I just have to concentrate on getting better. Concentrate on myself so your thoughts turn inward again. And if you get out of that you feel good again.

Another woman, when asked the same question, replied:

I just don't come out until I'm feeling well. I pull inside and then come out when I'm ready to face things.

There was a sense in the words of these women that turning inward allowed them to regain the strength necessary to move forward.

Inhibiting Factors

The key factor that interfered with adaptation in the Losing Hold phase was a stressor that placed undue burden on the individual by its prolonged presence or by
it's potential to generate a series of additional stressors. One woman described how a lengthy cold made her feel:

Well, I'm tired, but I think it could be the cold I have. I'm just very tired. When you're down, everything - sluggish, and heavy and you don't feel like going to the hospital any more. Just don't feel like I'm on the mend and wish you could get away from it...the cold. It wears you down.

Another woman described how the accumulation of physical problems affected her:

Well, my kidneys aren't working at all. And I have to take all these pills that are making me more constipated...it just means that my bowels are not working and it just keeps building up and building up until I'm so sick that I can't eat anything. I eat two bits of a piece of toast and that's all. I gag on it...every time I move around I get this nauseous feeling and I'm just at a point where I'm ready to pack it all in.

This woman described how one problem led to another until she was ready to give up. The data suggested that stressors that taxed the resources for prolonged periods or stressors that generated additional problems were negative factors in this Losing Hold phase.

In the Losing Hold phase, the presence of others and turning inward were key facilitating factors, whereas stressors that were lengthy and generated additional inhibited adaptation in this phase. A positive adaptational outcome of this phase led back to the Fighting to
Live phase whereas the data suggested that a negative adaptational outcome led to Giving Up.

Giving Up

Giving up is a tentatively formulated phase of this adaptation process since none of the informants actually appeared to be in this phase. Nonetheless, since two of the informants indicated that they could conceptualize giving up as an alternative, this tentative phase of Giving Up is addressed. Since none of the women were actually in this Giving Up phase, the data from this study is not complete enough to identify factors that facilitate and interfere with adaptation in this tentative phase. This section will therefore only present how the women conceptualized the possibility of giving up.

The account of one woman described a situation in which she considered giving up as an alternative. In the following words, the informant described a situation in which she experienced considerable distress due to an unresolved physical symptom:

I. I feel, why am I coming here if he's not going to help me. He's a doctor, whether he's a kidney specialist or not. He's a doctor and if I complained I think he should investigate it more. Or else say, go to see a specialist or go to see somebody else. But he never says that. I just feel like I don't want to go there any more.
R. And you want to do what instead?
I. Nothing. Give up.

Another woman described how she courted with the notion of giving up:

I'm tired of the whole thing. I just don't want to go anymore...but the fighting hasn't gone out of me yet. When it comes right down to it, I'll fight. I'm tired and I want to give up but I won't. I'll fight and then I'll say what for. You get right down and you think about things and say why bother.

These accounts suggested that there may be a phase in this adaptation process in which the chosen alternative was to give up the struggle with the demands of the illness and the dialysis regimen.

In this section of Chapter Four, one of the two central themes, the adaptation process, was presented. The phases of the adaptation process, Resisting Dialysis, Fighting to Live, Accepting It, Facing It, Losing Hold and the final but tentative phase Giving Up, were described. Factors that influenced adaptation to chronic hemodialysis were identified and discussed in relation to the first five phases of this adaptation process. In the following section, connectedness, the theme influential to each phase of the adaptation process, will be discussed. Factors influencing adaptation that are relevant to connectedness will then be described.
Connectedness

The theme of connectedness was the second major theme identified from the data analysis. Connectedness, or being connected, is defined here as being in a relationship with others and/or sources of life energy. Although connectedness is presented subsequent to the adaptation process, it is emphasized again that this theme is in no way of secondary importance. Connectedness has a primary effect throughout all phases of the adaptation process. Throughout the women's accounts there were descriptions of relationships and situations in which the women experienced a degree of connectedness. Connectedness was therefore conceptualized as a continuum, with being disconnected on one end and being connected on the other (see Fig. 4).

There was a sense in the women's words that when connected, they experienced enhanced well-being, a positive adaptational outcome. On the other hand, when the women were disconnected, they experienced a decreased sense of well-being, a negative adaptational outcome. Therefore, connectedness is part of well-being and as such is likely an indicator of adaptational outcome. Being connected to others and/or sources of life energy also appeared to be a facilitator of adaptation. One
woman articulated the purpose of connectedness particularly well:

    You've got to be in contact with ... it's like a power that will give you some drive ...

She suggested here that connectedness provided motivation for adapting to hemodialysis. Another woman described the sequence of events within her dialysis situation that had the potential to lead to social isolation:

    And I don't like to go around saying I'm tired. I don't feel good and sit and mope and just sit there. When you don't feel good you don't want anybody around.

The data suggested that connectedness was an indicator of adaptational outcome. This woman reported that feeling unwell was accompanied by not wanting to be involved with others socially. These two accounts, taken together, described the intricate relationship between adaptation and connectedness: connectedness was both an indicator of adaptational outcome and a facilitator of adaptation.

    The women's accounts indicated that the level of connectedness varied within the phases of the adaptation process. A sense of connectedness was experienced most intensely in the Facing It phase of the adaptation process. Disconnectedness was most intensely experienced in the Losing Hold and Giving Up phases (see Fig. 5 and 6). Figure 5 is a linear representation of the notion
that the level of connectedness varies in relation to the phases of the adaptation process. Figure 6 is a cyclical representation of the same phenomenon.

The data of this study suggested that there was a link between the women's perception of connectedness and the level of adaptation, factors that facilitated and inhibited this state were central to understanding the women's experience. While numerous factors were identified, only essential facilitating and inhibiting factors are presented here. Following is a presentation of the factors that were identified by the women that contributed to a sense of connectedness.

**Facilitating Factors**

Factors identified by the women in this study that contributed to a sense of connectedness included satisfactory relationships, normalizing by assuming a well role, nurturing others, harmonious atmosphere on the hemodialysis unit and pleasurable activities (see Table 3.)
CONNECTEDNESS

Being Connected  Being Disconnected

Figure 4. Connectedness as a Theme
Figure 5. Connectedness: In Relation to the Adaptation Process
(A Linear Representation)
1. Resisting Dialysis → II. Fighting to Live → VI. (Giving Up?)

- - - - - -
bottoming out

V. Losing Hold

III. Accepting It

IV. Facing It

Level of Connectedness

--- --- Connected
--- --- --- --- --- --- Disconnected

Figure 6. Connectedness: In Relation to the Adaptation Process
(A Cyclical Representation)
### CONNECTEDNESS

<table>
<thead>
<tr>
<th><strong>POSITIVE FACTORS</strong></th>
<th><strong>NEGATIVE FACTORS</strong></th>
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<tr>
<td>• Satisfactory relationships</td>
<td>• Isolation from others</td>
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<tr>
<td>• Nurturing others</td>
<td>• Unsympathetic others</td>
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<tr>
<td>• Normalizing</td>
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<td>• Harmonious atmosphere on unit</td>
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<td>• Pleasurable activities</td>
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<td>• Exclusion from activities</td>
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Table 3. Factors Influencing Adaptation in Relation to Connectedness
Satisfactory relationships is defined here as an involvement with other people that enhances well-being. One woman described the nature of her involvement with her husband in these words:

We save each other. So the more I can do, he helps me, I help him. That's the way it is.

Two other women recalled experiences with their family. One woman described a visit from her nephew and his son:

My nephew comes over and we cook up some things together. He has a little boy who's just turned four. And I find I eat better when I'm eating with somebody. Because when you're alone, you just don't feel like it. But when somebody else is there and you're talking and doing things you find you're eating and you don't realize you're eating.

Another woman recalled an outing with her son:

Well, my kids. My son come in one day and said, come on Mom, going to take you out to lunch, and he took me out to Steveston and they've got tables there on the dock, we bought fish and chips and had a drink and we sat there and had it and it was nice. It was unexpected and right out of the blue...and I like to be thought of.

In the case of the first woman, sharing meals with her nephew and his son improved her appetite and, in the case of the second informant, an outing with her son appeared to strengthen her self-esteem. Finally, one informant described how her involvement with the local Chapter of the Kidney Foundation was good for her. She said:

I feel good about it [volunteer work] because I think that I am doing something worthwhile. And I think
it's rewarding in that way. That it's helping others...people in the transplant program. It's good to see them that, you know, they're well and happy. It makes you feel good too.

Involvement with other kidney patients and seeing them thrive enhanced this informant's sense of well-being. These women's accounts indicated that satisfactory relationships is associated with enhanced self-care, an improved appetite and increased self-esteem.

Normalizing the illness by assuming a well role was also a factor that contributed to a sense of connectedness. One woman articulated how this worked for her:

I'm determined not to be an invalid. I think if I gave way to it I could you know. And that's because my husband needs me to be like that so I want to do that for him too. To keep his life as normal as possible because he makes a lot of adjustments...and for my girls too. I've always made a point of...not dwelling on my illness or my physical thing. I think it's a bore socially...discuss more interesting things...I'm not talking about being sick and so I'm sort of more of as normal person...I'm alright sort of thing. It means I'm one of the crowd...It makes me feel as if I'm coping with this.

This informant stated that she downplayed her illness to fit into the family unit, because it makes her more attractive socially and because it makes her feel like one of the crowd. She said that presenting herself as if she was not sick makes her feel as if she was coping with her illness situation. In this situation, normalizing the illness by assuming a well role enhanced connected-
ness and was an indicator to this woman that she was successfully adapting to her chronic illness.

Another woman recalled how and why she 'puts on a face' for others:

R. When you say you have to put a face on for people, who are the people you have to put a face on for. How does that work - putting on a face?

I. Well, I guess it's the nurses and family actually you know, I don't let them know how bad I'm feeling often times. If I told the nurses exactly how I would feel I kind of think they might panic ... I found my sister will phone up and ask me how I'm doing and like that and I'll be sitting here in a great deal of pain, but I just say, I'm just not feeling so good, I've got a stomach ache or something and put it off as that. But if I told her how I really felt, she would be worried and I don't want to worry her. She's got enough problems of her own.

This informant told how she minimized her physical discomforts with the nurses and her sister by 'putting on a face'. She did this to reduce the possibility of misunderstanding between the nurses and herself and to limit the imposition of her problems on her sister. It seems that she used these strategies to stay connected with important others. These accounts suggested that normalizing by assuming a well role enhanced connectedness by reducing the barriers between self and others.

Pleasurable activities were identified as factors that facilitated connectedness to others and sources of
life energy. In response to the question of what helped her cope with dialysis, one woman replied:

We go for a drive every morning that I'm not in the hospital to the bird sanctuary. We drive into the farmland early in the morning. It's lovely first thing in the morning.

The daily routine helped another woman deal with her situation. In response to the same question, this woman replied:

I. Just the everyday routine. I cope with the routine of getting up, having breakfast, washing and watching TV, going out for a walk. That helps. It brightens up my day.

R. That you're doing them?

I. That we're doing them together.

Participating in the daily routine lifted this woman's mood and provided an opportunity for closeness to her spouse. The women's accounts suggested that pleasurable activities were uplifting. As well, these activities provided an opportunity for being connected with others.

Nurturing others was a factor identified by the informants that enhanced connectedness. The women's accounts suggested that nurturing was expressed in the following activities: keeping in touch with friends by mail, interest in and concern for other hemodialysis patients, sharing activities with family within the role of partner, mother, grandmother or aunt. One woman
described how she expressed nurturing by keeping in touch by mail:

Yes, I write all the time. I'm having a little bit of trouble with my arthritis. But I've always sent birthday cards to everyone. Lots of my friends say, well, be sure and send my husband a card. You're the only one who does.

The same woman described how she and a fellow hemodialysis patient together supported another patient by celebrating a birthday:

Like, this morning, my friend and I brought in a birthday cake for one of the patients - it was her birthday. Any of the patients who have a birthday, she and I bring in a birthday cake. And they bring it in about half way in the morning and we all sing happy birthday and we all get a piece of the cake. It's just something that takes the monotony away from us being there all morning. So we just bring this birthday cake and balloons usually to put over their beds and that.

Another woman described how she nurtured her grandchildren. In response to being asked how her illness affected her role as a grandmother, this woman recalled time spent with her grandchildren:

I read to them and have fun with them otherwise and I don't know, just share things. I make a thing of having an apple. And we were giving little presents the other day...different ways...but mine isn't as physical a role as their other grandmother.

This informant described how she continued to nurture her grandchildren in spite of her limited energy: she fostered her relationship with her grandchildren by expressing nurturing in ways that required less energy.
The women in this study appeared to have continued their role as nurturer in spite of their illness situation. These women's accounts suggested that the women have adjusted the role to fit the new situation: choosing convenient opportunities for nurturing and selecting nurturing activities that required less energy. Nurturing enhanced connectedness; these women reported a positive involvement with others as a consequence of their nurturing activities.

Another factor that was important for an overall sense of connectedness was the harmonious atmosphere on the hemodialysis unit. One informant captured the importance of this aspect of her life in these words:

They are terrific nurses - just wonderful. If they see someone is down or that, it's just like a happy club in there. The same nurses come - they know us all.

Another woman, reflecting on a past experience in a hemodialysis unit, said:

The whole set up was good. The nurses were so congenial and happy to be working together. They'd been there for quite some time and from my point of observation, they were almost like personal friends...

This informant recalled the beneficial effect of the harmonious atmosphere of the hemodialysis unit. The same
woman commented on the effect of the physical set-up of the unit on fellowship among the patients in the unit:

The round room is better than the other room... it's more social I guess you might say. In the other room you're strung out six this way and you have quite a feeling of isolation down there.

A third woman commented on the affect of the atmosphere on her.

I turn up at the hospital and look on it as more of a social occasion. I enjoy the staff. They have fun in their own way too and so I enjoy talking to them. So this is part of the social business I enjoy and I like observing people and getting to know them.

The light and amiable atmosphere on the dialysis unit brought this woman pleasure. The characteristics of good fellowship, harmony and lightness on the hemodialysis unit allowed for enhanced well-being.

Connectedness was enhanced by satisfactory relationships with others, nurturing others, normalizing, a harmonious atmosphere on the unit and pleasurable activities. This enhanced connectedness was accompanied by factors that indicated the presence of effective adaptation: enhanced self-esteem, improved appetite, happiness, and contentment.

Inhibiting Factors

The women's accounts suggested that the key factors that weakened connectedness included isolation from others, unsympathetic others, ineffective communication
with health-care professionals, reduced energy and exclusion from former activities.

The informants described several factors that caused the feeling of being cut off from others. Limited access to their support network weakened the women's feeling of being connected. One woman described her situation this way:

Most of my friends have died or else they live too far away and they don't drive cars because they're too old. So you kind of get out of touch with them. I have two sisters on the prairies and one in Victoria. My sister has Alzheimer's.

Unsympathetic others was a factor that caused a sense of disconnectedness. One woman told of this:

The only thing I don't understand, all my friends, they can never get it through their head that I'm on dialysis and I'm not going to come off it. They just don't understand. And I get a little annoyed with people. Even neighbors where we live will say, oh, are you still going to the hospital?

Another woman said:

Well, people who have never been sick and don't know what it is like to be sick and figure all you need is a good kick in the butt. And I had that said to me the other day. And I thought, no way. I don't need that.

Lack of understanding from others was a source of frustration and led to a sense of disconnectedness for these women.
Ineffective communication with health-care professionals contributed to a sense of disconnectedness. One woman described this (referring to a transfusion reaction):

So a young nurse she just all of a sudden she would check, read the number off the way you're supposed to do it and then she disappeared with the bag. No explanation or anything. She just left me lying there wondering.

Another woman offered this reflection:

...so if you're asking them to do something and they didn't do it, or if they ignored you or they just bypassed you seeing them making a face or something, you wouldn't like it.

The first informant in the previous quotes felt isolated since she perceived that she was not kept informed about her situation. The second informant recounted a situation in which her requests were not honored. As well, this woman emphasized the potential impact of non-verbal communication on her sense of disconnectedness.

Lack of energy also interfered with the sense of being connected.

Well, I like doing things the same as anybody else. I want that energy. In my mind I want it, but my body hasn't followed my mind. In my mind I could do 101 things but I get one thing done - that's what the problem is. I want to do things but I don't have the energy to do them.

This informant described how lack of energy prevented her from participating in the activities she enjoys. This
lack of energy contributed to another key factor that interfered with the sense of being connected, exclusion from former activities.

I. I think the most frustrating thing to me about dialysis is that it takes me - I can't work and earn money. I would say that is the number one thing...

R. So when you say you can't work then, what does that mean to you?

I. It means you have to live on a limited income and living on a limited income cuts back in every area...the food you buy, the clothes you wear... You've just got to do without. By not working, I miss the contact with the people really bad.

Being on dialysis meant that this woman has fewer financial resources and was therefore more limited in the number of pleasurable activities that were available to her. She was also cut off from a pool of social relationships by not working.

The data indicated that connectedness, or the feeling of being connected to others and/or to sources of life energy, is both an indicator of the level of adaptation and a facilitator of adaptation. Factors identified as those facilitating adaptation were satisfactory relationships, normalizing, nurturing others, a harmonious atmosphere on the hemodialysis unit and pleasurable activities. Factors identified as interfering with connectedness included isolation from
others, unsympathetic others, ineffective communication with health-care professionals, reduced energy and exclusion from former activities.

In this chapter, the two central themes that emerged from the data analysis process, the adaptation process and connectedness have been described. In addition, factors that influence adaptation to chronic hemodialysis have been presented in relation to these two themes. In the next chapter, these findings are discussed relative to pertinent literature.
CHAPTER FIVE

Discussion of Findings

In this chapter, the sample and the findings are discussed. The phenomenological analysis resulted in a description of factors influencing adaptation to hemodialysis according to two central themes, the adaptation process and connectedness. The discussion here is presented in four sections. The first section discusses the sample; the second, the theme of the adaptation process; the third, the theme of connectedness; and the fourth, a discussion of factors influencing adaptation.

It is not the intent, with qualitative research, to generalize the findings but rather to understand the meaning of phenomena in particular situations (Burns & Grove, 1987). Understanding the same phenomenon in similar settings depends on the nature of the sample.

Discussion of the Sample

This study sample included approximately seventy-five percent of all those who met the criteria for the study in both study settings. Comparing the sample to subjects in larger studies, this sample was older and less well educated than a population described in a study by Evans et al. 1985. In this study, the mean age of the
subjects was 64 years compared to the Evans et al. sample in which the mean age of the women on in-center dialysis was 51.8 years. This difference could be attributed to the fact that the sample in the Evans et al. study included all women on in-center dialysis whether or not they were eligible for renal transplantation. Since the presence of complex health problems is a contraindication for renal transplantation, the likelihood of renal transplant decreases with an increase in age (Benvenisy & Hardy, 1986).

In this study, the women had a mean of 8.5 years of education whereas in the Evans et al., 1985 sample, the women had a mean of 11.5 years of education. This difference could be attributed to the fact the subjects in the Evans et al. study had a lower mean age than the sample in this study. Women in recent years tend to be better educated (Belenky, Clinchy, Goldberger, & Tarule, 1986).

The women in this sample were all English speaking and had strong roots in white anglo-saxon culture. This sample therefore did not represent the multi-cultural society of present day. Another unique feature of this sample was the presence of numerous health problems.
Perhaps the presence of these additional problems made it difficult for the women to cope with their situations.

The women in this study accepted as a fact of life that renal transplantation was not an option. The data did not indicate that they struggled with this situation as an issue or dilemma. This could perhaps be attributed to the fact that several of the women were diagnosed with end-stage renal failure when renal transplantation was not an option so they may not have given this possibility much consideration. Also, since most of the women in the sample had been on dialysis for more than five years their recall of events in the initial phases of adaptation could be clouded thus influencing the accuracy of the data collected in this study.

In summary, the women who comprised the sample in this study were older and less educated than similar samples reported in the literature, were all English speaking from Anglo-Saxon cultural roots, and accepted that renal transplant was not a reasonable treatment option.

The Adaptation Process

Adapting to chronic hemodialysis was described by the women in this study as a process. Hamburg, Coelho, and Adams (1974) also said that "adaptation is a
dynamic, evolving, unending process...As environments change so must organisms change if they are to survive" (p. 403). White (1974) concurred: "adaptation does not mean a total triumph over the environment or total surrender to it, but striving toward acceptable compromise" (p. 52).

The women in the current study described this adaptation process as a continual adjustment to change. Selye (1976), observing response to injury, pointed out that adaptation encompasses all changes as they develop over time during continual exposure to a stressor. The women referred to this adaptation process in terms of their sense of well-being. Lazarus and Folkman (1984) considered that adaptational outcomes were dependent on cognitive appraisals and coping processes. According to these authors, cognitive appraisals require judging the significance of a stressful event in relation to personal well-being then selecting coping responses that will influence adaptational outcomes. It appears that adaptation to hemodialysis involves changes over time that influence adaptational outcomes.

The subjects presented adaptation as a six-phase process in this study (see Figure 2). Similarities and differences between the phases of this adaptation process
and stages of adapting proposed in various sources in the literature will be discussed.

In structure, the adaptation process described by the women in this study is quite similar to The General Adaptation Syndrome (G.A.S.) described by Selye (1976). Selye's G.A.S. consists of three stages: the alarm reaction, the stage of resistance and the stage of exhaustion (see Figure 6). The Resisting Dialysis phase and the Fighting to Live phase taken together are similar to stage one of the G.A.S., the alarm stage. The alarm reaction is the initial response to a noxious stimuli that Selye (1976) envisions as "the bodily expression of a general call to arms of the defensive forces in the organism" (p.37). In the Resisting Dialysis phase, this 'call to arms' appeared to involve taking issue with dialysis and in the Fighting to Live phase, it involved "getting up the fighting forces". The Accepting It and Facing It phases are similar to the second stage of the G.A.S., the stage of resistance. In the Accepting It phase, the women described how they integrated the stressors of hemodialysis into their lives and in the Facing It phase, they describe how they enjoyed life. These phases are similar to Selye's stage of resistance which is a time of stability and enjoyment. Finally, the
Losing Hold and Giving Up phases are like the stage of exhaustion of the G.A.S. because they are all periods during which the individual is less capable of dealing with stress.

Some of the women's accounts indicated that the Resisting Dialysis phase culminated in 'bottoming out'. Selye (1976), in his work on stress, demonstrated that the alarm stage of the GAS culminated in a depletion of the stores of the adrenal cortex glands. Since 'bottoming out' occurred at the end of the Resisting Dialysis phase, a phase similar to Selye's alarm phase, perhaps the depletion of adrenalin stores contributed to 'bottoming out'. In addition, since this 'bottoming out' occurred immediately prior to the first run on dialysis, uremia may well have been a contributing factor. Retention of electrolytes and metabolic wastes produce uremia, the signs of which include confusion, convulsions and coma (Phipps, Long & Woods, 1979).

The women's accounts indicated that the four middle phases of the adaptation process were continually revisited (see Figure 2). This pattern is similar to the pattern of movement through the G.A.S. Selye (1976) points out that individuals go through the first two stages, the alarm stage and the stage of resistance
numerous times and suggests that even the stage of exhaustion is not irreversible and complete.

This study showed similarities and differences in the adaptation process with the three stages identified by Reichsman and Levy (1977) in a study of twenty-five hemodialysis patients. Reichsman and Levy identified three stages of adaptation, the "honeymoon" period, the period of disenchantment and discouragement and the period of long-term adaptation. The middle four phases of the adaptation process were similar to Reichsman and Levy's period of long term adaptation, periods marked by an acceptance of the situation and fluctuations in the individual's sense of physical and emotional well-being. As well, the Losing Hold phase is similar to the stage of disenchantment and discouragement, periods marked by hopelessness and depression. The "honeymoon" period identified by Reichsman and Levy is a period of marked physical and emotional improvement following the initial run on dialysis. There is no clear equivalent in this study to this "honeymoon" period. This difference could be attributed to the difference in data collection between the two studies. In the Reichsman and Levy study, the patients were interviewed for a four-year period following acceptance into the hemodialysis
program, whereas in this study, the women were interviewed between one and twenty-two years after acceptance into the program. The "honeymoon" stage may have been long forgotten by some of the women in this study only to remain in memory as a first run on dialysis that facilitated acceptance of hemodialysis.

The Resisting Dialysis phase is similar to stages identified by Rounds and Israel (1985) and by Murray and Zetner (1985). Rounds and Israel, in a study of hemodialysis patients, identified a pre-treatment stage, the period between the diagnosis and initiation of dialysis. Murray and Zetner identify the transition from health to illness stage as the first stage of response to illness. Emotional shock followed by denial is characteristic of these stages and the Resisting Dialysis phase.

The women's accounts indicated that there are similarities and differences between the phases of the adaptation process and stages of loss identified in the literature (Kubler-Ross, 1969). Stages of loss commonly outlined in the literature are denial, anger, bargaining, depression and acceptance. Denial was evident in the Resisting Dialysis phase, anger in the Fighting to Live phase and acceptance in the Accepting It phase.
Depression appeared to be present in the Resisting Dialysis and Losing Hold phases and perhaps the Giving Up phase. Data relevant to bargaining was not evident in this study. These stages of loss are outlined in the Kidney Foundation of Canada Patient Manual (1986) and are the same stages identified by Kubler-Ross (1969) in her book On Death and Dying. There are similarities between the phases of the adaptation process and the stages of loss possibly because adaptation to hemodialysis involves losses, particularly losses related to changes in body image and social roles. The differences between the stages of loss and the phases of the adaptation process described by the women may arise from the nature of the dialysis situation; the women in this study faced a much changed life, not death.

The process of adapting to hemodialysis evident in this study is reflected in an anecdote by Williams (1977) in which she describes her reactions to a pacemaker. Her words mirror those of the women in this study. Williams, a nurse herself, describes how initially she resisted the idea of a pacemaker (Williams, 1977). She writes that when the doctor asked her how she felt about having a pacemaker she replied "A pacemaker! Never!...I would not have a pacemaker! I insisted on a trial of
medications" (p. 288). This woman, like some of the women in the study, resisted the inevitability of a machine-dependent life. [Resisting Dialysis]. Williams goes on to say "I finally decided that I was going to have to **force** myself to accept it". [Fighting to Live]. Finally, Williams discovers that "As you learn to live each day with a prosthesis, you also learn to let it become part of you. It is always there and it will always be" (p.289). [Accepting It and Facing It]. It may well be that it makes less difference what the machine is, rather there is a machine that is necessary to sustain life.

The adaptation process identified in this study is similar to and different from stages of adapting to illness proposed in the literature. The adaptation process can be compared to Selye's (1974) General Adaptation Syndrome and the Stages of Illness proposed by Murray and Zetner (1985). Of three stages of adapting to chronic hemodialysis proposed by Reichsman and Levy, only one is clearly similar to the phases in this study, possibly due to a dissimilar research sample and research method. The stages of accepting dialysis identified in the Kidney Foundation Patient Manual (1986) that appear to be borrowed from Kubler-Ross's Loss Theory
have some similarities to the findings of this study. Williams (1977), a nurse with a pacemaker captures the essence of the experience of the adaptation process in writing about her experience of adapting to a pacemaker.

Connectedness

Connectedness, to the women in this study, meant being connected in relationship with others and/or to sources of life energy. The findings suggest that being connected to others and/or to sources of life energy facilitated adaptation. The findings also suggest that connectedness was an indicator of the level of adaptation to the women. Connectedness, therefore, appears to be both a facilitator/inhibitor of adaptation and a component of adaptation. There is evidence in the literature for this dual role of connectedness.

Connectedness, as a facilitator of adaptation, appeared to enhance adaptation by empowering the women. Perhaps this is similar to the concept adaptation energy introduced by Selye (1976) to explain hidden reserves of energy available for adaptation. Murphy (1974) suggested also that "there is something underneath coping that gives the push and the flexibility or possibility of resilience". Perhaps this "something" and Selye's adaptation energy are similar to connectedness. The
origin of this adaptation energy, as it is described by the women in this study, appeared to arise from involvement with others and with life affirming activities.

The literature on social support may explain the positive effect of connectedness on adaptation. Social support is a construct referring to interpersonally supportive behaviors and relationships (Tilden, 1985). Parkes, Benjamin and Fitzgerald (1969) found that widowers showed increased mortality over non-widowers of the same age cohorts. Berkman and Syme (1979) showed increased mortality rates in those who lacked social ties compared to those with extensive ties, and Gallo (1983) found a high statistical correlation between social support network and health. The literature strongly supports the notion that being connected to others enhances wellness.

In this study, there was evidence that being connected to sources of life energy was important to the women. There is some support in the literature for this. One writer describes this aspect of connectedness: "...a woman's path to power is more like engaging in life's energies in a swirling movement filling us up, out into wholeness...my power emerges from the well springs
of who I am and reaches out to touch and connect with others" (Goldman, 1988, 30). In this description, Goldman points out that being connected to sources of life's energy arises from within and is ultimately empowering. The activities that the women described as important for the sense of being connected to sources of life's energy included such endeavors as outings, housework and volunteer work, activities not highly valued in our society. It seems that there would have been more evidence of this aspect of connectedness in the literature, given the strength of the findings of this in the study. This could be due to a bias in the literature arising from western society's values about acceptable work and pleasure. It may well be that, if this bias does exist, it exists because women have not been given a strong enough voice. Anecdotal reports and research studies indicate that girls and women have difficulty with asserting themselves so that they are heard and appreciated (Belenky, Clinchy, Goldenberger, & Tarubre, 1986).

The findings of this study suggested that being connected to others was an indicator to the women of how well they were adapting. Perhaps this can be explained by the literature on the socialization of women. Bepko
(1989) writes that "Women are socialized to take care of the emotional needs of others" (p.411). Further, the literature suggests that a woman's worth and value is derived from their roles as wives and mothers and their relationships to men (McGoldrich, Anderson & Walsh, 1989). Perhaps when women are feeling connected to others they perceive that they are fulfilling their socially designated roles as wives and mothers and this in turn is an indicator to them of their competence.

The importance of the phenomenon of connectedness may be partially explained by the findings of a study entitled "Stress and adaptation of older osteoporotic women" by Roberto (1988). Roberto found that the women in her study used a variety of mechanisms that disrupted social roles and relationships to relieve the immediate symptoms of their osteoporosis. Roberto reports that in order to incorporate these mechanisms into their daily routine and prevent social isolation, the women in her study often had to reorganize their lifestyles, commitments and activities. Perhaps connectedness was foremost in the minds of the women in this study since they were continually having to reorganize their lives around the stresses of hemodialysis to prevent social isolation.
Connectedness - being connected to others and/or sources of life's energy - emerged as a central theme in this study. Connectedness was described by the women in this study as both an indicator and a determinant of adaptation. The literature on social support, the socialization of women and a study on chronic illness in women gives meaning to the findings in this study.

Factors Influencing Adaptation

Several key factors that either facilitated or interfered with adaptation were identified for the first five phases of the adaptation process and for the concept of connectedness. In this section, these factors will be discussed together in relation to the pertinent literature.

The women's accounts suggest that beliefs and commitments exerted a significant influence on adaptation. The data suggested that the diagnosis of end-stage renal failure was perceived as a threat to the women's beliefs and commitments. Hemodialysis appeared to be a threat to the belief that one was independently capable of managing one's health and to the women's commitments to others. The women reported that they responded to this threat by taking issue with or avoiding the diagnosis. This was to their detriment since the
Resisting Dialysis phase culminated in 'bottoming out'.

Although a diagnosis of end-stage renal failure was a threat to the beliefs and commitments of the women, the data indicated that the belief that 'they could do it' that was inspired by the role-modelling of other women along with commitments to family and health care professionals motivated the women to overcome the difficulties associated with this diagnosis. Devins et al. (1982) showed the link between beliefs and adaptational outcomes in a quantitative study of seventy patients with end-stage renal disease. It was found that self-efficacy and outcome expectancies contribute importantly to the processes of adaptive coping and the sense of psychological well-being. As the adaptation process unfolded, role modelling from hemodialysis patients, aunts, mothers and grandmothers inspired the women to believe that the on-going stresses of hemodialysis could be handled so that a meaningful life was possible. This, in turn, appeared to motivate the women to reorganize their commitments, lifestyles and activities so that cherished goals could be met.

Perhaps reorganizing commitments so that life has meaning is an essential element of adapting to hemodialysis when renal transplant is not an option.
Beliefs and commitments seem to confer meaning on a situation. Antonovsky (1987) suggests that meaningfulness is a motivational element when an individual is confronted with a stressor. If the situation that is stressful makes sense emotionally, the problems and demands are perceived as challenges and are worthy of energy investment. Personal factors, beliefs and commitments, according to Lazarus and Folkman (1984) influence appraisal and in turn adaptational outcomes.

The nature of end-stage renal failure appears to create a situation that is disordered and inexplicable for the women. The often slow onset of the disease gave the women time to regain self-control, "I can beat it", or avoid the situation. The ambiguous nature of the early stages of end-stage renal disease set up a cognitive dissonance. Because they were still producing urine, several of the informants believed that they could continue to manage their health independently without the assistance of medical intervention even though they were told that their kidneys were failing. The informants' strong personal beliefs that they could manage without medical intervention directed them to appraise the ambiguous information to support this belief. Personal factors, especially a belief in self-efficacy, interacted
with situational factors, specifically the ambiguous and gradual nature of the onset of end-stage renal disease which led to 'bottoming out', a negative adaptational outcome in the Resisting Dialysis phase. It was only when the situation began to make sense to the women as a consequence of a confrontation strategy used by a health-care professional or after the first run on dialysis that the women ceased resisting the inevitability of the hemodialysis treatment. Antonovsky (1987) identifies that comprehensibility is a key factor in successfully adapting to stress. End-stage renal failure seems to be a difficult disease for patients to understand. Health-care professionals appear to play a significant role in clarifying the meaning of the illness situation to the client.

Important factors that positively influenced the adaptational outcome in this study included physical health, energy, and social support. Lazarus and Folkman (1984) proposed that coping resources include health and energy, positive beliefs, problem solving skills, social skills, social support and material resources.
Reduced energy that is experienced as fatigue or limited activity is a one of the most consistently reported problems faced by individuals on hemodialysis (Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988; Eichel, 1986; Gurklis & Menke, 1988). Cotton and Holechuk (1989) report that preliminary trials of the drug recombinant human erythropoietin have demonstrated that this drug has increased both the sense of well being and the energy of individuals on hemodialysis. Perhaps reduced energy limits the extent to which the women feel their situations are medically manageable.

Social support in the form of emotional support was a key factor that influenced the personal well-being of the women. Reassurance, affirmation of self-worth and talking to and presence of others were specific kinds of emotional support that facilitated adaptation. Reassurance and affirmation of self-worth likely provide the women with information that they are esteemed and valued. Cobb (1976) suggests that this type of social support prevents the unfortunate consequences of crisis and change. Talking to and the presence of others may indicate intimacy with others. Lowenthal and Haven (1968) completed a study that indicated that
a confidant, someone with whom one could share life's burdens, has a positive effect on the morale of older people. Eichel (1986) found that seeking comfort from friends and talking with someone in a similar situation were coping strategies used by those on hemodialysis to buffer the stress of their situation. On the other hand, turning inward was a coping strategy used by the women during particularly trying times.

The women in the study indicated that the staff of the dialysis unit provided emotional support. Blodgett (1981) points out that relationships with staff are essential in resolving the many issues faced by the dialysis patient. Dimond (1980) claims that supportive behavior is central to nursing care for hemodialysis patients. She says that nurses assist the patients to maintain the hope and confidence necessary to pursue cherished goals.

The key environmental constraints identified in this study that influenced adaptation were the behaviors of the health-care professionals and transportation to the dialysis unit. Several studies identify that transportation to dialysis is a significant problem for individuals on hemodialysis (Baldree, Murphy & Powers, 1882; Bihl, Ferrans & Powers, 1988; Eichel, 1986).
Ferrans, Powers and Kasch (1987) found that transportation to dialysis caused considerable dissatisfaction in their study sample of 416 randomly selected hemodialysis patients.

Care by the health professionals was identified by some of the informants as a source of both distress and comfort. Ferrans et al. (1987) investigated the satisfaction with health care in patients on hemodialysis and found that hemodialysis patients were generally satisfied with medical and nursing care. Satisfaction with opportunities to ask the physicians questions and explanations were highly correlated to overall satisfaction. Aspects of nursing care that were highly correlated with overall satisfaction were the care given by the dialysis nurses, nurses' understanding of personal needs and concerns, nurses' management of emergencies and the time nurses talk to patients. This study emphasizes the importance to hemodialysis patients of effective communication and confidence in caregivers.

The foregoing discussion suggests that factors related to both the person and the situation appeared to influence adaptation to chronic hemodialysis. Antonovsky (1987) proposes that manageability is essential in coping with stressful situations.
Manageability is defined as "the extent that one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one...to the extent that one has a high sense of manageability, one will not feel victimized" (p.18). Coping resources and constraints arising from person and situation factors appear to be key influences on the women's ability to manage the dialysis situation.

A variety of coping strategies were used by the women in their adaptation process. There appeared to be a gender influence on the coping strategies selected by the women, specifically, normalizing and nurturing others were identified by the women as factors that positively influenced adaptation to hemodialysis.

One particular normalizing strategy that the women reported using was "putting on a face" for others. This meant that they presented themselves to others well. Lubkin (1986) writes that normalizing requires a great deal of energy for an impaired person. This was only partially true for the women in this study. Normalizing by "putting on a face" was draining for the women when confronted by those in the inner circle of their relationships, for example, sisters or nurses. Yet, in spite of the toll this behavior took on their energy, the
women continued justifying these actions as necessary for maintaining intimate ties. With strangers, another pattern emerged. The women describe that they took pleasure and derived energy from "putting on a face". Delauritis (1986) sheds some light on this. Delauritis suggests that the two terms *mask* and *masquerade* are meant as weapons of survival by women. She goes on to state that the mask represents a burden, constraining the expression of one's real identity, whereas masquerading is putting on a different identity, an identity "...put on like a new dress, which...does give some pleasure to the wearer" (p.17).

It appears that normalizing by "putting on a face" had the potential to both enhance and inhibit the women's adaptation to hemodialysis. Normalizing the illness had the potential to produce a negative adaptational outcome. By not revealing their true situation to close others, the women risked not receiving the help they needed. On the other hand, the women reported that "putting on a face" with strangers contributed to their sense of well-being. Lazarus and Folkman (1984) recommend that coping should be viewed as efforts to manage stressful situations regardless of outcome.
Another coping strategy commonly used by the women in this study was nurturing others. In the process of reorganizing their roles and commitments, the women found new ways of nurturing others - sending cards to friends rather than visiting, and finding new others to nurture - patients and staff. Warburton, Newberry, and Alexander (1989) point out that women are socialized to be caregivers with an emphasis on interpersonal skills and intimacy. New ways of nurturing seemed to afford the women the opportunity to maintain their role as caregivers in spite of the limitations of hemodialysis.

In spite of limited energy, the data suggests that the women in this study chose to use energy normalizing the illness and nurturing others. Perhaps energy required by normalizing and nurturing is more particular to women on hemodialysis than to men.

The data suggested that gender may influence coping effectiveness. Three women in this study reported that women cope more effectively than men with hemodialysis. This contradicts the findings of a study by Pearlin and Schooler (1978) who claim women cope less effectively than men because they are socialized in a way that inadequately equips them to cope effectively. Perhaps women have not been given ample opportunity to identify
the unique mechanisms of coping used by women in a variety of contexts.

Some of the informants in this study reported that they had difficulty asserting themselves with health professionals. That the women in this study reported difficulty advocating for their own needs at the expense of the feelings of the health-care professionals who provide life-supporting and sustaining care is not surprising. Gilligan (1982) sheds some light on this. She suggested that females respond to problems contextually, locating themselves in relation to the world and delineating self through connection with others.

Emotion-focused coping was characteristic of the Accepting It phase. Emotion regulation is the essence of emotion-focused coping according to Lazarus and Folkman (1984). Emotion-focused coping leads to a change in the way an encounter is construed. Reframing the experience and ignoring it were behaviors identified by the informants as factors that facilitated adaptation. These behaviors served to change the meaning of the situation. Pearlin and Schooler (1978) identify selective ignoring as the coping mechanism frequently used by women that exacerbates stress. Perhaps in coping
with the stresses of hemodialysis selective ignoring is a coping mechanism that is adaptive.

Problem-focussed coping was characteristic of the Facing It phase. According to Lazarus and Folkman (1984), problem-focussed efforts are directed at defining the problem, generating solutions, choosing among them and acting. Problem-focussed strategies include strategies that are directed both inward and toward the environment. In this study, the informants identified the following factors that likely contributed to the effectiveness of their problem-focussed coping in the Facing It phase: assistance with tasks, others with whom to discuss problems, care from health professionals and diversions. Murphy (1982), Baldree et al. (1982) and Gurklis and Menke (1988) found that individuals on hemodialysis reported using more problem-oriented coping methods than affective-oriented (emotion-focussed) methods. The most commonly used methods identified were praying, maintaining control over the situation, accepting the situation as it is, hoping that things would get better, looking at the problem objectively and finding out more about the situation. The informants in the current study reported using all of the above strategies except praying. Praying is a highly personal
activity, and the women were not asked directly if they prayed to cope. They may well have used this strategy but did not declare it to the researcher.

The adaptation process is similar to stages of adapting to illness and stress evident in the literature. Connectedness has been discussed in the literature primarily in terms of the socialization of women. Some women writers offer an expanded view of this concept that is similar to the findings in this study. The Theory of Stress and Coping developed by Lazarus and Folkman and Antonovsky's Sense of Coherence Concept provide insight into the factors influencing adaptation identified by the women in this study. In the next chapter, the implications for nursing practice, education and research that arise from the findings and discussion presented in Chapters Four and Five are highlighted.
CHAPTER SIX

Summary, Conclusions and Implications for Nursing

In this chapter, a summary of the study is reported and important conclusions arising from the study are presented. Finally, implications for nursing practice, education and research are proposed.

Summary

This study was implemented to explore and describe the patient's perspective of factors that influence adaptation of women to chronic hemodialysis when renal transplantation is not an option. While factors influencing adaptation are identified in studies available in the literature, these studies were generally designed from the perspective of the health-care professional leaving a significant gap between the perspective of the client and the perspective of the health-care professional in the chronic hemodialysis situation. Furthermore, no studies were found that specifically examined women's adaptation to hemodialysis when renal transplantation was not an option. It was therefore recognized that a study such as this had the potential to augment knowledge of this client group. Further, it was thought that since nurses are the health-care professionals who provide on-going, high contact
care for those on hemodialysis, a study of this nature was particularly important for professional nursing care.

Since this study was intended to explore the client's perceptions of her situation, the qualitative method was selected as the research method. To obtain the rich in-depth data necessary for qualitative analysis, audio-taped interviews were conducted with eight women. The women ranged in age from 50 to 77 with a mean age of 64. The length of time these women had been on hemodialysis ranged from 10 months to 22 years with a mean time of 8.6 years.

Data collection and analysis were concurrent. Semi-structured interviews were conducted to obtain the data. All participants were interviewed twice and two women were interviewed a third time. The questions posed during the first interviews were broadly stated to facilitate open discussion of the women's perceptions of their hemodialysis situation. The interviews were transcribed immediately following each interview and were then examined for patterns of response and significant statements. The questions for the second interview were developed to clarify and validate responses from the first interview, to capture additional data and to check
the emerging themes. The third interviews conducted with two women were designed to clarify the identified themes.

Two themes emerged from this analytical process: an adaptation process and connectedness. In addition, factors influencing adaptation in relation to these two central themes were simultaneously identified.

Adaptation was described by the informants as a six-phase process: Resisting Dialysis, Fighting to Live, Accepting It, Facing It, Losing Hold and a final and tentatively formulated phase, Giving Up. Since no women appeared to be in this final phase, it was proposed only as a tentative phase. Women who experienced a gradual onset of end-stage renal failure entered the Resisting Dialysis phase, a phase that culminated in 'bottoming out'. Once passed, this phase was not re-entered. Fighting to Live was the next phase. Negative adaptational outcome of this phase led to Giving Up, whereas a positive adaptational outcome led to a cyclical movement through the four phases Accepting It, Facing It, Losing Hold and Fighting to Live. At any given moment, a woman could experience two or more of these phases in a proportion related to the overall impact of factors influencing adaptation.
Several key factors that either facilitated or interfered with adaptation were identified for the first five phases of this adaptation process. Taking issue with or avoiding the possibility of dialysis was characteristic of the Resisting Dialysis phase and key factors facilitating adaptation in this phase were effective confrontation by a health care-professional and a first run on dialysis. Factors interfering with adaptation to hemodialysis in this phase were the gradual and ambiguous nature of renal disease and a perceived threat to independence.

Resilience was characteristic of the Fighting to Live phase, the next phase of the adaptation process. Facilitating factors in this phase were the role-modelling of other women, commitment to others, asserting control over the situation, previous experience with adversity, and emotional support, particularly reassurance and affirmation of self-worth. Inhibiting factors identified for this phase were reduced energy and lack of confidence in health-care professionals. Coming to terms with chronic hemodialysis was characteristic of the Accepting It phase. Factors facilitating adaptation in this phase were reframing the
experience, ignoring the situation, and being a woman whereas inhibiting factors centered on transportation to dialysis and loss of independence.

Dealing with the realities of the situation was characteristic of the Facing It phase. Factors that helped the women adapt in this phase were talking to others, assistance with tasks, confidence in health care professionals, diversions and adequate rest. Reduced energy, compromised somatic health, difficulty with assertiveness and lack of confidence in health care professionals interfered with adaptation in this phase. Low morale was characteristic of the Losing Hold phase. The presence of others and turning inward were factors that facilitated adaptation in this phase, whereas prolonged stressors or compounded problems interfered with adaptation.

The second central theme identified in this study was the theme of connectedness. Connectedness here is defined as being connected to others and/or to sources of life energy. Connectedness appeared to be both a facilitator/inhibitor of adaptation and a component of adaptation. Specific factors that influenced connectedness and in turn adaptation were identified during data analysis. The facilitating factors
identified were satisfactory relationships, nurturing others, normalizing, a harmonious atmosphere on the hemodialysis unit and pleasurable activities. Key factors interfering with adaptation related to connectedness were isolation from others, unsympathetic others, ineffective communication with health-care professionals, reduced energy and exclusion from activities.

The women described the experience of adapting to hemodialysis as a tremendous personal challenge. Factors related to their approach to life's stresses and factors beyond their control determined the adaptational outcome of this struggle.

The majority of the women in this sample had been on dialysis for more than five years so that recall of the initial period on dialysis may have been clouded. The women in this sample were older and less well educated than other similar groups reported in the literature. As well, these women suffered from a number of other health problems perhaps making it more difficult to cope with this dialysis situation. The women in this study generally had not given serious thought to the possibility of renal transplantation.
The adaptation process was found to be similar to stages of adapting to illness and stress evident in the literature. Connectedness was found to be discussed in the literature primarily in terms of the socialization of women. Some women authors offered an expanded view of this concept that was similar to the findings of this study. The Theory of Stress and Coping developed by Lazarus and Folkman and Antonovsky's Sense of Coherence provided insight into the factors influencing adaptation that were identified by the women in this study. had not thought much about the possibility of renal transplantation.

Conclusions

The findings of a qualitative study are generalized with caution. Nonetheless, because the data were analyzed for patterns of response and significant statements, a number of conclusions can be drawn from the findings of this qualitative study.

1. Women hemodialysis patients can experience a positive adaptational outcome when renal transplantation is not an option.

2. Adaptation to hemodialysis involves changes over time.

3. Several phases of adaptational responses may be experienced simultaneously.
4. Connectedness with others and sources of life energy influences adaptational outcomes of women hemodialysis patients.

5. Family, friends and health-care professionals make important contributions to this sense of being connected.

6. Hidden resources of energy for adapting arise from women patients' ability to be connected to others and/or to sources of life energy.

7. Women on hemodialysis are able to identify facilitators and inhibitors of adaptation that are related to both the person and the environment.

**Nursing Implications**

The findings of this study suggest implications for nursing practice, education and theory and research. The following section will outline these implications. Because of the focus of this study, the implications are directed to women hemodialysis patients for whom renal transplantation is not an option.

**Implications for Nursing Practice**

The findings of this study suggest that concepts related to adaptation as a process, social support, somatic health, socialization of women and boosting
morale could provide direction for professional nursing care in all phases of the nursing process.

In the assessment phase, the findings suggest that it is important for the nurse to recognize that adapting to hemodialysis involves an adaptation process that changes over time and consists of different phases, several of which can be present at any given time and which may recur. Therefore, of primary importance, is an assessment that determines how the client is experiencing the process of adapting to hemodialysis, since the findings suggest that interventions will be selected to some extent based on the specific phase of the adaptation process that client is predominantly experiencing at any given time. In addition, because the stresses of hemodialysis are constantly changing, it is important to assess the client on a regular basis for changes in how they are adapting to their dialysis situation.

The findings indicate that it is important for nurses caring for women clients on hemodialysis to recognize the impact that being connected has on a woman's adaptation process. Assessing the extent and effectiveness of the client's support network is therefore indicated.
Other aspects of the client's situation that the nurse should assess include the client's perception of how well she is able to ask for help and her understanding of end-stage renal disease, particularly in the initial stages of adapting to hemodialysis. The findings also direct the nurse to assess the client's energy level and how the client balances the needs for rest and activity. As well, the effect of additional somatic problems should be determined. The client's perception of the effectiveness of communication with health care professionals and how well the transportation system is meeting the client's needs should be determined by the nurse. In addition, it may be useful to gain an understanding of the client's usual response to adversity and to identify activities that are energizing for the client.

Planning care can occur at both the individual level and the unit level. To assist the client to move from phases of the adaptation process in which she experiences a lower level of health to phases in which she experiences optimal health, the nurse may be directed from the data analysis to include the several interventions in the care plan for the individual. The client should be taught about the nature of end-stage
renal failure using methods that ensure that learning has occurred. Anticipatory guidance should be provided to assist the client to accept and face the dialysis situation. Pre-treatment education and counselling to assist the client to consider life-style changes should be considered. As well, anticipatory guidance could include an explanation of the adaptation process, allowing the client an opportunity to place herself within that process.

The findings about connectedness direct the nurse to strengthen the client's social support system. The nurse is directed by these findings to consider herself/himself as an important source of social support for the client. The nurse can provide this support by developing a trusting relationship with the client, by providing unconditional positive regard and skilled technical nursing care, by providing reassurance and affirmation of self-worth to the client whenever appropriate and by providing opportunities for the client to talk over problems and concerns. The client may need to discuss problems with the diet, energy, pain, mobility, other health problems, transportation to dialysis, travel plans and family situations. The time following the
dialysis run when the nurse is applying pressure to the graft may be a time this discussion could occur.

The nurse can also be instrumental in strengthening the social support available to the client from family members, friends and other hemodialysis patients. The nurse may consider establishing teaching and counselling programs to assist family members and close friends to understand the demands of hemodialysis. A booklet about end-stage renal failure developed specifically for families and friends of those on hemodialysis may be useful. The nurse could also establish peer-counselling programs to assist the client with adaptation, particularly in the early stages of end-stage renal failure or, perhaps better, facilitate the naturally occurring support group. Other sources of support that the nurse could consider developing include telephone access to health care professionals for emergencies and to the unit dietician for on-going advice, and printed material about travelling and hemodialysis and community resources.

If the client is having difficulty advocating for her rights and needs, the nurse could plan to assist the client to develop skills for dealing with conflict. Finally, the findings direct the nurse to plan
interventions to boost the client's morale. These interventions might include supporting the client's positive beliefs, assisting the client to explore new interests and acknowledging achievements.

At the unit level, the findings of this study suggest unit adaptations that may improve the specificity of care. The physical set-up of the unit could be planned to facilitate communication between patients: chairs or beds set up in a circle to allow the patients to talk; patients who speak the same language placed close together for their runs; and a comfortable waiting room which encourages conversation. Support for the staff at the unit level to maintain high morale or to raise low morale might include a plan for training and introducing new staff to the unit so that the status quo of the unit is not too disrupted. The findings suggest that the transportation to dialysis system should be reviewed on a regular basis to determine its effectiveness. Although this may not be a unit responsibility, attention to transportation problems can benefit patients.

The findings suggest that nursing care that is implemented with kindness, empathy, humor and sincerity is particularly effective in supporting the clients'
efforts to adapt to their hemodialysis situation.

Implications for Nursing Education

The findings of this study suggest that the following content should be included in a curriculum designed to educate professional nurses to care for women clients on chronic hemodialysis. Concepts relevant to adapting to chronic illness including content on hemodialysis, loss, role change, coping, and response to illness are appropriate for this curriculum. The findings suggest that it would also be appropriate to include content on social support, women and illness/wellness and family nursing. In addition, the findings indicate that it is appropriate to include skill development in such a curriculum. The skills that could be developed would include communication skills: verbal and non-verbal, interviewing and counselling skills, patient teaching skills, including skills relevant to preparing written and audiovisual materials for patients and their families.

The findings also suggest that is appropriate to include content relevant to the impact of the physical and emotional ambience of the hemodialysis unit on a client's response to illness.
Implications for Nursing Research and Theory

The findings of this study raise additional questions that could be explored in further nursing research and provide a basis for theory building. Specific areas for further research suggested by these findings are women's response to hemodialysis, women's coping, and spouse and family coping when a member of the family is on hemodialysis. To build on this knowledge base, further research could explore the experience of women when they feel that they can no longer live with the stresses of hemodialysis (The Giving Up phase).

A similar study to this one with a sample of men may help to clarify the meaning of some of the findings in this study. As well, a study that specifically describes the differences between women and men adapting to hemodialysis would be useful.

The findings also suggest that it would be useful to explore the needs of spouses supporting women on hemodialysis when renal transplantation is not an option. Determining the effect on the family system when a woman within the family system is on hemodialysis and is not eligible for renal transplantation is an area that could be researched.
Additional areas for further research suggested by the findings of this study include identifying the elements of the concept of connectedness as it was described by the women in this study, exploring health care relationships within the dialysis situation, measuring the effect of the transportation to dialysis on the health of women clients, and exploring the effect of the social atmosphere on the hemodialysis unit on women's health.

The findings of the study indicate that the Lazarus Theory of Stress and Coping is a useful framework for examining nursing problems. Factors influencing adaptation to hemodialysis can be placed within the categories of this theory allowing for a comprehensive examination of the multiple relationships between the data. Selye's General Adaptation Syndrome and Antonovsky's Sense of Coherence also appear to be theories that contribute an understanding to problems relevant to this discipline. The literature examining the socialization of women contributes to the understanding of women's response to illness. While social support theories contribute to an understanding of the concept of connectedness, the findings of this study
indicate that additional theory is needed to fully understand this concept.

The study contributes to the knowledge of women adapting to hemodialysis and factors influencing that adaptation, and provides insight into how women in particular gain the strength to adapt to this illness situation. In addition, the findings of this study suggest direction for nursing practice, education and nursing research.
References


APPENDIX B

Consent Form

I have read the information sheet that describes a study investigating those things that help and hinder coping with my life on hemodialysis. I understand that my participation would involve talking about my experience of coping with hemodialysis to Lynne Maxwell during two or three interviews that will last approximately one hour each. I understand that the interviews will be audiotaped.

I understand from having read the information letter that my name and any identifying information will not be used or revealed in any way. I also understand that I am not obligated to participate and withdrawal from the study or refusal to answer questions will in no way affect my future medical or nursing care. I give my consent to participate in this study and have been given a copy of the information letter and consent form for future reference.

Signed:

Date:
APPENDIX C

Trigger Questions for Data Collection
(First Interview)

1. How do you think you're doing with your situation with your kidneys?
2. What's it like for you right now to be going through this?
3. What have you done to keep going?
4. How do you manage when it feels hard?
5. What has made it easier?
6. What have you drawn on in yourself? Outside yourself?
7. What gets in the way? What makes it hard?

Trigger Questions for Validating Interviews

1. Tell me what would complete this picture of what it's like to live with hemodialysis; of what helps and what gets in the way?