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Life on Dialysis and its Effects on Meaning-Making in People's Lives

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LIFE ON DIALYSIS AND ITS EFFECTS ON MEANING-MAKING IN PEOPLE'S LIVES

By

Helen G. Smith

A dissertation submitted to the Faculty of Human Sciences, Saint Paul University,
in partial fulfillment of the requirement
for the Degree of Master of Arts in Pastoral Studies.

Ottawa, Canada.
2003

ABSTRACT

ABSTRACT

This collective case study of three men, from a pastoral care perspective, looks at how people change their meaning making and sources of support they find useful as they begin life on hemodialysis. Meaning making, a spiritual process, involves appraising the significance of ourselves and our lives in changing circumstances. The stresses of beginning dialysis may lead to altered meanings. Processes and themes in the subjects' narratives are compared to those from accounts by two more experienced dialysis patients. The new patients regarded this stage in their lives as temporary; the more experienced men had come to greater acceptance. Themes identified included illness cognitions, body images, changing relationships with families and others, the tension between dependence and autonomy, and optimism versus pessimism. The role of the men in determining who they wished to be in the circumstances was noted. Suggestions for further research and for pastoral support are provided.

DEDICATION AND THANKS

This work is dedicated to my husband, Brian David Smith, whose help and support were essential to its completion.

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INTRODUCTION

0.1 Preamble

Developing End Stage Renal Disease (ESRD) brings major changes to the life of the victim. He/she has to go onto dialysis, at least until kidney transplantation, an operation that may not occur for months or even years. Initially all patients undergo hemodialysis, going to a clinic at least three times a week to have their blood purified by a machine, a process that takes four or more hours each time.[1]

According to the Canadian Institute for Health Information (CIHI), the number of patients on dialysis in Canada in 1998 was 12, 808 (that is 421.6 per million inhabitants), a growth from 10,146 in 1996. About 73 percent of those were on hemodialysis. In Ontario about 76 per cent of the 5,180 dialysis patients were on hemodialysis (CIHI, 2000 b). From 1989 to 1998, 59 percent of dialysis patients in Ontario were male and 73 per cent were Caucasian. Their mean age was 59.0 (standard deviation 15.9 and median 62). Their mean survival rate was 2.8 years (standard deviation 2.4, median 2.1) (CIHI, 2000 a).

Kidney disease is often part of complex medical problems. In Canada in 1998, 73.7 percent of the new patients, aged 18 years and over, were taking medication for hypertension and 36.4 percent suffered from diabetes (CIHI, 2000a). Moreover many of

[1] A brief discussion of End Stage Renal Disease and dialysis is provided in Appendix I.

these patients will die young. Analysis of non-diabetic, Caucasian patients, aged 18 to 44 at the beginning of treatment, showed a 10-year survival rate of about 80 percent with a mean survival of 4.7 years (standard deviation 2.8 and median of 4.6 years) (CIHI, 2000a).[2]

Dialysis and organ transplantation enable people to survive ESRD; however the stresses of their changed health status lead people to change their ideas about who they are and the meanings of their lives.

While working as a chaplain intern on a dialysis unit, I learned of the changes that people had to adjust to. Thus I became interested in the psychospiritual processes involved as people grew used to life on dialysis; such processes involve changes in their ideas about who they are and the meanings of their lives seemed to change. Thus I began to ask questions about these processes.

0.2 Purpose and Organization

The purpose of this study is to look at the experience of becoming accustomed to life on dialysis and how this changes the ways people think about themselves and their lives, a psychospiritual process I refer to as meaning making. Moreover as a pastoral caregiver, I was interested in the supports people use to alter their meaning making; thus participants were asked for their advice on how to assist others as they come onto dialysis. Life on dialysis alters people's lives; physical changes often affect people's capacities to

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[2] On the basis of the figures available to me, it is difficult to determine whether the survival rates are better for patients who receive transplants, since the figures given do not break down into comparable groups. Persons receiving kidney transplants usually are those without too many medical complications and figures available were not broken down as to age. However such figures as were available suggest that those receiving transplants have a better survival rate; for 1991-1998 the five-year survival rate for transplant recipients was 85.9 percent (CIHI, 2000c, Table 4) while the survival rate for Ontario dialysis patients was 47.4 percent. However, this survival rate may be skewed by the proportion of elderly people receiving dialysis.

function in many areas. The experience may change their relationships with others, as well as their plans and hopes for the future. As their lives change, I thought, people's understandings of themselves and of life also probably change.

To answer the questions about how people make meaning of their lives as they experience becoming accustomed to life on dialysis and about how pastoral care givers might assist people undergoing the process of becoming used to life on dialysis, I interviewed three men and examined the accounts they gave of their experiences of beginning life on hemodialysis. As I listened to the stories of these men, I began to wonder if the time frame I had set was not too narrow. Perhaps, I thought, the processes of adaptation involve longer time periods. Thus I interviewed two other men who had been on dialysis for several years. Examining the results of all these interviews, I then searched for common themes, noting how these appeared in each man's narrative and considered how each differed in his responses to the stresses of life. Next I considered the answer to the original questions about the processes each had gone through and the kinds of supports they had relied on. Finally I reflected on the effectiveness of my project design, on possible further research on these questions, and on uses for the knowledge gained.

This paper is organized as follows: Chapter One, "Previous Studies", deals with literature on the research that had been done on the connections between religion and health and kidney disease. Thus this chapter is a brief examination of studies on spirituality, meaning making, adaptation to major disability, and kidney disease and psychology, as well as on those on religion and health.

Chapter Two, "Methodology", discusses how this study relates to other research, explains how and why information was gathered through unstructured and semistructured

interviews, and describes the case study method used. The chapter also deals with the selection of participants; with ethical concerns, and with possible uses of the study results.

Chapters Three and Four describe the interviews with the participants and my interpretations of their stories. Chapter Three, "Major Case Studies", deals with the three participants on whom the study focuses and on the change processes that I noted in each. Chapter Four, "Brief Case Studies", covers the two men who had been on dialysis for several years and on how their processes of change differ from those of the men in the focus group.

Chapter Five, "Discussion", outlines the major themes I found in the meaning making processes and how these themes differ in each man's story. It also deals with other individuating factors. In "Conclusions", I consider my answers to my initial questions, comment on the effectiveness of the research design, suggest lines for future research, and point out some of the implications of my study.

CHAPTER ONE

PREVIOUS STUDIES

Although there have been no studies that asked the kinds of questions I have posed, from the point of view of pastoral care of dialysis patients, there have been studies that looked at religion and health, adaptation to major illness, and living with dialysis. These works have provided important ideas and information as background for my study.

1.1 Religion and Health

Until the last half century the goals of medicine were established by physicians and concerned the body and physical disease, a view that grew out of the body-mind dichotomy that prevailed until relatively recently (Cassels, 1982). Ellison and Levin (1998) have surveyed recent literature on the religion-health connection. They found that in the late 1980s a number of survey articles indicated that religion, broadly defined, has positive effects on the physical health, morbidity, and mortality of a variety of people. Works produced in the nineties, using more refined methods, bear out earlier findings that religion affects morbidity and mortality. Studies also reveal the effect of religion on mental health. More recently, Ellison and Levin (1998) point out, researchers have tried to identify the aspects of religion that affect health, such as healthy lifestyles, positive emotions, and healthy beliefs. Of particular interest were studies, such as the one by Pargament (1997),

that focused on the way religious cognitions may offer ways to reappraise life and situations and to develop meaning in times of stress.

Ellison and Levin (1998) propose several models to test the religion-health connection: (a) a preventive model to examine the role of religion on life-style choices; (b) a stressor response model that emphasizes religion's role in coping with health-related stressors; (c) a stressor effect model on how health problems may affect religiosity; and (d) a moderator model on how religious supports, coping, and meaning making reduce the harmful effects of health stressors. The stressor and moderator models are of particular relevance to my study.

Koenig, McCullough, and Larson (2001) recently published a compendium of ideas and research on the influence of religion on health. Their examination of the influence of religion on health includes cognitive, affective, and behavioral effects on both physical and mental health. Religious behaviors, such as prescriptions governing the use of alcohol, tobacco, and street drugs, as well as attitudes towards family stability and social involvement, may lead to healthier lives. Religion may also provide strength for healthy coping with stressful life events; Western religions may provide for cognitive appraisals of negative events to help people maintain self-esteem, to see suffering as meaningful, and to allow some continuing sense of control through prayer and alliance with God. In addition, religious communities continue to value people even when they are ill and provide social and spiritual support to members. However, negative effects of religion occur when beliefs are too rigid to deal with stressful events or deter people from utilizing medical advice or cut people off from involvement with family.

1.2 Religion and Spirituality

As we have seen, part of the problem with any studies of religion and health is how to define religion and or spirituality. Ellison and Levin (1998) make no distinction between the two, but they do regard healthy religion as producing healthy behaviours and life styles, social integration and social support, self-esteem and personal efficacy, coping resources, positive emotions and healthy beliefs. They also refer to other kinds of spirituality when they argue that "religious symbols and beliefs offer only one of the many tools for constructing a sense of meaning and coherence" (p. 716).

The definition of religion, used by Koenig, McCullough, and Larson (2001), emphasizes its organized, authoritarian nature, while they see spirituality as more individualistic. Religion and spirituality are defined as follows:

> *Religion*: Religion is an organized system of beliefs, practices, rituals, and symbols designed a) to facilitate closeness to the sacred or transcendent (God, higher power, or ultimate truth/reality) and b) to foster an understanding of one's relationship and responsibility to others in living together in community (p. 18).
>
> *Spirituality:* Spirituality is the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community (p. 18).

Koenig, McCullough, and Larson distinguish a variety of types of spirituality, depending on whether they are tied to or grow out of established religious traditions or non-religious philosophies. They describe cognitive, behavioural, and affective aspects of religion. Religion, they argue, includes beliefs, affiliations, organized religiosity (that is, involving the organized dimensions of a group), nonorganized religiosity (that is, private religious devotions), subjective religiosity (that is, sensing religion's importance in one's life), religious commitment, religious quest, religious experience, and religious coping.

Kenneth Pargament (1997) develops a broader, less institutionally focused definition of religion. He outlines some of the diverse definitions of religion that sociologists and psychologists have produced. He then divides them into two categories: the substantive tradition that emphasizes "the sacred as the mark of religion" and the functional tradition that "emphasizes the struggle with ultimate issues." He concludes by defining "religion as a process, a search for significance in ways related to the sacred" (p. 32). He uses the term "spirituality" to cover the non-institutional functions of religion; thus religion and spirituality are, for him, closely related terms. Religion, he argues, involves ways of feeling, thinking, acting, and relating to others. It affects ideas about human-sacred relationships, the searches for meaning in life and comfort in time of trouble, ideas of self, strivings for intimacy and community, and finally the need for hope for one's-self, for others, and for the world. Religion involves a journey towards personal and socially significant ends of meaning, identity, community, and comfort in an uncertain world.

Zinnbauer, Pargament and Scott (1999) describe the many diverse meanings of religion and spirituality. These include the following content categories:

> experiences of connectedness or relationship; processes leading to increased connectedness; behavioral responses to something sacred or secular; systems of thought or sets of beliefs; traditional institutional or organizational structures; pleasurable states of being; beliefs in the sacred, the transcendent, and so forth; attempts at or capacities for transcendence; and concern with existential questions or issues (p. 894).

In traditional psychological research, according to Zinnbauer et al., spirituality was often not differentiated from religion, and the functional aspects of religion were emphasized, as having both good and bad effects. Recently religion has been narrowly defined as institutional, often negatively, with spirituality as personal and often good, a distinction that

Zinnbauer et al. claim is false. Building on Pargament's definition of religion as "a search for significance in ways related to the sacred" (1997, p.32), they extend the meaning of sacred to include all the objects, processes, and concepts associated with the transcendent. Thus they see spirituality as overlapping with religiosity, especially what Ellison and Levin (1998) call functional religion. They also comment on the value of spirituality, pointing out that, according to a number of studies, those who describe themselves as spiritually motivated have "manifested higher levels of purpose in life, marital satisfaction, and general life satisfaction" (p. 909) and have valuable coping resources in their beliefs.

Emmons (1999), in a study that tries to bring personality psychology and the psychology of religion and spirituality together, defines spirituality as "encompassing a search for meaning, for unity, for connectedness, for transcendence, (and) for the highest human potential" (p.92).

A group of British health care workers, Dyson, Cobb, and Forman (1997) did a literature review of spirituality for nurses interested in providing holistic care. To them, spirituality and religion are "neither synonymous or coterminus" (p.1184). Reflecting on the work reviewed, they decided that spirituality involves relationships between the self, others, and 'God': "themes of meaning, hope, relatedness/connectedness, beliefs/belief systems and the expression of spirituality" (p. 1186). They define 'God' as a person's "highest value in life" (p. 1185), whether it be a deity, work, family, or personal gain.

1.3 Meaning making

Thus the search for meaning has been recognized by many of these writers as an important component of spirituality. Frankl (1959/1985) laid the groundwork in the

psychology of meaning making, pointing out the importance of meaning for well being and even survival. D. P. McAdams (1993) believes that we make ourselves through the stories; we tell ourselves about ourselves, our histories and the universe in which we live.

In the study referred to earlier, Emmons (1999) emphasizes the importance of goals to life itself. He argues that well being has to do with the individual's concept of his/her idealized self and how close that cognition is to actuality in the individual's perception. Mentally healthy people are integrated and develop appropriate life goals that are associated with self transcendence. Such transcendence "connects them to higher powers, other people, institutions, and broader societal and global concerns (p. 133)."

Thus as a person's circumstances change so too does their meaning making— and the major changes associated with ESRD surely results in revisions of life meaning.

A number of studies of coping with major disease suggest that meaning making is an important process. Barkwell (1991) found that meaning making, particularly learning to see pain as a challenge, gave cancer patients an advantage in coping with and minimizing pain. In his phenomenological study of men who underwent coronary by-pass grafts, Radley (1997) looked at how these men acknowledged and adapted to their coronary disease, using meaning making of their physical symptoms in order to cope.

Angen (2000) argues that making meaning of illness was an important part of healing, "a potent human magic", for a group of female cancer patients. In-depth conversations focused on experiencing illnesses, on learning to live well after developing cancer, and on what improved or detracted from the patient's sense of well being. The cancer experience can lead to a "healing beyond curing" (p.9). The women's stories "were rife with the need to consider the meaning of their illnesses and at the same time expiate

themselves from any sense of guilt or shame from becoming ill in the first place (p.8)". Many of these women found new, richer, life meanings in their illness, being less concerned about societal constraints, and learning to live life with the "exuberance and freedom" (p.7) that an awareness of the nearness of death can bring.

1.4 Coping and Adapting

As we have seen a number of writers see that part of coping with a major illness involves making meaning of the illness and its role in the person's life. However other points of view have also been used in considering adapting and coping.

Pargament (1997) notes that a variety of factors have been mentioned in definitions of coping: stress, cognitive and behavioral responses, strategies to deal with problems, negative emotional responses, and personal resources. Pargament himself emphasizes that coping is a process, and involves a search for significance.

Pargament, Smith, Koenig, and Perez (1998) studied both positive and negative patterns of religious coping. These included: religious reappraisal in which a stressor is seen as benevolent or a punishment from God or caused by the devil; reconsidering God's power in a situation; expressing discontent with the church or with God; praying to God for problem solution, for comfort and support, or for the ability to work cooperatively to find the solution; seeking for connection with God; looking to religion for forgiveness or to be released from negative feelings or as an alternate focus for the mind; and looking to religious community for support or as an outlet for need to comfort and support others. These were found to be especially used in connection with ill health.

Park (2000) outlines the meaning making model of coping she developed with Folkman to show the factors involved in their adjustment of meaning making when people encounter heavy stress:

> When individuals encounter potentially stressful events, they appraise the meaning of the event (i.e. "What has happened?") and then determine the extent to which this appraised meaning is discrepant with their global meaning system. Global meaning systems are the internal cognitive structures that orient and guide people throughout life.

Thus under the stress of traumatic events, people adjust either their views of the events or their "global meaning system" to reduce the uncomfortable discrepancies.

In their outline of the history of the extensive research on stress and coping, Somerville and McCrae (2000) report that studies in the nineties point to the influence of individuality on coping behaviours. They were particularly concerned about the gap between process theories and the methodology of coping research with its emphasis on short term cognitive studies. They call for long term studies that will take into account "the cognitive unconscious".

Moving from examinations of generic life crises to illness, we have already seen how writers like Barkswell (1991), Radley (1997), and Angen (2000) have looked at the role of religion and spirituality in coping with illness. The journal, *Psycho-oncology*, contains many studies of the role of religion and spirituality in coping with cancer

Chronic illnesses provide on-going stress. Chamaz (1995) points out how chronic illness changes a person's sense of him/herself in major ways. The experience of altered bodies changes people's sense of identity. Originally most of the people she studied "took their bodies for granted as instruments or vehicles subjugated to the self" (p. 662). Patients' reactions take different modes of living with an illness, including "ignoring it,

minimizing it, struggling against it, reconciling one's self to it,... embracing it" (p. 657), and finally adapting and even accepting it. All these modes have to do with how personal identities alter as people live with their illnesses. They start by battling an illness, seeing themselves as separate from it. Later they "allow a receptivity to bodily experience" (p. 664). As they continue adjusting, they change their identity goals. Some people view their illness as an enemy to battle while others "struggle *with* the illness... and struggle to (make)... their lives normal to whatever extent possible" (p. 663). Eventually, she says, some "people cease to measure their body against past perfection, or past hopes of perfecting it, and begin to live with it. The sick body becomes familiar and perhaps even comfortable" (p. 664). People change identity goals, as they continually adjust.

Writers like Charmez see chronic illness and impairment as the driving forces in the process of change, whereas pastoral care specialists may chose to regard people as making choices about how they respond to their impairment. Louise Giroux, a woman with a chronic illness, who has worked to help others find healthy ways to live with their chronic illnesses, looked to her love of dancing for her central image and the title of her book, *Taking the Lead: Dancing with Chronic Illness* (1998). She desires to control her responses to illness and teaches others to make their own meanings in the on-going processes of their illnesses.

1.5 Kidney Disease and Psychology

A number of researchers have examined renal disease and its psychosocial effects. Several older works deal with the psychiatric and psychological aspects of hemodialysis patients. Czaczkes and Kaplan De-Nour (1978) looked at adjustment, including vocational

rehabilitation, social activities, family life, and stresses of living on dialysis. O'Brien, (1983) studied a number of patients (126 initially) over a 9-year period. Using both unstructured and structured interviews, she examined a representative sample of patients as to social support, dialysis unit relationships, life-satisfaction, family relationships, adaptation, religion, and modification of life goals. She also interviewed patients' families and staff on the dialysis unit. Patients underwent great psychosocial changes. The majority were depressed, suffering from alienation and loneliness. Many were unable to work or only able to work part time. Family roles changed. The fear of death that seemed to have been important was rarely mentioned, despite the high mortality rate among their numbers.

Of particular interest is O'Brien's work on religion. Although she did not define it clearly, she found it was important to her participants; almost all said they were as or more religious than before, although many could not attend church regularly due to their physical limitations. Religion provided support in accepting their condition and for many, church members or clergy provided important social support.

In their metastudy of the many qualitative studies of the chronic illness experience published since the early eighties, Thorne et al. (2002) found that the variety of professional backgrounds of the researchers influenced the nature of their studies. This observation is born out in recent studies of renal disease.

In 1992 a multidisciplinary, predominantly medical, group held a workshop in England to explore the concept of quality of life in ESRD patients; this was followed by the publication of papers (McGee & Bradley, 1994). Topics included the psychosocial impacts of renal failure, ways of measuring the quality of life of ESRD patients, the challenges of the treatment of renal failure, and the management of renal failure to improve the quality of

life of patients. Of particular interest was the study of illness cognitions by Horne and Weinman. They claim that patients first recognize the threat of the illness, develop coping behaviours, and finally appraise the effectiveness of these behaviours. They emphasize the role of hope, especially of renal transplant, in the lives of their participants.

Health psychologists, Symister and Friend (1996), also focused on quality of life, examining studies of renal patients and comparing patients following different types of treatments. Although these studies show some reduction in objective quality of life, such as participation in normal activities or employment, they do indicate that ESRD patients show little significant differences from healthy people in their subjective views of life satisfaction. Symister and Friend hypothesize that life satisfaction is closely related to the ability to achieve personal goals and that patients' life goals can be modified.

A relatively new field, that of heath behaviour, looks at how people behave in different health conditions. Gallagher and Stratton (1997) examined the behavioral implications of ESRD and developed a model of changes in self-concept with chronic conditions; these changes range from being asymptomatic (that is not showing any signs of change) to a sense of being dominated by the disease.

Nephrology nurses are often interested in the psychosocial conditions of their patients. Weil (2000) explored the role of hope in the lives of a variety of dialysis patients. She found that most maintained hope supported by their families, friends, and religious beliefs. Hopes were often focused on others, such as world peace or a spouse who will be all right. Lindquist et al. (2000) interviewed 86 ESRD patients using different modes of treatment as to their perceptions of the consequences of their illness and treatment. The

patients wished for normalcy, wanted to be able to control their own lives, noted their losses and dependency, and had some very negative feelings about their conditions.

Last year some British researchers, half of them psychologists, King et al. (2002), published a report on how a group of diabetic patients experienced adapting to renal failure. Using a phenomenological approach, they developed templates of themes: (a) diagnosis and immediate reactions, (b) explanations of disease, (c) living with the disease, and (d) hopes and fears, but they reported only on the last two. All but one of their twenty participants used stoicism as a coping strategy. They argue that these chronically ill people adopt old-fashioned stoicism because emotional self-disclosure would lead to alienation from "the healthy world". Emotional self-disclosure may assist in "'getting over' a traumatic event" (p. 343), but is not helpful in dealing with a chronic condition.

To study patients' perceptions of ESRD and dialysis, with grounded theory methodology, medical researchers Gregory et al. (1998), used semistructured interviews of 44 participants who had been on dialysis for at least 12 weeks. The model they developed emphasized "redefining the self" (p. 77) amidst the ups and downs of life on dialysis, through attempts to maintain hope and optimism. Redefining the self involved participants' perceptions of the quality of support they received from staff, family and friends, and other dialysis patients. In addition participants' self images was influenced by the meanings they attached to their illnesses, meanings that varied with their health status; consciousness of vulnerability and the limits of treatment lead to hard work to improve health.

Psychologists of religion, Tix and Frazier (1998), studied the effects of religious coping on persons' experience of kidney transplant over time. They argue that religious coping leads to better psychological adjustment than reformulating the stressful experience,

social support, and increased sense of control. Such religious coping includes prayer, confession, and seeking strength and comfort from God, their results indicate intrinsically religious Protestants achieved less distress and more life satisfaction with religious coping than Catholics. However only about 20 percent of their participants identified themselves as other than Catholic or Protestant.

1.6 Definitions and Purpose

1.6.1 *Religion and Spirituality*

I have adopted Pargament's definition of religion as "a search for significance in ways related to the sacred" (1997, p.32), as extended by Zinnbauer et al. (2000), who expand the meaning of 'sacred' to include all the objects, processes, and concepts associated with the transcendent. However, like Dyson, Cobb, and Forman (1997), I am aware that many people treat as sacred matters such as family, work, and personal gain.

From these writers, I have developed a concept of spirituality closely related to the more personal aspects of religion. Spirituality has affective, cognitive, and behavioural aspects and involves needs for identity; relationships with one's-self, with others, and with some form of transcendence; affiliation and interdependence; and hope and/or creativity, particularly Emmons' (1999) "ultimate concerns."

1.6.2 *Meaning Making*

As already implied, meaning making is a spiritual process, with psychological undertones, that involves the appraisal of the significance of ourselves and our lives as we grow and change and as our circumstances change. It is an on-going cognitive process that

involves what Emmons (1999) calls "ultimate concerns". As Park (2000) indicates, when stressful events occur, meaning making involves assessing the meaning of the events to decide how threatening they are, whether they can be controlled, or if their results can be predicted. Meaning making involves identity, relationships, and goals.

1.6.3 *Purpose*

The purpose of my paper is to examine how people make meaning of the experience of learning to live on dialysis and to learn how pastoral care givers might assist people undergoing the process of becoming used to life on dialysis through learning about the kinds of supports people found most helpful. Thus it examines some of the psychospiritual processes undergone by people becoming accustomed to ESRD.

While related to previous work, my study takes a different approach, focusing on the experiences of people who are newly come to dialysis with little perceived advance warning. My emphasis is on understanding the experiences of individuals, as opposed to developing a theory or discovering the "essence" of the phenomenon. Thus it differs from phenomenological and grounded theory studies such as those mentioned above. Plus, it is obvious that apart from the study by O'Brien little attention has been paid to religion in studies of dialysis patients. (Tix and Frazier's study deals with kidney transplantation.) Moreover, my concern with religion is focused on the spiritual processes of meaning making in people's lives, not on the individuals' religious affiliation and its role in their lives.

CHAPTER TWO

METHODOLOGY

The purpose of this chapter is to outline the relationship of my study to existing research, to give possible uses of the results, to provide an outline of the methodology I chose and why I chose it, to explain the selection of participants, and to deal with ethical concerns.

2.1 Relationship to Existing Research

Kenneth Pargament (1997) argues that stressful events are given significance and change the meanings people make of their lives. Thus a stressful health event, like going on dialysis, should impact on the sense people make of their lives. Research has been done on the spirituality of cancer patients and cardiac patients (Koenig, McCullough, and Larson, 2001) and especially on the making meaning of cancer patients (Barkwell, 1991). Like Angen (2000) and others, I regard meaning making as a spiritual task, one of the functional aspects of religion. Thus I interviewed three men who had recently gone onto dialysis as to what meanings they had given their lives before going onto dialysis and how these meanings changed in the stressful time of adapting to life on dialysis. I then analyzed the narratives to discern their processes of meaning making and compared their processes to those of two men who had been on dialysis for some time. While others have looked at coping with dialysis (O'Brien, 1983; King et al., 2002; Gregory et al., 1998), my study

differs in that I was trying to understand what the experiences were like for these men and the meaning making processes they went through.

2.2 Theoretical Use

This project fills a gap in the existing research, according to the literature survey done by Ellison and Levin (1998), and may serve as the basis for on-going research, to see how persons' meaning making is affected by going onto dialysis. This work is also related to the studies done by Pargament and others on how religion and/or spirituality affect persons' abilities to cope with such situations. It also adds to the understandings of the lives of dialysis patients as developed in such works as those of O'Brien (1983), McGee and Bradley (1994), and N. King et al. (2002).

2.3 Applied Use

The results of this research may allow health care providers to learn something of what it is like to begin life on dialysis. Such knowledge might enable them to better appreciate how patients experience such a crisis. In addition, the material on support may provide guidance to health care professionals as to what people have found helpful. The questions relating to support systems may be of use in studies to determine the most effective ways to provide support for those undergoing life-changing health crises.

2.4 Objectives

As previously indicated, the purpose of this study is to see how the meaning making process develops in the lives of a few individuals as they get used to life on dialysis, and to

learn what supports these people find useful in dealing with related psychospiritual dilemmas. It is also concerned with how the changes in these individuals compare to those in two other men who have had longer experience with ESRD.

2.5 Rationale for Selection of Methodology

In describing my selection of methodology, I begin by looking at some of my underlying assumptions and then developed a methodology for my study. Thus I begin by looking at feminism and what that means to me in terms of my study. Next I consider interviewing, as qualitative research; then I look briefly at the case study method; and finally I describe my own methodology.

2.5.1 *Feminism*

I started realizing that my attitudes and ideas about research grew out of my thinking processes as a feminist. I began by looking at feminist writers on epistemology and on methodology. Ideas in the work of writers like Munro (1993), Reinharz (1992), and Alcoff and Potter (1995) applied to the kind of research I wanted to do and were not limited to gender studies, but also applied to any power imbalances. Alcoff and Potter (1995) point out that feminist epistemologies and other postmodern philosophers have much in common, particularly in their understandings of the importance of power relationships:

> Growing awareness of the many ways in which political relationships (that is, disparate power relations) are implicated in theories of knowledge has led to the conclusion that gender hierarchies are not the only ones that influence the production of knowledge. Cognitive authority is usually associated with a cluster of markings that involve not only gender but also race, class, sexuality, culture, and age (p. 3).

As I saw patients as disempowered by a strongly hierarchical, medical culture, I thus consider that many of the insights from feminist epistemologies are of value to my study.

Moreover, like other feminists, I have tried to construct a text in which I am conscious of my own role. I have tried to be self-reflective, to allow for intersubjective creation of the stories, and to tell the stories of the participants in their own terms, frequently even in their own words (Munro, 1993, p. 173).

2.5.2 *Why Qualitative Research*

I chose a qualitative method of study for several reasons. First, a high level of complexity is involved in the close consideration of a process of change. The external circumstances (that is, social relationships, class, age, medical condition, etc.) of the various affected individuals differ. The elements of change may vary from one person to another. Also the rate of change may differ.

Secondly, I wished to consider the participants as the experts on their own stories, and only the close-in perspective allowed by qualitative research permitted me to deal with the participants in this way. Moreover, all too often questionnaire studies fail to consider the contexts in which the participants live (Douglas, 1985).

I used unstructured and semistructured interviews as my primary research method. Bernard Roy (1997) characterized the unstructured interview as the "Speech Event" model in which any question asked

> is thought of as part of a circular process through which its meaning and that of its answer are created in the discourse between interviewer and respondents as they try to make continuing sense of what they are saying to each other– respondents'

> accounts can be understood as narratives, or stories (meanings are textually grounded knowledge).

According to Reinharz (1992), "interviewing offers researchers access to people's ideas, thoughts, and memories in their own words" (p. 19). Moreover, examination of narratives demands very self-conscious work on the part of the researcher:

> Working with narrative material requires dialogical listening to three voices (at least): the voice of the narrator, as represented by the tape or the text: the theoretical framework which provides the concepts and tools for interpretation; and a reflexive monitoring of the act of reading and interpretation, that is, self-awareness of the decision process of drawing conclusions from the materials (Lieblich, 1998, p.10).

2.5.3 *The Case Study*

I chose to use a case study approach. The case study's emphasis in in-depth study of individuals and their situations provided the balance that I wanted between analysis and focus on the individuals and their stories. This approach is often used by social psychologists with their emphasis on developing meaning to make sense of situations and experiences (Prus, 1996).

Stake (2000) argues that there are three types of case studies. In the *intrinsic* type, the case itself is of primary interest. In the *instrumental*, the case is chosen as an example of an issue or generalization to be examined. In the *collective* case study, a number of cases are examined to learn about a population or general condition. Whether the cases have common features is yet to be determined. Thus, Stake points out, the collective case study is like a series of instrumental case studies that were selected in order to understand them, an understanding that may lead to the development of a theory or generalization about a larger number of cases. This seemed a good starting point for a relatively unexplored condition, like the experiences of those adjusting to being on dialysis.

Even though a study like mine may provide the basis for later generalizations or theories, I wanted to learn about each participant's experiences as perceived by him and to enable my readers to recreate these experiences. I tried to do this through encouraging the participants to explore their experiences and by providing my readers with "thick description". Moreover in my report I have tried to provide sufficient descriptive narrative to enable the reader to "vicariously experience these happenings (the interviews) and draw (their own) conclusions" (Stake, 2000, p. 439).

2.5.4 *Methodology*

In developing my method I followed a modification of the procedure as outlined by Yin (1994). First to define the situation under study and to consider what is involved in the situation: I looked at how meaning making might be affected in a stressful situation like going on dialysis. Meaning making might be affected in a variety of areas:

(a) self-identity: that is, how people see themselves;

(b) social relationships;

(c) social values;

(d) religious traditions and affiliations;

(e) sense of the transcendent: that is, of forces outside him/herself; and

(f) anthropology: that is the person's answer to the question, "What are human beings?"

Then I developed a data collection protocol, the unstructured or semistructured interview. Subsequently I decided on criteria for the selection of participants. My plans were to interview each participant and to write the individual case studies, organizing the

materials according to the categories above. Next I would look for common themes in the different case studies. Finally I would draw cross case study conclusions.

2.6 Method of Data Collection

In unstructured and semistructured interviews the participants developed their life histories for the time period under discussion (that is, from the premorbid period up to 5 months after the health crisis). I began each interview by asking, "Tell me about yourself and what has been going on in your life." I then used questions to clarify and expand their answers. If the participant had difficulty with such a general question, I used a series of open-ended questions designed to elicit his story in his own words. (See Appendix II.)

Each participant was interviewed three times: first, within a month or six weeks of first dialysis (depending on his general health and strength); second, approximately six weeks later; and third, about two months after that. To build a picture of what the illness meant in the life of each participant, the first interview focused on illness, the participant's sense of self, how the illness had changed the person's life and sense of self, and what sources of support he found helpful in the process.

The two subsequent interviews focused on changes and continuities.

As much as possible, the interviews were conducted in a relaxed, informal manner. The interviewer's role was to stimulate the participants to tell their stories in their own words. The predetermined questions were used where necessary.

Interviews were conducted between January and September 2001. Participants chose the place and time of each interview. The interviews were taped and later transcribed.

After the tapes were transcribed, each tape was listened to as the transcriptions were read, careful notes being made on the emotional content of each interview.

2.7 Selection of Participants

Initially I contacted the staffs of the dialysis units at the Civic and General Campuses of the Ottawa Hospital and requested they identify and approach any potential candidates as to whether they were interested in participating in the study. (See the letter in Appendix III.) I contacted all patients referred to me. After explaining my study, its purpose and methodology, I asked if each wished to participate in the study. Each patient was assured that their willingness to participate or not in the project would not be known by anyone else on the unit. Each signed consent forms approved by the ethics committees of the Ottawa Hospital and St. Paul University. (The consent form is given in Appendix III.)

The participants recruited were to be persons from 18-65 years who, with little or no advance warning, had gone into renal failure and required dialysis. Persons who had previously undergone a major life-changing health crisis were excluded. Exclusion factors included but were not limited to diabetes, amputation, and major heart attack.

As I set out to contact suitable persons I found that very few actually met my criteria. Other than the three men I interviewed, I was able to contact only one woman and one man who met my criteria in a six month period. The woman decided she did not want to participate and the man quit after one, not-very-satisfactory interview. Thus the fact that the main participants are all men was happenstance.

It is worth noting that, like many studies based on interviews, most of the participants come from roughly the same social strata as I do– "middle, urban, higher

educated groups" (Benney & Hughes, 1986, p. 219). The man who withdrew his particpation after only one interview had little formal education himself and experienced considerable difficulty answering my questions[3]. One individual who withdrew, albeit after two lengthy interviews, came from a lower social class and for reasons to be explained later, seemed to be in a fairly repetitive factory occupation, although he had a diploma in a technical participant from a community college and obviously had an educated person's vocabulary and speech patterns.

After I had completed most of the interviews with these men I realized that patients who had been on dialysis longer had gone through more changes than the men I was interviewing. Thus with the approval of my advisors, I chose to interview two men who had been on dialysis for some time. (With only males as my primary participants, I decided to similarly restrict my secondary focus subjects.) These men were interviewed as to how they had experienced coming onto dialysis and what life on dialysis was like for them. They too signed consent papers and underwent semistructured interviews like the others.

2.8 Description of Participants

Five men, all patients on the dialysis units at the Ottawa Hospital, were interviewed for this study. As indicated above, three were newly come on to dialysis. They all chose to be interviewed while on dialysis; quiet positions were assigned by staff.

In the following descriptions all patients were given pseudonyms.

[3] It was interesting that when I approached this individual later, in my role as a chaplain, he relaxed more and revealed a lot more about himself and without the tape recorder and the self consciousness of an interview we were able to establish a closer relationship. I have not included this individual in my paper.

Abdul, in his early thirties, a patient at the Civic Campus of the Ottawa Hospital, took about 1 1/2 hours for his first two interviews and about 3/4 hour on the third. The other two men were contacted at the General Campus. Vivian, in his mid twenties. chose not to complete the series, but gave me permission to use the two completed interviews, each about 1 1/2 hours long. His first interview was at the General Campus, but later contacts were made with him at the Riverside Campus. John, in his mid fifties, chose to have his partner, Melissa, stay with him through the first two interviews because at that time she was accompanying him to dialysis. His first two interviews, to which Melissa contributed, lasted almost two hours each and the third lasted about an hour.

David and Wayne, two men I had met while working as chaplain intern on the dialysis unit, were the two participants who had been on dialysis for some time. David chose to be interviewed in his home and Wayne in a small office at the hospital.

All but one of the participants had children; four lived with female partners; and the other had a regular girl friend. Three were born in Canada and two were immigrants. One was a Moslem; two were Christians; and the other two were raised as Christians, but have rejected the faiths of their childhood. The causes of their renal failures varied: two associated with high blood pressure; one, IgA nephropathy; and one, granulomatosis.

2.9 Validity

Most forms of case studies involve developing and using multiple sources, often as a form of triangulation to verify the findings (Stake, 2000 and Altheide & Johnson, 1994). However I rejected adding patients' charts, interviews with medical staff and family members, and other observations as sources since they might be counterproductive to my

purpose, the examination of the participants' experiences from their own points of view. To consider other sources of information might lead me to get involved in the relationships and value judgements that others impose on the participating individuals and thereby could deny these individuals something of their own roles as the creators of their own stories[4]

So how could I determine the internal validity for a study that considers how persons feel about themselves and their circumstances? Only, I decided, through examining how these views are expressed over time. Thus I have noted and commented on internal differences in the interviews.

2.10 Method of Data Analysis

I developed a case study of each participant separately. First I worked to produce a longitudinal picture of each. In order to do this I followed the following steps:

I. Premorbid Personality:

I developed pictures of premorbid personalities from information provided by the participants during their interviews. In particular I read and reread each interview trying to determine the participant's view of himself before the onset of his illness.

II. Participant at the Time of Each Interview:

I developed a picture of the participant, his life, the dominant themes of his meaning making, and his mode of adaptation. In order to determine the dominant themes of meaning making of each participant, I followed the following procedure:

[4] The phrase, "non-compliant", on a chart referring to an incident outside my study suggested a judgmentalism that indicated lack of respect for the patent's experience.

A. I read and reread each interview in turn to consider the themes and metaphors that the participant used in talking of his present life, being particularly sensitive to the individual's image of himself, including values, goals, and relationships to others.

B. I identified major themes and categories and then reread the interview concerned, identifying particular passages that stated or implied those themes in order to define them.

C. I adjusted any categories that needed to be changed according to my latest reading of the material. Then I again reread the relevant interview, identifying the passages that revealed each revised category.

III. Process of Change

Next I examined the themes of each interview to determine changes in meaning making apparent within the interview. The features of the different interviews by each participant were examined to determine the processes he had gone through in his attempts to retain or alter his identity and life meanings in his changed circumstances. This formed the basis for my comments on the process of change I observed for each participant.

IV. Comparisons

I compared the themes and processes of each of the individuals involved. First I looked at the case studies of the three men whose stories are the primary focus of my research and later I compared them to the two men whose stories of ESRD covered longer periods of time. The hypothesis regarding the analysis of meaning making themes was then examined in light of the analysis and the hypothesis was adjusted.

V. Support

For the questions about support, I examined the interviews for any material that dealt with the sources of support used by or recommended by each participant. I searched the material for common themes and noted similarities and individual differences.

VI. Advice

For advice from the participants on how to assist persons experiencing similar health problems, I used the same methodology as I had for sources of support.

2.11 Ethics

As indicated above, this study met the criteria for studies involving human persons. The research proposal was submitted to and approved by the ethics committees of both the Ottawa Hospital and St. Paul University. (A copy of material provided in the applications to the ethics committees is provided in Appendixes II and III.) Potential participants were assured that their involvement was optional and were given the chance to withdraw at any point. Most participants chose to be interviewed while on dialysis and unfortunately that meant that interviews could be overheard by others. The transcriptions of the interviews are being retained at St. Paul University for five years, but all other records of the interviews have been destroyed. Identifying details have been altered in order to protect the privacy of the participants as much as possible.

The perceived level of risk in this study was low. It was feared some participants might experience psychological distress through remembering painful events or psychospiritual distress due to the difficulties of their circumstances. However, none showed signs of distress and so it was not necessary to refer any to other professionals as

had been planned. Several participants expressed satisfaction with the opportunity to take part in a study of this kind, seeing it as an opportunity to give meaning to their experiences by having them serve as the basis for learnings that might serve others. Several of the participants seemed to experience greater psychospiritual integration of the crisis through talking about their experiences to a supportive empathetic listener.

CHAPTER THREE

MAJOR CASE STUDIES

The primary focus of this study, Abdul, Vivian, and John, each met the criteria of coming onto dialysis without much advance warning. All had suffered previous major illnesses but they had not made these problems important parts of their stories; yet none seemed to have reacted to their earlier problems as they did to the crises precipitating dialysis. Radley's (1997) distinction between bodily symptoms and illness is important here as each of these men had clearly had earlier health problems.

Each case study begins with an introduction to the participant and his illness, and a description of our relationship. Following are the results of the analyses of the interviews under the following headings: Premorbid Personality and (a) Illness and adaptation; (b) Identity; (c) Social relations, including family; (d) Values; (e) Religion and hope; and (f) Support. Then important themes are commented on and the nature of the processes of change noted.

3.1 ABDUL

3.1.1 ***Introduction***

Abdul was a thirty-year-old male, born in the former Yugoslavia, who started dialysis in late 2000. He suffered from immunoglobulin A nephropathy. He had been

admitted to the hospital in 1995 with an infection and a creatinine level of about 300; treatment was successful, but a biopsy in October 1996 revealed nephritis with considerable activity and moderate glomerular obsolescence. Gradual regression occurred. In the summer of 2000, he was seen at the Nephrology Clinic and warned that dialysis was approaching. Although there was no follow-up at the clinic, he continued to see his family doctor for medication. Early in the winter, Abdul became very ill and was hospitalized and began dialysis. During our interview period, Abdul was being tested to see if he was eligible for a transplant. In the mid-nineties, in the process of treating and testing him, a cardiac problem had been discovered and aortic valvoplasty was performed in 1997.

I interviewed this participant during his periods of dialysis; the first two interviews lasted almost 1 3/4 hour each, while the third lasted about 45 minutes. The first interview took place about three weeks after Abdul started dialysis, the second about seven weeks later, and the third about five weeks after that.

During the first interview, Abdul seemed to need the guidance of a semistructured interview form, and so I used the set questions I had developed with him, adding further questions to get more detail or clarify my understanding. Later interviews were, however, much less structured. Generally Abdul answered my questions in a forthcoming way, but occasionally he had difficulty comprehending what was being asked.

Abdul was married with one daughter, aged 6. He lived with his wife, his daughter and his mother, aged 72, who suffered from debilitating arthritis. Abdul's father died many years ago. Abdul, his wife, his mother and a brother came to Canada in 1995 from their native country. Abdul was the youngest of seven children, the oldest twenty years older

than him; four of his siblings live in Europe and two live in Canada. After his kidney failure, several of his siblings expressed an interest in donating a kidney to him.

3.1.2 *Premorbid Personality*

In the period before kidney failure, Abdul seems to have been an active person, involved in sports, especially soccer where he served as a referee. He worked hard for a high technology firm, often working overtime to assure the prompt delivery of a sales order. He liked his job and seems to have been regarded as a valued employee. As we shall learn later, he was devoted to his family, especially to his daughter and his mother. He spoke of friends who appeared to be people who worked for his company, neighbors and immigrants from his country, some of whom he assisted.

3.1.3 *First Interview*

3.1.3.1 *Illness and adaptation*

His illness seemed to fill Abdul's mind. He kept returning to the shock of the discovery of his need for dialysis. About six months before, a renal specialist had warned him that his kidneys were not functioning properly, but he had apparently had not fully understood. When Abdul showed strong symptoms of kidney disease, his family doctor prescribed medication that was not effective. (Abdul showed some anger at his family doctor for not sending him to the hospital earlier.) Eventually his family doctor told Abdul to go to the hospital Emergency Department. The following morning Abdul left for the hospital, expecting to be home in a short time: "I'll go to have blood tests and be home very

soon,"[5] he said to his mother. The news that he would have to be admitted and dialyzed immediately shocked Abdul. How would his family react?

The explanations provided by the medical personnel, as well as their kindness and gentleness, helped Abdul through his initial disbelief and shock. He was soon able, he said, to bring to bear his inner resources: "After a couple of seconds maybe, I just told myself, 'It has to be like that.'"

In addition to this kind of fatalistic acceptance, his understanding of his situation and of the sources of his illness were essential parts of Abdul's longer-term adaptation. Abdul saw his kidney failure as an accident and the dialysis machines as life saving. He questioned himself and the doctors as to "the cause of my problem". Was it, he wondered, due to "the very, very strong infection" he had had several years before?

Abdul had decided that he must live a "normal" life: "Basically I think I should live a normal life like I did before that happened to me." At first, he implied, he had been afraid that his life was effectively over, but his family's encouragement and his own determination had led him to decide to go back to work a few days after our first interview. He was also encouraged by another patient's story of his active, involved life.

The amount of time dialysis requires bothered Abdul: "I have to come here three times a week and I have to stay four hours that means— three times four is twelve hours.... It's not easy," he emphasized. The dialysis time and dietary restrictions had affected Abdul's social life. Although the restrictions on travel were not very important to him, they contributed to his feeling of being closed in, of living a restricted life.

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[5] I have altered Abdul's words to clarify his meaning since his English, largely self-taught, is often ungrammatical. I have maintained the sense of what he said and used his own words as much as possible.

Of course Abdul saw a transplant as the route to the return to normalcy and was anxious to have one as soon as possible— life with a transplant would be easy. Return to normalcy would also benefit all those around him. Moreover his age was also a factor: "Because of my age and my daughter and my family and the people around me, I would like to solve my problem as soon as possible." Still he knew there would be no complete return to life as before. There would always be something different: "When I say 'solve my problems' I did not use exactly the right words, but I mean I would like a transplant and I would like more freedom." Meanwhile Abdul would listen to the doctors and follow the regimen they prescribed strictly.

3.1.3.2 *Social relations, including family*[6]

Abdul's family was very important to him. His immediate family consisted of the five people who came to Canada together: himself, his mother, his wife and his daughter, and a brother who now lived nearby. Abdul had nothing but praise for his family; his mother and wife were both "really good" in their roles. His mother was a role model, the teacher of religion and the instiller of optimism, so important at this time. "She always told me— not only me, but all the kids— if something was wrong, she always said, 'That's O.K. That's only temporary. Things will get better.' That's how she looks at life." His wife too filled her role: she came immediately after he called to say he would have to be hospitalized; she prepared his food, being careful to follow his diet; and she encouraged him to be optimistic. His brother too is ideal: concerned about him, devoted to his mother

[6] For Abdul his social relations are especially important and really seemed to be the basis of his identity. Therefore I have placed his social relations before the sections on his identity.

and his niece, visiting the family regularly. His daughter, now aged six, was especially important to Abdul— a model daughter: pretty, intelligent, and understanding of his situation. Following his mother's lead ("The kiddies first before everything else"), Abdul put his daughter first.

Abdul put his responsibilities to his family foremost. His first thought on hearing of the seriousness of his illness was about how worried they would be. Later when he came to think about returning to work, he consulted his family as well as his doctors. A transplant and a return to normalcy were needed, at least in part, so that Abdul could live out his responsibilities to his family, especially his daughter.

The practical and psychological support of his wife and mother were very important to Abdul. The women may have shown too much concern for Abdul, but he certainly was not going to criticize them: "They always think I worry, but it is not like that. They are just wondering if I think...."

The family unit had played a vital role in their successful integration into Canadian society. " I have met many people who have a hard time when they change countries. But I am sure it was much easier for me and my family because we came here together." Moreover Abdul was very proud of how successful the family had been in the short time they had been in Canada. In only five years they had bought a house. At first this happiness seemed threatened by Abdul's illness, but the family was reassured because he was "feeling very good (and) life was returning to normal".

Abdul felt very thankful for the care of the hospital medical staff. They had been gentle, especially on the dreadful first day as they inserted the catheter in his neck. They had been helpful and supportive, both of him and of his family, answering their questions

and making sure they knew what was going on. The staff on the unit all continued to be helpful and supportive. The need to be grateful to all those on whom he felt so dependent was clear.

He got along well with others. His friendliness and willingness to talk to the people around him were, he thought, part of the reason for others' high regard for him. He had received calls from many people from his company— not only workers at his level but some engineers too.

3.1.3.3 *Identity*

Especially important to Abdul's identity was his role as an integral part of his family. He also saw himself as a fine person, highly regarded by his neighbours, friends, and co-workers. He was a good person: "I never did anything bad back in my country or since I arrived here." He loved his work and thought of himself as a good worker, always on time, a co-operative team member, and concerned for the well being of his company of which he was proud.

He was satisfied with his life as it had been. In the relatively short time the family had been in Canada they had been very successful. He saw himself as a simple person, wanting financial security for himself and his family, but with no great ambitions. He longed for a return to his life as it had been. The desire to return to work was part of a desire to regain a life that seemed to be in control, going the way he wanted. The circumstances of his life might have changed, but he himself had not.

3.1.3.4 *Values*

At the core of Abdul's values was the importance of family. And of course, the future generation, represented by his daughter, was vital. All the members of his family saw things that way, he said; this was what they had learned at home. In the family, each person had a role, and all filled them well.

The optimism his mother had taught him was important. Her optimistic philosophy made her exceptional—"Not many mothers teach that"— and was at the core of his high regard for her as "one of the really good mothers". Abdul tried to be optimistic even in this time of difficulty. He accepted his illness stoically: "It has to be like that and I have to live with it, " he said. His sadness was overcome by looking forward: "But looking into the future, I'm young and I have my daughter, my family behind me."

Although Abdul wanted comfort and security for his family, money was not of great significance to him. Good health, however, was to be valued and prayed for regularly. Thus, the return to health and to a normal life was especially important. It would allow Abdul to take up his role in the family again and ensure their continued security.

Abdul also valued good relationships with people outside his family. He was impressed by the varieties of nationalities who live together in Canada. In his native country everybody is the same nationality, but in Canada things are different: "I love (the fact) that so many different people live in the same city." Nevertheless the most important thing about people is how they treat each other and whether they "can build a good relationship".

3.1.3.5 *Religion and hope*

Abdul is a Moslem. His view of God– transcendent, in control, to be prayed to regularly– was consistent with his religious heritage. He had always prayed for good health for all his family, but now he prayed especially for help in getting a transplant quickly in order to return to normal life. God is the source of good: he thanked God for dialysis machines to save his life and for returning strength so he could go back to work. Abdul said he was not very religious, and he relied on his mother as the authority on religion, she was the guide in matters spiritual.

A very important element of religious life was the observance of festivals and their role in community-building. When he was asked about his religion, the first thing he mentioned was a recently-passed holiday and how much he had enjoyed it. Family and friends gathered, ate the specially- prepared foods, and talked.

"You have to believe in something," according to Abdul. And he loved his religion "very much" but he "appreciates other people's religions" too. His own religion was the basis of his respect for the beliefs of others: "if you don't like your religion, you cannot appreciate or like another's, that's my policy."

Abdul's greatest hope was to get a transplant and solve his problems. "I hope with God's help that the day is coming when I will get a good kidney and when I do have that operation (a kidney transplant), it will work well. And I can live life as I did before this happened to me." More immediately he hoped that he would be able to work— at least part time, but he regarded the possibility of a return to a physically active life with some trepidation, fearful of not being able to fully participate as he had before.

3.1.3.6 *Support*

In addition to the practical and psychological help provided by his family and the medical staff, Abdul also felt supported by the friends and fellow workers who had wished him well and offered help. Prayers too brought God's help and support, and they were being answered in his returning strength.

Of special assistance in adjusting to life on dialysis, in pulling him out of his initial despondency, was another patient. He could identify with this man because he too had a good wife and children, he loved sports, and he was optimistic. This man, 10 to 15 years older than Abdul, told of how he lived a normal life, looking after his children and frequently going for runs. According to Abdul, this man had told him, "'Life does not stop. Life goes on, but you just have to understand... how things have to be and it is not a problem.'" Abdul felt this was excellent advice and he was going to try to follow it.

As far as others were concerned, Abdul's advice was very simple. He would tell them of his own experience and he would say, "Don't worry. Life goes on. Don't think that life is over. Don't let yourself get upset. Act normally. Follow the doctor's instructions strictly and don't worry. One day things will be much better."

3.1.4 ***Second Interview***

3.1.4.1 *Illness and adaptation*

Abdul was still very concerned about his illness, but this time he focused his discussion with me on his previous experiences with ill health. He spoke of two earlier illnesses. He was unclear as to which of these was at the root of his present difficulties. A

bad infection he had several years before had involved his kidneys and after his recovery, he had gone yearly to the renal specialist for check ups. But the valvoplasty he had had the following year might also have been a source of his kidney failure.

The search for the roots of his kidney failure were tied to Abdul's desire to understand his illness. Understanding and stoical determination to accept his illness as part of his life had provided the means for him to overcome his initial shock at being on dialysis, he said. Not only had he found dialysis very nerve-racking, but he had also feared losing his job. But he was becoming accustomed to dialysis and seemed to have used self-talk to calm himself down and convince himself that his life had not ended.

Going back to work too was an important part of his adjustment. Work was a sign of normalcy, and Abdul aimed to be "normal". Furthermore, an active life allowed time to pass faster as he waited for a transplant, and his mind was no longer filled with his "problem". Some people, especially those at his workplace, were surprised by his quick return to work, but Abdul had discussed the matter with his doctors, and they had given permission. At first he had found work difficult, but now he found things easier, and he said that he felt good. Abdul saw working, at least part time, as so vital that he would urge other young dialysis patients to follow suit.

Living a "normal" life was so important that Abdul prided himself on not taking naps as most dialysis patients do. He followed the prescribed regimen carefully. He insisted he felt good, especially after a good dialysis. However life had not really returned to "normal"; that would come only with a transplant. Meanwhile he had returned to many of his former activities, but he feared reinvolvement in sports or any other strenuous activities. Going to dialysis was a real burden: the time on dialysis was slow, and he

missed spending time with his daughter. Also he could no longer work overtime. He seemed to be grieving his losses: overtime, sports, travel, and a sense of normalcy. Finances too seem to have been a problem; his food was expensive, he said, and the lack of overtime must have had an impact on the family budget. (Abdul did not like to complain about finances as he regarded money as not very important, but he did allude to his diet stretching the family budget.) The time until a transplant took place was an in-between time, a time to "survive".

3.1.4.2 *Social Relations, including Family*

Again Abdul spoke at length of his family. The group made all major decisions, such as having the valvoplasty some years before and the decision to return to work. Immigrating to Canada had been a family experience. Although Abdul, his wife, his brother, and his mother had all applied at the same time, papers came for his mother and brother but not for Abdul and his wife. Abdul was very upset because the family was split up. His pregnant wife could not go right away. However later that year the family was reunited when the baby was old enough to travel.

Since then the family had lived together, even buying a house together. (Although his brother had moved out, he lived nearby and was frequently referred to as part of Abdul's daily life.) Finances were a group effort; Abdul said of the money he and his wife earned, "That is not your money." It went to pay the common expenses.

Abdul's illnesses seemed to involve the whole family. In discussing his earlier infection, Abdul said, "We solve that problem." Of his present illness, Abdul said, "They (his family) are challenged with me" and "They live that problem with me". The whole

family felt included in Abdul's recovery and hoped for a transplant soon. They encouraged him not to become despondent, to keep up hope, and to look towards a brighter future. In addition, the women worked to ensure that Abdul's health remained good: checking on his medication and appointments and preparing his food. While he had a permacath, his wife had aided him with washing. Abdul appreciated these efforts even though, he assured me, he was himself very careful with his self-care and did not need reminding.

His illness had changed Abdul's role in the family somewhat, he felt. Now "everybody was fighting for him". His health was a priority and he "was the first now".

After his family came his work. He believed that he was well-liked by his fellow workers, who had always been friendly and who now watched to ensure that one of them took over if the tasks were too hard for him. Abdul said that few occasions of this type had occurred, but he appreciated his fellows' thoughtfulness. He prided himself with getting along well with the office staff.

But he was particularly touched by the concern of the president of his company who had phoned Abdul in the hospital. When Abdul burst into tears about the possibility of losing his job, the president reassured him, "'Don't even think about that. If I am here for another twenty years, you will be with me all the time.'" Thus Abdul felt very uplifted and appreciative. He felt this was a reflection on his own behaviour; he had earned the respect of this man by his excellent work habits. He was always on time for work; he got along well with his fellows; he communicated well with "his" engineers; and he had often worked overtime, even returning from home to help to solve a problem.

Overall Abdul saw the company he worked for as "his" company. His overtime had helped to ensure that the company maintained good contracts and got even better orders.

The other people who worked for the company were well educated and smart; they all knew about dialysis, even if they did not know the exact details. Moreover he felt the humane treatment he received was a sign of an unusual company:

> Today you know you cannot find too many cases like that because, in my field– high tech– so many people are available. If you cannot (do the job) another will be hired. They don't care about you. I mean they want people who are healthy, who can do the job. But it's not like that in my company.

Abdul's pride in the business suggests he saw it as an extension of himself.

Abdul's friendly nature and positive attitude towards people showed up in his care for the others in his dialysis room. They were like another family, talking about their daily lives and concerned for each other. Abdul empathized with another man who had a difficult time when the nurse tried to insert the needles; Abdul himself found the needling painful: "the needle is huge and very big and it's very painful".

3.1.4.3 *Identity*

Abdul saw himself as a young man with family responsibilities, especially to his daughter. His youth and responsibilities gave him strength and encouraged him to keep hoping for a transplant, to bring him back to a "normal" life. He saw himself as being tough, never giving up despite his despondency.

He prided himself on being organized. He always arrived over forty minutes early for dialysis to get things ready. He did not like to be rushed; he said, "I don't want to voom-voom." Similarly he had always arrived early for work, to set up his work or to chat with friends. Planning things was good, but plans could be broken: "I'm not the kind who becomes angry and screams and yells. No, I am very relaxed about everything."

Abdul prided himself on being a good worker, prompt, getting along well with others, and being willing to work overtime to enable the company to fulfill its orders on time. The recognition he got from the president of the company fed his pride in himself as a good worker.

Kidney failure made him incomplete: "I don't have kidneys." Now he was not able to participate in sports. "I was a big sportsman," he said. "I am not able to do that any more. I cannot run."

Abdul's ties to his family were very important and they too found in his continued survival a source of happiness. He saw his family as an extension of himself. His conscientiousness was a family trait, something taught him by his parents. He saw the role of his family this way: "That means nothing is important— nothing except you, and if you have a family, you and your family. That comes first, especially if you have kids."

Recent events have made Abdul more dependent on others, but he took pride in the return of independence. While he had a permacath, his wife had had to assist him to bathe, but now that his fistula was working, he was able to look after himself. He told me how thoughtful his fellow workers were being, taking over at his work station when the task was too hard for him, but this had happened only a few times because "I am trying to do my job." It is worth noting that his friends must have been aware of his continued desire to be seen as competent as one of them offered a face-saving gesture of an exchange of tasks: "'I will do that. You (Abdul) can do something else.'"

3.1.4.4 *Values*

As we have already seen, Abdul's family came first, followed by his work. His values fit into this scheme: his sense of responsibility, especially to his daughter; his work ethic; his desire to get along with people; and to be optimistic.

Life and health are important; money is not important except to pay for the necessities of life; he would not complain about the low wages he and his wife earned.

Teamwork as a value showed in his comments on his work and in his response to the transplant evaluation team. They were very well-coordinated and did good work.

> I went to the General Hospital (sic) to see the transplantation team and I was very surprised to see how these people were doing their work and how everything goes. It was excellent how the team did that. I like that. I spent time with so many nurses and so many doctors. I am feeling very good after that.... They showed you where everything is because the General Hospital is a big hospital. You have to go to so many rooms and so on. Generally they work very well. They work like a team and that surprised me and I really like that.

In facing his problems, Abdul turned to his values for support. He was generally optimistic; being positive was important. He tried to remind himself of what his mother said, "Things will get better." He felt he must be tough and strong. He must look at difficulties as problems to be dealt with, problems that could be solved; his problem now was like a difficulty with a car— a breakdown might delay the beginning of a trip, but it was solvable. Nevertheless, he realized all problems could not be solved immediately; so he told himself that life goes on and he had to accept his problems, not worry about them.

3.1.4.5 *Religion and Hope*

During this interview Abdul made no reference to his religion except to thank God for the blessings of life and feeling good and to pray for a quick transplant.

Abdul's hopes for a speedy transplant were fed by the pretransplant procedures done earlier on the day of our interview. He had been warned that there are risks associated with the operation, but he reminded himself of how he had come through his earlier operation, an aortal valvoplasty. He dismissed the risks involved saying, "In life you have to take some risks. If you don't take risks you won't get what you want. That's life." Moreover he was beginning to be aware that even a successful transplant would not bring a return to life as it had been before: "Anyone who gets a transplant has to be careful. That means taking care of your kidney."

He laughed at his image of himself after the transplant. The transplant would be "my baby". It would be the start of a new life for him, relieved of the burdens of dialysis.

3.1.4.6 *Support*

In addition to the support in his family's encouragement and practical help, Abdul drew strength from their caring and the realization of his importance to them. The kindness of his fellow workers and the regard of the company president also gave him strength. The concern of the medical staff was also very helpful, as was the knowledge that he was acquiring about his illness and about the process of kidney transplant.

A number of times Abdul commented on how other persons newly come onto dialysis might assist themselves through self-talk. Like him, they should remind themselves of the need to be strong, to fight against despair, and to maintain hope. Young people especially should put their hope in getting a transplant soon.

3.1.5 *Third Interview*

3.1.5.1 *Illness and adaptation*

While I was arranging for our third interview, Abdul asked me if I could help him get his transplant faster; however my explanation that I had no influence seemed to satisfy him. He had tried, but did not seem to have relied on me as a possible source of help.

During our interview, he had a problem with dialysis. A nurse had to manipulate his needle until the blood flowed properly again— a painful procedure. The previous night he had refused our scheduled interview because he had been so bothered by a similar problem. Now Abdul continued with the interview when the procedure was over.

Abdul said he was feeling well, sometimes as well as he had before he started dialysis: "Some days I feel like nothing happened to me." He lived an active life much as he had before, except for sports. He found dialysis time-consuming and boring. Moreover, needling was painful. The long wait for a transplant was discouraging. By now he had been on dialysis for more than four months and several of his family members had offered to donate a kidney. He felt "frustrated".

So Abdul drew on his strengths. He worked hard to maintain his optimism and looked for the positive, telling me— and himself— how well he was feeling, how well he was eating, how well his fistula was working. Only twice before had he had problems on dialysis. Life on dialysis was a challenge to be met with courage, but sometimes it was hard to fit everything in. So using self-talk in order to make himself "content", he reminded himself, "That's life! Some situations come along that are very frustrating."

3.1.5.2 *Social relations, including family*

Abdul's social relations seemed much the same as before, except that it was clearer now that his status in the family had changed. His daughter had joined the women of the family in encouraging him: "Daddy, one day you will stop going there (to dialysis)." This made him especially proud of his daughter and her understanding of his illness. But still the cared-for was joining the caregivers.

In addition to his family's encouragement, Abdul was appreciative of the support he received from the coordinator of the transplant team and from the staff of the dialysis unit in general, especially those experienced nurses whose skill made needling easier.

3.1.5.3 *Identity*

Abdul took considerable pride in having a very active life. "I didn't cancel anything," he said. This gave him the feeling of having control over his life: "That gives me a lot of power over my life." He feared if he stopped he would be in trouble.

Although he was conscious of not being healthy, he wanted to be independent and certainly did not want his family to wait on him. Although he saw others on dialysis who needed a lot of assistance, he was not one of them: "But I am still young." Sure the women of the family prepared his food, but this was part of the family teamwork.

Abdul also emphasized how strong he was. His strength gave him the self-control that enabled him to help the nurses when they were doing the painful needling. All the people of his native country were strong; they had survived five years of hardship during the recent war. Now his family were Canadians, and he saw Canadians as strong too.

3.1.5.4 *Values*

As time passed and a transplant seemed to come less rapidly then he had hoped, Abdul focused on the value of optimism, as his parents had taught him. Also he tried to be tough in the face of difficulties. He stated his philosophy as follows:

> Sometimes in life a lot of problems come along **very fast!** Some people have financial problems; some people have problems within their families– many kinds of problems! But you know you have to try and solve that. You should never go away and say, "Ah well, whatever happens will happen." That's not good thinking. You have to try to solve the problem with positive things. Never look on life as something negative.

He was proud of the country where he was born and now extended that pride to Canada. He loved his native land because he had been born, raised there, and educated there. Now Canada gave him a chance to work and "bring home money to care for (his) family". And after him, "another generation (his daughter) would go on like that".

3.1.5.5 *Religion and hope*

His hopes of transplant were becoming harder to maintain as time passed with no word. He did not know if he was even on the transplant list yet. As he looked around, he feared he would become one of those patients who are real invalids, requiring a lot of assistance. Thus his determination to remain optimistic became acute.

3.1.5.6 *Support*

For support, he continued to use self-talk about being positive and the support of family and friends. Now even his daughter worked to encourage him.

3.1.6 *Themes and Changes*

Thus going onto dialysis had brought a number of changes to Abdul's life. Going onto dialysis was a great shock, which threatened his sense of himself. In the face of this threat he struggled to live his life in such a way that he could maintain his old identity. He saw himself first of all as an integral part of a family, a family in which each person played a set role. Secondly he saw himself as a good worker. Going onto dialysis initially seemed to threaten this concept of himself but he struggled to live a "normal" life.

The shock had changed his position in the family. His mother and his wife seem to have been very worried about Abdul and his response to his health crisis. He assured the women their worry was unnecessary, but he appreciated their care and concern. Even his daughter, who formerly had been the special recipient of his care, contributed to his well-being by reassuring him about his future.

He was becoming less dependent than he had been at first. A fistula enabled him to do away with help in bathing and he felt more normal. At work he occasionally had to accept help for some jobs. However, those who recognized his need for assistance offered him alternate tasks to do and he could see this as part of teamwork.

Abdul's return to work in less than a month was an attempt to return to normalcy. He emphasized the need to work as a normalizing action, as well as a way to pass the time between going on dialysis and a transplant. Still occasionally he could not perform as he had formerly and he could not be as invaluable employee as before since he could not do overtime to meet company emergencies. A transplant was important as it would bring the return to his old, familiar way of being.

The pressures of life on dialysis were difficult for him. His time with his daughter was shortened. He could no longer be the sportsman he had been. He could not work overtime. He could not travel. He had to follow an expensive diet— a pressure on the family's tight financial resources. But he strove in every way he could to normalize his life, not only physically but also mentally. He used his inner resources to come to terms with his condition: self-talk, optimistic outlook, a reliance on an all-powerful God, and his sense of his importance to his family.

At the beginning Abdul seemed to be in shock over the change in his life. During the second interview he grieved his losses. By the third interview hope for a transplant, the chief aid in maintaining his equanimity, seemed more distant. Now he had to reassure himself that dialysis was going well and that his hopes would in time be realized.

The value Abdul placed on social relations provided him with an additional source of strength. He saw the medical staff, especially the pretransplant team, as working for him. He found in the other patients too a source of support: the patient who helped him to see that life continues even on dialysis and the other patients in his dialysis room who became a kind of family to him.

Thus, as we have seen, Abdul's aim was to maintain himself and his life much as they had been before, a life that had given him much satisfaction. However circumstances forced him to make changes in his life and to accept a new role in his family. He relied on his family, his learnings from past experiences, and his values to keep up his optimistic approach despite anxiety about the future.

In terms of advice on how to assist people coming onto dialysis, Abdul emphasized the importance of information and the role of optimism. People should live as normal a life

as possible, including a return to work— even if part time. He would encourage others to use self-talk to maintain a positive outlook. Although Abdul did not mention it when asked for advice, it is clear from his own story that his early time with another patient with whom he could identify was very worthwhile.

3.2 VIVIAN

3.2.1 *Introduction*

Vivian, a man of African ancestry, in his mid-twenties, had renal failure associated with malignant hypertension. Vivian was admitted to the hospital in early spring 2001 with high blood pressure and a high creatinine level. By our second interview, he was being considered for a transplant; his brother and sister, as well as several friends, had volunteered to act as donors.

Vivian was born in the Caribbean, where his father, aged 50, still lived. He and his brother, 18 months older than him, had lived in the Caribbean with their grandparents until the old people died when the boys were nine and ten. The boys had cared for themselves in the rural community for several years until their mother, who was working in Ottawa, was able to bring them here. Vivian was 15 at that time.

Vivian lived with his brother. His mother, aged 50, suffered from high blood pressure. She, Vivian's 20-year-old sister, and some aunts and cousins lived nearby and made up his family. He had a girlfriend whom he saw everyday. He was in regular contact with his five-year-old daughter who lived with her mother in another city.

I first met Vivian, in the dialysis unit at the General Campus, about seven weeks after his entry to the hospital. That interview lasted about seventy-five minutes. Our

second interview took place about five weeks later at the Riverside Campus to which Vivian had been transferred. When I went to arrange for our third interview, he said that he did not want to continue with the interviews but that I could use the material already collected. (Why he had decided he did not want to complete the series of interviews he did not say. The only thing I learned was that he was still not back at work. Possibly he was feeling despondent because of a lack of progress towards better health. Or possibly the openness and talking he had done with me was so foreign to his preferred image of himself as silent that he did not want to continue with our interviews.)

My interviews with Vivian were quite unstructured. I asked him to tell me about himself and his illness, and our conversation continued from there. Only at the end of each interview did I use preset questions about sources of support for himself and others.

3.2.2 *Premorbid Personality*

In the period before going on dialysis, Vivian worked on the assembly line at a large, high technology manufacturing plant. He had trained as an engineering technician, but had not been able to get a position at that level, a fact that disappointed him. He had been told this was due to his lack of experience and he did not seem to have found any way to gain the required experience. He and many friends went out to clubs in the evening and played a lot of sports, particularly basketball.

3.2.3 *First Interview*

3.2.3.1 *Illness and adaptation*

Throughout this interview Vivian spoke of his illness and his sense that his own actions had brought on the need for dialysis. He told of how he had suffered from severe headaches and nausea, especially after basketball. He had ignored them at first, taking over-the-counter analgesics and resting. Finally the headaches became so severe and persistent that he went to a doctor in the early autumn of 2000. After telling him that he had high blood pressure and failing kidneys and warning him of the possibility of kidney failure, the doctor prescribed medication. However, after three months the headaches returned, so Vivian discontinued the medication, and the headaches stopped for a while. When the headaches returned after several months, Vivian tried to ignore them. Eventually extremely nauseated and weak, Vivian went to the Emergency Department, where he was diagnosed with kidney failure and malignant hypertension. Vivian believed that if he had returned for medical help when the headaches returned in the early winter of 2000, he would not be on dialysis: "I just stopped taking it (the blood pressure medication). I never talked to the doctors or anything. I **should** have!"

The shock of this experience is obvious in Vivian's description of his time in the hospital. He emphasized the extremely high blood pressure ("really really high") and creatinine readings— the "highest they had ever seen". He had always hated hospitals, and **there** he was a patient. He spent three days in ICU, which "really **sucked** because I missed **everything".** He was cut off from life. This feeling of being outside, away from his world, continued throughout his stay in the hospital. He described that week as unbearably long; it

felt like two years, he said. This time was disconnected from his life. And his time on dialysis was a continuation of this surreal experience: "It feels so weird."

When he got out of the hospital on a holiday weekend, the whole family was gathered for a celebration. However Vivian's happiness and sense of normalcy were soon disrupted by his awareness that his life had changed: "I went home and everything was on the table and I just stood there, looking at it, and I couldn't eat it and I was **really hungry** too." His dietary restrictions prohibited him eating so many of those foods. In addition, Vivian had grown conscious of how weak and thin he had become, but he was unable to regain the weight because of his food restrictions and dialysis.

Vivian was very ambivalent about life on dialysis. He hated the restrictions of life on dialysis and he disliked the bother of coming to the hospital so much. Nevertheless he appreciated the fact that he felt better: "**I know this works! This dialysis, it works.**"

Vivian was now very conscientious about following doctor's order and taking care of his body. He avoided behaviours that might raise his blood pressure or get him overheated. He no longer went out to the clubs with his friends or participated in sports, particularly his favourite, basketball. Occasionally he played pool with his friends, but as he emphasized, "That's it!" Most of his time was spent reading and listening to music.

Vivian's life pattern was altered. Not only did he have to come to a formerly-hated place, the hospital, three times a week for dialysis, he also did not return to work during the period of time covered by the interviews and he was not able to enjoy his old leisure activities. Moreover he could no longer travel as he had before. He used to go to Montreal or Toronto on weekends and to New York several times a year to visit family. He had planned, in July 2001, to go to Jamaica with his daughter to see his old home.

Moreover he now had to rely on others in a way he had not formerly. His girl friend babied him and prepared his food. His brother, with whom he now lived, drove him to the hospital every day. He had not been able to make his usual support payments for his daughter as the disability insurance money had not arrived, despite his efforts in applying for it. Moreover to these frustrations was added a sense of his own incompleteness: "It's kind of depressing to know that I'm depending on the machine, to clean me out, and not my own organs that I had before."

The difficulties of this time period were exacerbated by his anxiety about the forthcoming operation to create a fistula in his arm. This seemed to be a time of waiting, waiting for the fistula operation and waiting to learn if he would be put on the transplant list. "It's just like a big waiting period," Vivian said, emphasizing the feeling he had of living between the real times of his life.

Vivian seemed to be struggling to reconcile himself to his illness. After talking at some length about his illness and treatment in very negative terms, he paused and then shifted the subject. Now he spoke of looking forward to a better future, to getting a transplant, the escape from the unpleasantness of this time: "It's quite a hassle though, but eventually you get through it, I guess".

For strength he drew on his previous experience of a traumatic time of change. After the deaths of their grandparents, when the boys were 10 and 11, he and his brother had lived without adult care for five years. Vivian rarely went to school; when he did go, "they used to call me a visitor." Canada, Vivian found, was really different from the Caribbean. "Before I was always outside all over the place. I came (here) and it was so cold. I couldn't go anywhere. I had to be in my room every day." This time, Vivian said,

changed him. In his room grieving over the loss of the old freedoms, he came to terms with his grief and said goodbye to his old ways. He thought, "OK, I can't be doing that any more and I can't be doing this." Vivian described this as "straightening (himself) out" and "putting (things) into perspective a bit".

Vivian told of dealing with other disappointments. He resented spending a year in an English Second Language class when he first came to Canada even though his math was good. But he soon broke away from the bitterness, laughing about skipped classes and learning to play basketball. Later when an injury prevented him from making the college basketball team, he got a spare time job to pay off his student loans. Thus he had learned to accept losses and try to make the best of what he had.

Obviously during this traumatic period, he was grieving his losses and struggling to come to acceptance. He used humour to try to put the difficulties of life into perspective, laughing about his past actions. And he refused to dwell on his illness. His advice for others reflected this view: "Just take it one day at a time. Don't think too much."

3.2.3.2 *Identity*

Vivian described himself as an athletic person, fond of sports, with many friends, "always a happy-go-lucky person". However, when he told the story of his life, he emphasized how hard he had worked when he was at college— classes all day and a restaurant job every night, often until two in the morning. To my challenge about this incongruity, he said that the birth of his daughter had made a big change in him, so much so that he laughed at his younger self with his interests in a "wild life". Now he was very conscious of his responsibilities to his daughter. His inability to pay child support due to

the slowness of the insurance company in paying his disability insurance was a source of some distress. These conscientious qualities were supported by the disappointment Vivian felt in not being able to get the kind of position he had trained for[7].

Vivian regarded himself as tough, a survivor who had come through many difficulties. The years alone trained him for that. Moreover he did not like to complain or focus on the unfairness of life or people. For example, after telling of his frustration over being held back a year when he first went to school in Canada, he dismissed the topic with "But that's OK." When I commented on how he seemed to feel that he had been unfairly treated, he agreed. But he immediately went on to show how there had been advantages in having a relaxing year. Similarly he did not like to concentrate on the negative. The story of his disappointment over failing to make the college basketball team was refocused into an opportunity to get a job and avoid heavy loans for his fees. From his description of how horrible he found the restrictions of life on dialysis, he shifted to more positive ideas about feeling better and hopes for the future.

Perhaps the most obvious change at this point in Vivian's sense of himself was the difference in his sense of his body. Previously he had taken his body for granted. He had seen himself as physically strong. He had ignored his worsening illness, going to work even when he was very sick:

> Sometimes I used to get up and I couldn't even lift my legs. I just dragged my legs to work, with my head down. I didn't feel like going, but I knew I had to go. I went to work but slowly. I did my job but slowly. Yeah there was no energy– no, nothing there.

[7] I am not sure why Vivian had such difficulty getting a position appropriate to his training. Is that due to the unconscious racism in Canadian society to which recent studies have referred?

This sense of his body as something to be taken for granted was probably at the root of Vivian's choosing earlier to ignore the prescribed medication, the act which he later felt caused his kidney failure. The shock of his experiences had changed Vivian's perceptions of his body. He was very much aware of inadequacies of his own body and his dependence on the dialysis machines: "It's kind of depressing to know that I'm depending on the machine to clean me out and not my own organs that I had before." So he was conscientious about following his diet and following doctor's orders. Also he was very conscious of his body as not as attractive as before— much too thin in fact.

3.2.3.3 *Social relations, including family*

Vivian saw himself as a member of a large family; he had two siblings and a mother in Ottawa, as well as aunts and cousins here and more family in New York City.

His relationship with his mother was sometimes strained. She had often accused him of irresponsibility for spending so much time socializing and coming in late and now he felt she fussed over him. Their lack of closeness was probably not just due to the distancing of youth, but also to the boyhood years alone. Vivian was careful to avoid blaming his mother for leaving the boys alone so long, explaining how she had spent years trying to arrange immigration for them. Nevertheless Vivian said that his independence was due to this premature period of having to care for himself, and this had created a special closeness to his brother, "the only person I really listened to".

Vivian appreciated the concern of his family, particularly their shock over the seriousness of his illness. However, he seemed to have been irritated by the way they fussed about him and so he chose to live with his brother. Not wanting to blame his family

for their caring, he said it was because he did not "want to be a burden to anyone." He was really grateful to his girl friend and his brother for their assistance and support: "Yeah, those are the two people that are really helping me through this!"

Vivian felt a strong sense of responsibility to his 5-year old daughter. She lived with her mother several hours away, but he called her every evening that he was not on dialysis. Her birth, he said, had caused him to mature, ending a period of going out with different girls every night. He spoke of his enjoyment of her as a baby. During his first year at college, he and the child's mother lived together. Later after he and her mother split up, Vivian went every day to see his daughter. Now he could not see her as often but he contributed regularly to her financial support. His desire to be involved in his daughter's life grew out a sense that, when he was young, neither of his parents was present: "She's going to depend on me to bring her up.... When I was small, I don't think there was anyone around for me like that."

Despite the importance of his friends in his life, Vivian seemed to have difficulty letting them know how ill he was. They came to visit him in the hospital, but he seemed his usual joking self so they went away, saying, "'He's OK. Let's leave.'" One long-time friend seemed to be an exception; he spoke to him every day and this friend had visited him frequently in the hospital; "I consider him my good friend, yeah."

3.2.3.4 *Values*

Vivian placed considerable value on responsibility to children. He had been really lucky, he felt, in his quiet country, island childhood; people there looked after children and

did not hurt them, unlike those in the violent cities. Part of his sense of responsibility for his daughter grew out of this concern.

Another value that came through was freedom. Looking back, the childhood years alone seemed hard, but in a way they also were a boy's dream. The boys were always outdoors. They lived off the land, eating fruit from the trees, without any adults to tell them what to do. Vivian went to school only when he wanted to, but "the time I did go I made it time well spent." The arrival in Canada was a break with this boyhood Eden, but Vivian adjusted. The cold (and perhaps the shock) drove him to retreat: "I didn't want to leave my room!" Here he grieved and said goodbye to the lost freedom.

The plans he had made to visit the island seem to have been a return to the idylls of his childhood and a way to introduce his daughter to this Eden. He planned to live off the land as he had before in return to Paradise. What a contrast to the prison of dialysis!

Vivian's sense of responsibility and the efforts to which it drove him created stress. The summers of his college years were times of escape, out every night. His mother accused him of irresponsibility, but he saw this as a celebration of his freedom:

> And it was summer so I – it was just a relief to get away from all the stress and stuff I went through. All that working, going to school, leaving school, going to work, and coming back home at maybe 2 o'clock, 3 o'clock in the morning. I think it was just to get away from that side by going clubbing and just feeling free for a while.

Perhaps the hatred of the hospital and the relief he felt on getting out were related to of freedom. But, as we saw, Vivian soon realized that release from his hospital stay was not a return to some of his old freedom. His life was now curtailed by the requirement of dialysis: "You're just limited so much!"

3.2.3.5 *Religion and hope*

Vivian often seemed to be struggling to find hope, and hope lay in return to a kind of normalcy: "I don't know how long this is going to last." He looked forward to returning to work, possible because he had been able to work earlier even when he had had to drag himself there. Now he felt much better: "So I know I can go back to work. Within a month I can go back to work." This, despite the fact that some days he was so weak he "just wanted to stay home and not go to dialysis." In the longer term, a transplant would provide the answer to his health problems.

Vivian did not mention religion during this interview.

3.2.3.6 *Support*

Vivian's girl friend and his brother could, he felt, be relied on to provide him with practical help. His brother drove him to the hospital. His girl friend was especially important. She came every day to the hospital and cooked for him in a very caring way: "I'm just like a little baby," he laughed fondly.

Other members of his family irritated him by their fussing, Vivian felt they supported him by encouraging him to continue to come to dialysis: "Go there for your own good," they told him. They also assured him that a transplant, whose possibility and success were never questioned, would provide an exit from the situation in which he found himself: "Eventually it will be all over. Once you get a transplant.... It will be over soon." Thus they encouraged his hope in the efficacy of the regimen he was following and in the certainty of escape in the not-to-distant future.

Vivian's advice for supporters of those just coming onto dialysis grew out of his own experience:

> Listen to your doctor.... Stay on your diet. Don't go over the amounts you're allowed because that will make you feel worse than you feel right now.... And just think positive.... And it will work. It will work. Just take one day at a time.... You don't know how long you are going to be here. So just take one day at a time.... There's not much to tell.

3.2.4 *Second Interview*

3.2.4.1 *Illness and adaptation*

During his second interview, Vivian spoke of feeling much better about his situation. Earlier, he said, he had been almost overwhelmed by the stress of his experiences: "It was too much too fast to go through!" Now he spoke of trying to live one day at a time, hoping that eventually he would get off dialysis.

He had also learned of a cookbook for people on dialysis, and could now eat better, with more enjoyment, and to regain some of the weight he had lost. He had more variety, and yet his daily blood work continued to show satisfactory levels. The recent two-week visit with his daughter had been a source of many delights. The fun of having her around took his mind off his troubles for a while. He had taught her to write her whole name. She had understood about his limitations, how he could no longer lift her over his head. Now the memories of that time filled him with joy. Thus, in these simple pleasures, eating and visiting with his daughter, Vivian seemed to be learning something of living in the moment, one day at a time, as he said he was trying to do.

Nevertheless, sometimes Vivian found his condition "the biggest burden to overcome." Being on dialysis was still a kind of in-between time. Moreover he was

frustrated over the slowness of progress towards a transplant: "I was hoping everything would go by fast: get the operation, get the medication, get on with my life! But it's been four months now. I don't know how fast it's supposed to be but to me it's going slowly." The waiting was hard for him to understand and a bit worrisome; some tests were being repeated, and besides he already had several people lined up to serve as volunteer kidney donors. He showed considerable anger over his powerlessness, laughing bitterly, "I don't have much to say about my situation." So Vivian was caught in the tension of shifting from one attitude towards his illness to another. Sometimes he just ignored it and "pretended there's nothing wrong with me." Other times he found it almost more than he could bear: "Sometimes it's so hard it's like, 'Man I don't want to do this anymore.'" Still other times he used laughter as a way of putting his illness in perspective, a way of not "taking things too seriously."

3.2.4.2 *Identity*

Vivian felt his biggest change had come in the way he was able to talk about his feelings. He was surprised at the way he was able to talk during our interviews. Moreover he had learned a new way to handle his problems with his family, a new way to deal with his anger: expressing it, not walking away from anger-provoking situations. This he knew was "**really** different." Nevertheless he felt ambivalent about this change as he liked the image of himself as "being quiet", a part of his independence, but he said, "Sometimes you just have to stand up for yourself."

Vivian continued to avoid going out with his friends to the club. This, he felt, was due only partly to the fact that the permacath and its protective bandage had to be protected.

Even when he got his transplant and "this thing was all over", he did not think he would go back to going out every night: "It's not really my type of life anyways, to be going out clubbing anymore." He saw himself as becoming more serious, more aware of his responsibilities, especially to his daughter.

Vivian was still very conscious of his body as needing care. He avoided the clubs and active sports because of his permacath. Moreover the permacath in its protective bandage was hot and uncomfortable; also it had to be protected from harm; if someone bumped into him it might start bleeding. He anticipated that even a fistula would have to be consciously protected from harm. The body that he had always taken for granted now was weak; he could not run— even walking long distances was tiring.

The changes that Vivian had undergone made him feel very uncomfortable. He was surprised by how much he missed work; he hoped to go back within a month. Partly he missed the social contact with friends at work; partly a daily life of TV watching and reading was boring. His physical weakness too was bothersome, and he planned to try to get back into shape. His loss of weight had affected his appearance, and part of his pleasure out of the cookbook was that better eating had enabled him to increase his weight. Thus in a number of ways Vivian was striving to regain his old self.

Vivian dressed in the style of hip young Black men, a group that he understood are seen as violent, but he did not want to be prejudged based on his appearance.[8] He was not someone to be feared or rejected. He saw himself as friendly, a good person who liked to help others. He was participating in this study to "help other people."

[8] Why did he adopt that style if it aroused prejudice? Was it a way of identifying himself with the young men he saw as his friends?

3.2.4.3 *Social relations, including family*

Vivian felt that he had changed very much in his relationships with the members of his family (except for his girl friend and his brother). Formerly, he said, he had been bothered by the way his family pestered him about his illness. Many times a day he would hear, "'Do this. Do that. What about this? What about that? Should you being doing this with that (the permacath) in your chest?'" And he wanted to reply, "'Look, man, just leave me alone!'" He felt "crowded" and just wanted to get away from it all. Now he had changed. He was able to assert himself:

> I called them up and I talked to them and I told them how things are. I said, "Sometimes I'd like it if you guys would just leave me alone because it's just too much to deal with already. And you guys asking all these questions about me--- I know you're trying to help, but just give me time and I'll talk to you. I will talk to you. **But not at that time.** It's just too many questions and things like that. So I'll go at my own pace and let you know.' So I think they understand. They eased up.

Now Vivian felt he could appreciate his family's concerns without anger. He could tell them his concerns about his illness. Now family members "knew their roles." They came to the doctor with him and asked questions and he felt closer to them.

His love for his daughter and his pleasure in her was obvious. He was really satisfied that his disability insurance had come through so he could resume child support. His relationship with his brother and girl friend had not changed. He mentioned little about his friends, just saying that he only went out with them occasionally.

3.2.4.4 *Values*

In this time of stress, Vivian had come to value what he had taken for granted before, his health. As we have seen, he was especially pleased about the cookbook that had

enabled him to regain some weight. Moreover conscientious following of the prescribed diet, with the aid of his cookbook, allowed him to maintain his blood at the appropriate levels. (Clearly he was watching the results of his daily blood tests, another indication of his concern for his physical well-being.) In addition he was conscious of the need to care for his permacath, protecting it to prevent it from bleeding. The one occasion he had gone out with his friends— a special holiday— he stayed to the side, out of the crowds.

In some ways, Vivian was satisfied not to go out with his friends. A quieter life was more mature. He said, with satisfaction, "Yes it's coming to an understanding of responsibilities.... I can't really go out every night. It's just growing up--- I think so."

He valued an active life, "living life to the fullest." This time was a "set-back"; after his transplant, he would "just go out and do things." He would go hiking "out in the environment." He had never considered himself an outdoorsman, but hiking would be "something different." (Was the thought of being outdoors was a reaction to being confined indoors or was it, at least in part, a return to the freedom of his childhood days?)

3.2.4.5 *Religion and hope*

In response to a question about religion, Vivian said his grandparents had raised him as a Christian. Since their deaths, he had not gone to church regularly, but he still prayed every night. God was "a higher spirit", the creator who had sent his son to die to save the world. Now that he was ill, he prayed for healing and believed that God gives healing to those who have faith. God had kept him from dying and was making things better for him: "Just so long as you have faith and hope, you know, that's when everything will come through. Just believe in Him and He will take care of it." In his prayers lay a

hope for healing, a hope in which he felt supported by his family who prayed for him. However talking about religion made him uncomfortable and, at the end of the interview, he made a crack: "We talked about everything, even religion."

Vivian's hope lay in a return to normalcy. In the short term, he hoped for the development of a good fistula so he could get rid of the permacath. He hoped to return to work soon, but was fearful he might not have the strength. He also hoped to get back into shape and to take a vacation. (Even though he would still have to go for dialysis, a vacation would take him away from the usual dialysis room, a kind of prison, and allow him to forget his troubles for a while.)

But the important long-term hope, all too slow in coming, was a transplant, the way back to being what he had been before. Still fears preyed on his mind: would life on dialysis ever come to an end? Nevertheless this hope for a transplant was encouraged by the feeling that he was moving along through the testing to get on the transplant list.

3.2.4.6 *Support*

Vivian indicated he had found support from family and friends, but also from the dietitian who had told him about the special cookbook and the social worker who had got him into a group where he had been encouraged to speak to his family of his frustrations.

His advice to people wanting to support those coming onto dialysis was to give them information, such as information about the cookbook and about the possibility of arranging for dialysis in other cities. But most important was still to follow medical advice and to take care of the body. Added to this was psychological advice: "Take one day at a time." Family and friends had important roles in accompanying the patient to the doctor

and to the hospital. An experienced person would be a real help because their knowledge of what the patient had to go through could help them know answers to problems.

3.2.6 *Themes and Changes*

Initially Vivian had been overcome by shock, and he was still struggling with it and grieving his losses. Being forced to spend time in the hated hospital had been a trial. But returning home, he realized change continued; he looked hungrily at holiday food and realized he could not eat it! His body too had changed, thin and weak— not well-built and strong as formerly. His body was incomplete; he depended on a machine for survival. His body as fallible, not to take for granted as he had in the days before kidney failure, became a reality. He could not travel; his trip to his boyhood home had been cancelled. He could not, at this point, even provide financial support for his daughter. He could not work and depended on his girl friend and his brother for physical aid. So many losses!

Vivian drew on the coping strategies he had learned during earlier crises. He grieved his losses and told himself he had to accept the changes. He had come through bad times before. He would not complain. He would laugh, to put things "in perspective." He hoped for a transplant and a return to normalcy, and in this his family encouraged him. Despite his ambivalent feelings about them, his family's support was important.

By the time of the second interview, Vivian had entered a different stage of adjustment. He had been introduced to a cookbook that made regaining some weight possible. He was learning to live in the moment at times— not always but sometimes. He had learned to talk about his feelings and had found a new, satisfying way to relate to his family. Nevertheless learning to speak of his feelings involved a change in his view of

himself. He felt ambivalent about this change. Always before he had seen himself as silent and he still liked that image. Clearly too he found new value in health.

The changes of this time fit into his image of his maturation. Earlier events, especially the birth of his daughter, had encouraged this growing sense of responsibility. Now he was maturing in several ways. He was growing out of his pattern of "clubbing" and sports every day with his friends. He was ready now too for another kind of maturity; he had learned a new way to stand up for himself, to become independent without cutting people out. Learning to express his feelings clearly had resulted in an increased closeness to his family. The interdependency of emotional maturity was replacing the old striving for independence from his mother and his aunts and cousins. Now he could accept their support and appreciate one of the benefits of a large family, without feeling smothered.

Faith and prayer were important in his recovery. God had kept him alive and would help him to return to normalcy.

The theme of freedom runs through Vivian's story. The idyll of his boyhood in the Caribbean was replaced by the cold and routine of life in Canada. Later after hard work at college, he broke free during the summers. Now he faced another loss of freedom: tied to a machine, restricted in his diet, not able to travel or to work. He was eager for the return to freedom that a transplant would bring, and then he would try different things, living life to the fullest. He would go out "in the environment", hiking. This would be something new, but wouldn't it also be a reminder of the outdoors life, the freedom of his boyhood Eden?

Why Vivian chose not to complete the series of interviews with me he did not say and I chose to respect his wishes and not to push him to explain his reasons. However even in the two interviews I had with him, I had seen a number of changes in Vivian. He

was maturing in his relationships with his family and friends. He was coming to see his body in a new light. And he seemed to be finding some new or renewed values in reconnecting with the theme of freedom and in trying to focus on living in the moment.

3.3 JOHN

3.3.1 *Introduction*

John, a Canadian-born man of British ancestry, in his mid-fifties, had moved to Ottawa when he was around ten and had lived there ever since. His marriage of over 25 years had broken up about nine months before I met him. At the time of the interviews he was living with a woman, about ten years younger than him, who had several children. John had two sons by his first marriage, one in senior high school, who lived with his mother, and the other a young adult living in another city some eight hours' drive from Ottawa. He was an accountant who had worked for a small firm for a number of years; at the time of the first interview he assumed that he had lost his position with them.

John had had a series of operations as a child to correct a clubfoot and had been left with very negative feelings about hospitals. About six months before I met him, he had a cerebrovascular accident that left relatively little apparent damage. Later he had an operation in hopes of preventing a recurrence of this problem. Six weeks after that he took ill and it was some time before the illness was diagnosed as Wegener's granulomatosis[9].

At the time of my first interview with him, about five weeks after the diagnosis

[9] Wegener's granulomatosis is an uncommon form of vasculitis, i.e. an infection of the blood vessels. The infection results in damage to the vital organs, especially the respiratory tract and kidneys. Symptoms vary, but the lungs or upper respiratory tract often first show the first signs. Kidney damage does not show up clearly except in blood tests, and early treatment may prevent permanent kidney damage. The disease is difficult to diagnose definitively (NIAID, 1997).

and a month after his first dialysis, he was improving, but still very weak– unable to walk or function independently. A possibly malignant growth had been detected and a biopsy was planned. Later the growth was determined to be benign. By our last interview John's strength was returning, at least enough to walk and drive. At first it was hoped that kidney functioning might return, but by the time of our last interview that hope had almost disappeared and he was preparing to go onto peritoneal dialysis.

John chose to have his partner, Melissa, with him during the first two interviews and she frequently spoke for him, often at his request, usually turning to him for confirmation, or she gave her perceptions of his situation. Her interventions were less marked in the second interview. By the third interview, Melissa had returned to work.

John was very labile during the first interview, but seemed nearly normal by the third interview. Whether this was a reflection of physical weakness, a side effect of medication, or an indication of the psychological effects of his illness was not clear.

3.3.2 *Premorbid Personality*

Prior to his illness, John had been heavily involved in the Scouting movement, serving as a leader of a group of young adults, as the organizer of a major camp, and as a member of the regional executive.

As an accountant he had worked for a large firm at one time, but he had left that firm and gone to a smaller firm where he had more independence and more contact with the clients. He had enjoyed his work at first. However he said that in the last few years it had begun to be more stressful than fun. After his stroke he recognized that he no longer enjoyed his job and so he had begun searching for another.

He obviously had a strong social conscience. He had tried to provide support and assistance, not only to the youth but also to the adults with whom he came in contact. The breakup of his marriage seemed to cause him concern as he had done considerable thinking about how and why he and his wife had grown apart.

3.3.3 *First Interview*

3.3.3.1 *Illness and adaptation*

After several weeks of illness John had finally been diagnosed with Wegener's granolomatosis about five weeks before I met him, starting dialysis about a week later. He was still very weak, spoke in a low voice, and coughed a number of times.

He and Melissa outlined the story of his medical problems in some detail. These had started with a stroke about six months earlier. He had, he felt, recovered well from it and had undergone surgery about five weeks later to prevent a recurrence. After recovery from the surgery, he went back to his usual busy life. Now he believed he had "pushed things"; he seemed to feel that his present illness was at least partly the result of not heeding the earlier warnings. Thus he saw his illness as a consequence of not having recognized the earlier warning signs, of having failed to look clearly at his life.

Now he saw how he had set himself up for this illness. He had remained in a job that had lost its "fun" for him. He had undergone the stresses of a failed marriage for years. (The commitment to a relationship with Melissa was only the culmination of this process.) He had put pressures on himself in giving to others, through support of sick friends and with all his Scouting work. Checking with John, Melissa explained to me that they saw his ill health as a kind of catharsis, a preparation for a new phase in his life:

> I think we see this as a type of life transition. It's almost like clearing out the old. He's made decisions in his life of how he wants his life to change. His life purposes are developing or changing for him and I think a lot of this is just clearing out old stuff that he had in his body and once we get through this he'll rise from the ashes.

After the nearly three months of illness, he was recovering. His lungs were clearing and he felt stronger. Melissa said, "He's getting started on a process of getting back into his life slowly." He had recently gone to a memorial service for a Scouting colleague and was beginning to talk again to his old friends. However he was too weak to resume work and he could not remember the details of his illnesses.

The doctors had found a growth and he was awaiting a biopsy. Melissa said the fear of cancer did not overwhelm them; he had come through so much that he would survive this too. (But I wondered if she was trying to reassure John or herself.)

3.3.3.2 *Identity*

John now saw himself as an invalid. When his health improved, he would again involve himself in Scouts, and life in general, but at a much slower pace.

He had been a very giving person, he felt, always ready to support his friends. Now he was going to concentrate on self-care; "I'm not going to give you 150 per cent; I'm going to give you 50 per cent." Maybe that view was due partly to his present weakness, partly to his disappointment in those friends who had fallen away, and partly to the idea that his illness was a sign he had taken on too much.

He saw himself as a man who often did not express his ideas or feelings; like his father, others had to "draw them out of him." (Perhaps this was why he wanted Melissa present during our interviews.) He had liked to be in control. The large accounting firm he

had worked for earlier wanted its employees to check everything with their superiors so he had switched to a small firm. As he had planned a process of withdrawing from some of his Scouting tasks, he had involved younger people and had warned people of his imminent withdrawal. He and Melissa laughed, saying he certainly had ensured that he would live up to his promise.

Some of the changes he had undergone pleased him. Formerly hospital smells too vividly reminded him of the pains of his childhood operations. Recently he had been able to visit a sick friend in the hospital, and the old feelings were not there. Also in another incident the needs of a troubled friend no longer bothered him as they had in the past.

John liked to look at the positive. He dismissed hurt feelings about friends who had not visited or seemed cold by providing excuses for them. Such excuses included the fact he had not been available to visit in the hospital and that people were uncomfortable approaching him, not knowing what to say.

Giving up of old roles was difficult. On a recent visit to the camp he had had so much to do with, he had felt out of place, no longer being one of the organizers. Also the need to withdraw his candidacy for a regional office in Scouting had caused him grief.

3.3.3.3 *Social relations, including family*

John was very dependent on Melissa now. He insisted that he would not participate in the study unless she agreed to assist him. John's memories were not complete so he asked Melissa to tell of some of the events. She had taken two months' leave from her job to be with him. Not only had she provided support, but she had also taken his abuse when he was overcome by stress or pain. Neither spoke directly of such moments, but in

discussing how to support someone through such trying times, John said the caregiver should "be prepared to be slapped in the face." However, Melissa had told John how his ill treatment made her feel, and now he let her know how much he appreciated her openness.

John spoke at length about how his marriage had broken down. His wife had become so involved in her job and its demands that family weekend camping trips had stopped, and the two had drifted apart. And he was aware of the effect of the breakup on his younger son. (No mention was made of the older son.) But he felt pride in the younger boy's maturation, learning to relate to his mother in a more adult way.

Due to the overreaction of his wife, visitors during John's hospitalizations were limited. Some were offended, but others were more understanding. However John felt that some fence-mending would be necessary. On a recent trip to Scout camp, only the youth greeted him with warmth; many of the adults seemed distant.

The Scouting organization was John's community. Its values were important and he enjoyed camping. Scouting had given him the opportunity to get to know people from different backgrounds— Melissa spoke of what a variety of people had " opened their doors and hearts to him." He had given many hours over many years to Scouting, and took great pleasure in this work.

3.3.3.4 *Values*

John had placed great value on helping and supporting others, not just through his Scout work, but more informally, through listening and assisting his friends. A cancer victim had cried on his shoulder many times. Now he felt he would consider himself more. Melissa saw this as an important learning of this period: "I certainly think one of the things

John has been learning through this process is to love himself and to allow other people to love him. That's the main theme of what's been going on."

3.3.3.5 *Religion and hope*

John had been raised as an Anglican, but now had no religious affiliation. He approved of Scouting's emphasis on spirituality, but had thought of himself as an agnostic. As a teenager, he had rejected his mother's faith and begun a spiritual search, a search that he was reopening. Melissa believed that "his whole spirituality was changing." She related how he had said he believed in God as the prime mover, but as a result of a conversation she had had with a member of their Scouting group, he had begun to look at the possibility of a more personal God. He described himself as very "eclectic" in his religious approach; he could be comfortable in many kinds of worship: Jewish, Mormon, Roman Catholic— it did not matter. He believed that different religions provided him with new ideas and different truths. A joke by Groucho Marx expressed an important truth: "'I have my principles and if you don't like them, I have others.'"

Melissa saw him as a bridge between people of different religious beliefs. This was too grandiose for John: "that's like elevating myself to a god." All he was willing to focus on was their role in opening people up to new ways of seeing things, as they had with a young Mormon who had been especially upset by Melissa and John's relationship.

Feeling he was getting better, John hoped to resume his Scouting work, especially with the young adult group, albeit at a slower pace.

3.3.3.6 *Support*

John's primary support came from Melissa. He also felt supported by her three children, who even thought to offer him assistance carrying things. Her dog too, formerly a man-hater, had adopted him and given support: "he gets in there and does his thing— whatever dogs do to support— which is a good feeling." His family of origin too provided support. A brother called from Northern Canada to offer a kidney. The Ottawa family members were supportive too, even when John was curt with them.

John's advice to those caring for persons undergoing a health crisis was to be tolerant and understanding of what the patient was going through. Self-care was important for the caregiver; he/she should take advantage of whatever support was available, from friends, religious organization, or through the hospital.

3.3.4 *Second Interview*

3.3.4.1 *Illness and adaptation*

Since our first interview, John had been hospitalized for an infection, but he seemed to have recovered well. He was less labile than earlier. His strength was returning; he was now able to drive and to walk a kilometer or more. The wheel chair, formerly an uncomfortable item to be joked about, was now a thing of the past. He was getting bored with reading and sleeping, and returning strength gave him confidence and spurred him on to try to resume activities. Relearning how to do things was somehow uncomfortable though, coped with by regarding each learning as a new experience.

With his recovery came too the desire to take control of his life again. Before the first camping trip after his illness he had rested, allowing Melissa to load the vehicle, but he

had supervised a more recent one. When he and Melissa had not been able to contact a specialist before the scheduled biopsy of the growth on his testicle, he had refused to sign the consent form, using that as a way of getting attention from the medical profession. He and Melissa had disliked doing something so negative—"we don't fight"— but there had seemed no other way to get the attention they needed.

During the earlier interview, John had not admitted how upsetting he found being an invalid or how anxious he had been about the possibility of cancer. Now he did so, insisting that he had become less worried by these problems, and less disturbed by small setbacks. Earlier he was overwhelmed by all the problems the doctors kept telling him about; now he "had time to sit back and accept it."

3.3.4.2 *Identity*

John liked to get along with people. He and Melissa seemed to have felt uncomfortable about refusing to sign the consent form. The nurse's understanding attitude relaxed them; she had joked and seemed to recognize him from his earlier surgical procedures. He excused the hospital staff's brusqueness by explaining how busy they were. When he spoke of his relationships with his sons; he would have liked to have given them his story of the marriage breakup— not to convince them he was right, but so they could hear both sides and make up their own minds.

He disliked the dependency of being an invalid. He said he would "just feel better being able to contribute somehow or other" and was glad to have given up the wheel chair, a symbol of dependency.

He wanted to become what he had been before, except for some "bad parts ... unhealthy parts." Melissa said that they were working to break old patterns in their relationship; she thought the crises he had been through had brought a lot of changes in John. He was able to talk more of his feelings, to be less like his father who never spoke of his emotions or beliefs. Melissa explained:

> He's lived where he never had to live before– which has made him more open. So when we sit down and talk and I say, "Why are you doing that? Why are the walls going up when I say, 'Need to talk' without even knowing what it's about?" And we talked about it and I think we finally got through that wall. I see my part in it too. I think that would be that much much harder to reach that point if he had still been where he was when he moved in.

When asked about how he had changed John spoke, as he had in the first interview, about giving up smoking a pipe. (Was smoking a pipe part of an image of himself— a stereotype of the strong, silent, pipe-smoking man who loves the outdoors? Was giving up the pipe the symbol of the kind of changes he wanted to make in himself?)

However some questions John would not answer. Asked what he found important in his life, he replied, "I hate questions like that. I have to think."

3.3.4.3 *Social relations, including family*

John's relationship with Melissa was the most important one in his life. Two different processes were going on at this point. First had been the development of their relationship to each other. When he had first moved in with her, eight months before, she felt that he had ideas of taking care of this single mother, even though he knew she was a strong woman. However, any thoughts of such a relationship were soon put to rest with the onset of ill health. Even though she mourned the too-quick passage of "the honeymoon

period", Melissa felt that the crises they had gone through together had broken down their facades very quickly. She was surprised by how well they were getting on, spending so much time together. He said part of that was due to them being older, and then he commented on her energy level, suggesting that was a function of her being ten years younger. (Or was it that his illness had drained all his energy while she was healthy?) Moreover, as previously noted, the crises had forced him to change, and she had pushed him to reveal his feelings and to open up. They used humour to build and maintain the bond between them; often as we spoke he turned to her and made a joke. His returning strength gave them the chance to take advantage of special moments; her children's visit to their father provided an opportunity to try cooking many new dishes without thinking of her children and their finicky eating habits.

The second aspect of their relationship was her role as his caregiver through his illness. She had provided not only physical care but also psychological protection, often acting as his protector and advocate. She had ensured that all the specialists involved in his care were communicating with each other and on occasion had come between him and others whose demands he could not cope with: "I would literally stand in front of him, between things, to shield him because he couldn't handle it."

Now she felt John could take responsibility for more aspects of his life. She spoke less than in the first interview; when he turned to her for a contribution she said, "Your interview." She did not want to be his caregiver, but rather his partner. She encouraged him to regain control of his life. When he wondered how much of his old strength he would recover she insisted recovery would be total.

John's relationship with Melissa's children involved some conflict. At one point he suggested that he would have insisted on less finicky eating habits if they were his children. The idea of a camping trip with them raised some trepidation. Moreover the time off during the children's visit with their father was being "paid for now."

John's relationships with his own sons were a source of pain. Since his breakup with their mother, he had not had the opportunity to rebuild contact with them. Because of his illness, only recently had he had able to meet them away from Melissa's home, where the boys were uncomfortable, she felt. He had not heard from the younger one for over a month, and the older one rarely called and had only spent a short time with him on his recent visit to Ottawa. The legal process he was going through with his estranged wife was heightening the tension in which his sons were caught. But John felt he could not "chase" his sons; he had to be open and to hope that they would come around.

John's relationships with his own family of origin and with Melissa's parents were good. Again he mentioned the unsolicited offer of a kidney by his brother.

His relationships with his old friends, especially from Scouting, were going through a rocky period. He spoke of the coldness of people during the earlier trip to the Scout camp. He was having to contact people and inform them that he was getting better and able to reengage. Part of the disconnection, Melissa blamed on an old friend, herself a cancer victim; she had contacted people during John's illness and told them to replace John in many of his roles in the organization. John was hurt by her actions, but excused her by saying he knew numerous brain aneurysms had affected her cognitive processes.

John spoke of enjoying time spent with Melissa's friends whom he was getting to know. (Friends other than those in Scouting were not mentioned, but the falling off of old friends may have been a ripple effect of his marriage breakup.)

3.3.4.4 *Values*

John said he did not like to think of values and certainly did not like to speak of them. However the way he valued fairness and seeing others' points of view came through. He spoke of wishing that he could speak to his sons of the breakup of his marriage, but in a way that would encourage them to make up their own minds. Of the 'cancer friend' who had so hurt him by her insensitivity, he spoke of the need to continue to support her as her health declined.

In his many experiences in the hospital, he was bothered by the impersonal treatment he received from many people outside of the dialysis unit who did not deal with him with respect. However he excused them; "They have a job to do. You know they've got so many people lined up."

3.3.4.5 *Religion and hope*

John did not wish to speak of religion at this time, anymore than he wanted to talk of values.

He remained hopeful, hopeful of a return to active life. He wanted to take up his leadership of the Scouting group in the fall and some of his administrative work with the orgainzation. There was no talk of return to gainful employment. Indeed Melissa felt that although he had lost his job, only the loss of income bothered him.

3.3.4.6 *Support*

Melissa's support of John had changed, as indicated above, from providing care to encouraging him to try new things to regain his independence. While some old friends, including people whom he had assisted in their own times of trouble, had disappointed him by their absence, others were, he felt, supportive. His family of origin, particularly his mother, also provided support.

John's advice to those who faced similar health problems to his own was to maintain hope. Some days this was hard, he said but people should persevere:

> Keep the faith. It will improve. And be patient. Recognize that things are not going to be the same as they were before. Yes, there are days when you're going to get fed up with having to come in with this treatment. And yea, there are going to be off days. There are going to be days when you trip and go back. And if you're lucky, you'll remember to pick up the pieces, not only for yourself, but for those around you. And every once in a while you'll forget to do that too.

Melissa pointed out the importance for the patient in having support, someone to talk to and to be a protector and advocate as she had been. With so many doctors— five, she said, at this point— it was necessary to have someone to coordinate and to ensure that none of the specialists lost sight of the totality. Moreover, when he had been very ill she had, at times, kept the stresses of the world away.

John's advice for caregivers included listening, being patient and understanding that sometimes circumstances may so overwhelm patients that they abuse their caregivers. As he said this, John began to cry; he obviously was remembering when, "so wrapped up in (his) own feelings and thoughts", he did not consider Melissa.

3.3.5 *Third Interview*

3.3.5.1 *Illness and adaptation*

During this, the only interview with John by himself, he spoke of the intensity of the initial shock of learning about having Wegener's granulomatosis– "having the lungs and the kidneys and everything say, 'It's time to quit.' " Melissa had responded by going on the internet to learn as much as she could about the disease. John too found knowledge provided a source of control, a way of coping with his problems. At first John said he had asked the angry question, "Why me?" But he soon moved from that and saw the disease as just something that had happened, probably as a result of the kind of pressure he had put on himself and the pace he had kept up, even after his stroke. Now he wondered if a new, more relaxed lifestyle, with more care of himself, might "end up being better than one anticipates."

Now John was focusing on relearning old skills, such as walking and driving, and developing confidence in himself. He had been "weaned off" his dependence on Melissa, and was helping around the house. He was enjoying the greater freedom his returning strength was offering him— strength for daily walks and for drives in the country to take Melissa's daughter to her Scouting group in a rural area. On weekends when Melissa's children were with their father, he liked to go out to restaurants; on these occasions he might break his diet a bit but he felt this was necessary to avoid excessive frustration. They had gone for a second weekend camping trip.

He struggled to accept his limitations, including his inability to work, and the change in social role this entailed. Increasing strength and hope of the eventual return to

nearly what he had been able to do before gave him encouragement. He used humour, as he had before, as a way of coping, a method of putting his situation in perspective:

> We've already figured out how we're going to take one of these monstrous machines (pointing to the dialysis machine beside him) on our camping trip with us next time. We'll just set it up in the campsite and plug it in and sit back under a large umbrella and let the machine do its work, while I sit back and camp.

Finances were a concern. He had applied about four months earlier to the Canada Pension Plan, but had still not heard from them. When money became a little easier, he planned to go out to the theatre— but he joked about not going formally clad; he would wear shorts and a T-shirt to shock the pretentious people in the audience.

Until recently he had hoped his kidney functioning might return. Indeed he still had a faint hope that when he was taken off the medication for Wegener's granulomatosis his kidneys might begin to operate again. However he seemed to have resigned himself to long-term kidney failure, to be relieved only by the possibility of a kidney transplant.

His catheter was nearing the end of its time, and so he had decided to go on peritoneal dialysis. This would save him from going to the hospital three times a week and would allow him more freedom to go camping. In addition the diet would be different and he would be able to eat more cheese, a food he especially seemed to miss.

3.3.5.2 *Identity*

When John had first fallen ill, he was taken aback; he had always thought of himself as a strong, healthy person. The stroke was a shock, but he recovered well and was soon back to his regular routine, as if nothing had changed. Then ill health really struck him; he became a total invalid and had to deal with that. Now regaining his strength, he took some

satisfaction in his growing independence and involvement in life. He was able to contribute to family care, especially keeping the kitchen clean. He resisted the idea of cooking, but accepted that Melissa would eventually pressure him into doing that as part of his share of the household chores. He was able to walk to the mailbox, but Melissa did not yet think he was strong enough to control the dog. Nevertheless he was not really comfortable with the idea that he was a stay-at-home man.

In his reinvolvement with Scouts Canada, he found himself sitting watching and listening, offering advice as a "wise old sage, resource person." He was no longer treasurer of the local area nor was he the leader of the youth group. He found the pain of these role losses easier if he could understand people's responses. Moreover he did not like to internalize insults or feel bitter about people pushing him to the side.

He still did not want to talk much about his feelings, but of course these came out in the ways he talked of his situation and his relationship with others. His love for Melissa showed in pride in her recent promotion, in gratitude for her support, and in the way he thought of the two of them as being one. Several times he responded in the plural, "we" when he could have used the singular, "I."

In the past he had been too willing to let others set his agenda, to give them the care they wanted, and to work beyond his comfort level. Now he had to think of his own needs first. As he recovered he hoped to be able to return to giving, to commitment to Scouting and to his work. But he felt he would seek a balance, never returning to thinking of others before himself: "So this time around I'd be imposing my own limits.

The idea of balance came out too in his thoughts about following his prescribed diet. Sure he followed it fairly carefully, but he felt the occasional taking of "illegal" foodstuffs was necessary to avoid frustration. Here too he spoke of finding a balance.

3.3.5.3 *Social relations, including family*

He spoke little directly of his relationship with Melissa, but obviously his dependency on her was lessening. His appreciation of her came through in his references to her desire to understand his illness and in his allusions to the stresses on her during the worst times of his illness.

John saw himself as part of several families. With Melissa's family, he worked on food preparation and cleanup, getting members to meetings, etc. When a crisis arose, such as when his estranged wife sent him a nasty e-mail, he consulted Melissa and his mother over the appropriate reaction. The family support for which he was so grateful seemed to come from both his new family with Melissa and his family of origin.

His relationship with his younger son was improving; they spoke about once a week. Now that he was able to get out on his own they could meet in neutral surroundings like a doughnut shop. However the relationship with his older son had not changed. Moreover relations with his estranged wife had become so strained after a meeting with his second son that he had contacted his lawyer to have her warned off.

He was still hurt by the aloofness of his friend who had cancer and angered by the way many of his Scouting friends seemed to have walked away from him. The people in his office had not contacted him for months and even when they had called him earlier it was for business purposes. (However he showed no signs of being hurt by this omission.)

He wondered how all these people would react when he got better. Nevertheless others seemed especially supportive; people he hardly knew greeted him with real warmth and interest and he was touched by their consideration.

Especially hurtful was the action of the youth group of which he had been a leader. They had chosen not to have him as their leader this year. He blamed this on another leader who had often criticized him and who, he felt, had persuaded the young people that he would not be able to serve them well.

3.3.5.4 *Values*

Although John felt hurt by the way some people had treated him, he did not want to bear a grudge or let his anger colour his dealings with them. In the past he had found he could work with people whose actions had angered him; he tried to make an opportunity to explain his feelings and then he left the matter. He saw this as a way of "turning the other cheek." He felt his refusal to let anger govern his relationships with others sometimes disturbed them, but he was determined not to let bitterness rule his life. He felt that those who had mistreated him were responsible for their acts and he should not internalize their misdeeds. "It's just not worth it (holding a grudge)," he said.

Contributing was important. He was glad to be contributing to the household. He was able to contribute to the Finance Committee of the local Scouts Canada area. And he looked forward to increasing contributions as his health improved, but always to be balanced by the need for self-care— a new theme that had grown through his illness.

John's application for a disability pension under the Canada Pension Plan had not yet been approved after four months. He understood the need for rules, but the slowness

and what he saw as the insensitivity of the bureaucrats frustrated him. He spoke of his anger over "all these programs that they advertise— until you go and actually try and apply for one." Still he did not want to become cynical over this matter; nevertheless the experience had felt like hitting "one brick wall after another."

The importance of understanding was also an important theme. He sought to understand his disease, to understand why people behaved the way they did, and to understand the need for rules in government programs.

Not being bitter and keeping things in perspective was important. Difficulties were handled by putting what could not be changed out of his mind as much as possible. Other times they could be handled by humour.

3.3.5.5 *Religion and hope*

Despite unchanged beliefs, John expressed more fully his religious ideas. Religions are man-made, but their common foundation is an indication that God exists:

> Everybody has the right to believe what they wish, whether it's Roman Catholic, Anglican, Islamic, Buddhist, and so on. And when you think of it, they all really go back to a common source—whether you call it God or Jehovah or whatever. So **there's something there**. What it is I don't know.

John hoped for recovery. Although the return of kidney function was unlikely, he still had a faint hope that it was possible. Moreover he also looked forward to return of strength; recovery from Wegener's granulomatosis might take two years, but recent tests had revealed a remission. A sorting out of his relationship with his estranged wife, continuing improvement in his relationships with his sons, a renewal of contributions to Scouting, and a return to work were all to be hoped for in the future.

3.3.5.6 *Support*

In addition to formerly mentioned supports, John commented this time on support from the medical community. He had found this good, except for long waits to get appointments with specialists and late appointments. The only serious criticism he had was the difficulty of coordinating the care of many specialists; often they each seemed to focus only on their area of specialty, not considering problems in other areas. In addition he found many of the people he met outside the dialysis unit were cold and impersonal.

Melissa had received good support, he said, from the medical staff and social workers at the hospital. Such support was very important for family members and he appreciated staff concern for Melissa. Information from the Internet had been important in finding a sense of control through information and understanding of the disease.

3.3.6 *Themes and Changes*

John's pattern of change was complicated by his recent change in marital status. The breakup of his marriage and the influence of Melissa altered his life course and the meanings he made of his life. He had left his wife of 25 years, who had become so engrossed in her job, for a relationship with a woman who seemed to put his interests first. The trauma of his illness coming so close after their getting together complicated the process of change. After his stroke, he had given up smoking a pipe, possibly a signal of a change in his vision of himself as a strong, silent, self-contained person. With John's approval, Melissa said that they saw his illness as a catharsis, cleaning out some of the bad old parts of him.

Throughout the interviews, John revealed how much the illness experience had shocked him. A formerly healthy man suddenly became a total invalid. An independent person who saw himself as an important source of support for other ("a broad shoulder to cry on") suddenly became totally dependent on others. It was clear that the gradual return of strength and autonomy were important as a source of hope and a way of maintaining identity. And in this change Melissa encouraged him.

The shock of finding himself so dependent had been traumatic. It seems to have broken even his ego strength and he turned to Melissa for reassurance about who he was. In fact he hardly seemed to have been able to find himself without her. Thus he would not agree to being interviewed without her. In the initial interview she often spoke for him, in the second she spoke less, and by the third she had gone back to work and he spoke for himself. Melissa was aware of his need for a lot of psychological support at first but did not want dependency to become a habit.

Now John understood his illness as a wake-up call to slow down. Even if his health returned, he was determined to balance commitment to friends, work and Scouts Canada with the need for self-care. No longer would he try to give "150 per cent." Among the changes for the good, according to Melissa, was John's ability to be more open with his feelings. The shock of his illness had forced him to go inward in a way he never had before and with her encouragement, he was becoming more open in expressing his feelings. Nevertheless he hid from me his fear of cancer being added to his problems until after the crisis had passed; so much had seemed to be breaking down at the same time, it had been hard to absorb and react to one more item of bad news.

The extent of his illness had prevented John from rebuilding his relationships with his sons until just before our last interview when he succeeded in reestablishing regular contacts with his younger son. The broken relationships had caused John pain and the reestablishment of contact with his younger son pleased him.

John's social values were of great importance. He liked to be fair and see others' viewpoints. He wanted to be a contributing member of society again, even if all he could do at this point was to help with housework and act as advisor to the Scouts' finance committee.

As far as religion was concerned he was open-minded. He was respectful of different religions, seeing them as human-made searches for God. He himself had no religious faith. But it seemed that a new stage in his religious journey might be opening to him; perhaps God was not just the one behind the Big Bang at the beginning of the universe, but somehow present in people's lives. Perhaps behind the diversity of religions lies God. This was, however, an idea for another time.

3.4 Comments

The differences between the stories of these three men's lives must be taken into account when considering how each experienced his early months on dialysis. Abdul came to maturity in a war-torn country. He seemed to have come from a middle-class background. (A number of relatives referred to were people of some education and social position.) However Abdul himself made no reference to his education and his job was in the production sector of a high tech manufacturing company. His strong ties to his family

stood out in his account of his experiences. Whether the strength of this bond was due to his immigrant experience or whether it was a feature of his culture of origin was not clear.

Vivian was conscious of himself as moving to full maturity and he came from a culture in which the burden of child rearing often falls most strongly on the women. He came from a working class background although he had a diploma in engineering technology. However, as indicated earlier, like Abdul, he had a working class job in the production sector of a high tech manufacturing firm.

John had a middle class, Anglo-Canadian background. His job had clearly been middle class and professional.

As we have seen, Abdul fought any changes. He regarded any variations that were happening as due to his circumstances— hence, by implication, reversible. Nevertheless his familial role had altered; he was now the centre of his family, the one to be cared for. Even his five-year old daughter, the former focus of family concern, was now trying to help care for him. Apart from their care for Abdul and worries about Abdul's frame of mind— worries that Abdul said were unnecessary— little else about their reactions to Abdul's crisis came through in his story. He fought against despair through reliance on self-talk, optimism, certainty of his own strength, and belief in an all-powerful God. All these were part of his family tradition, the family in whose existence he found meaning for his life. He was sure, he said, that he would get a good transplant; the family especially needed him and he was young. Then things would be much as they had been in the past.

Vivian, by contrast, did see this as a time of change. He was continuing to mature. He was becoming less social, cutting down on his "clubbing" with friends. He had learned to speak up for his needs and to express his feelings. Although he regarded his newfound

ability to speak up with some ambivalence, on the whole he was satisfied with his new pattern of showing his family their proper roles in his life. He looked forward to a time when he could reconnect with the outdoor living of his boyhood, an adult version of his old freedom. He had grown aware of his body as somehow fallible, and hence was very conscientious about following medical instructions. He was anxious to get a transplant as a way out of the restricted life on dialysis, to regain old freedoms.

John's initial illness had confirmed the knowledge of his vulnerability that he had denied after his stroke several months before; the extent of his illness was a real shock to him. The personal changes he was undergoing were partly due to this shock and partly due to the newness of his life with Melissa. He seemed to be learning to talk more about his feelings than he had before; no longer did the image of the strong, often silent, man fit. He had learned that his concern and caring for others was not always returned.

His weakness and the opportunism of others seemed to have led to him being pushed aside in the Scouting organization. Now he was sitting on the edge, learning to be the "old sage"; like a weakened, old wolf, he was pushed aside by younger, stronger men. However despite his hurt feelings, John did not want to give in to bitterness.

His illness had added to the complications introduced into his life by his relationship with Melissa. He had only just begun to reestablish a relationship with his younger son and his dealings with his estranged wife had become more bitter. He was striving to regain some of his old assurance as he regained his strength, but how far this would go was unclear. He was certain that he did not want to go back to old ways where he "gave 150 per cent." From now on he would take care of himself first.

What would happen to these men as their diseases progressed is uncertain. I kept asking myself questions about the high rate of transplant failure and wondered how Abdul and Vivian would react if this happened to either of them. Will their conscious optimism continue? How will their old sources of support continue to serve? How will their relationships with families and friends change? Will their faith in an omnipotent God change? Will John find more answers to the questions about values and religion?

Of interest is the degree of repetition each man did in his various interviews. Part of this may be due to the similarity of conditions from one interview to another— same interviewer, the same or nearly the same place, the same situation. However some of the similarities are probably an expression of a continuity of ideas; if the life meanings the participant had already developed seemed congruent with his new circumstances, he would have no reason to change these meanings.

CHAPTER FOUR
BRIEF CASE STUDIES

Wondering how the processes of change might continue, I decide to explore what life on dialysis was like for men who had been on it for several years. With permission from my advisors, both my thesis advisor and my hospital supervisor, I interviewed two men, both of whom had been on dialysis for several years. I asked Wayne and David about their experiences coming onto dialysis and about their lives now. Thus their stories provide some insight into the continuing processes of change.

The short case studies of these men are organized much as the longer ones in the preceding chapter are. Each man is introduced; a brief statement of his premorbid personality is given; and then the narrative of his experiences are given under these headings: (a) Illness and adaptation, (b) Identity, (c) Social relations, including family, (d) Values, (e) Religion and hope, and (f) Support, followed by a reflection on their changes and how they differed from the men in my focus group.

4.1 WAYNE

4.1.1 *Introduction*

Wayne, in his late forties, was married with no children. He had been a student until he developed renal failure four years before in England. He had had diabetes since he was a teenager, but it was a form of vasculitis, not diabetes that destroyed his kidneys.

(Vasculitis is a swelling of the blood vessels that marks certain systemic diseases.) Wayne was a very introspective, thoughtful person who spent most of his dialysis time reading and taking notes. He chose to be interviewed in a small office at the hospital. His interview lasted about 1 1/2 hours.

4.1.2 *Premorbid Personality*

Prior to kidney failure, Wayne maintained that he had been extremely energetic, ambitious, both while in school and at university. He had been a "perpetual student", pursuing university studies in four countries. Just before he took ill he had earned a doctorate from a prestigious university in Britain, while simultaneously studying for three other degrees.

However his life had been formed by a fear of renal failure. In fact he had studied medicine in Germany for six years in order to gain knowledge in an attempt to avoid kidney failure. Only when he had decided that he had passed the point where most diabetics develop renal failure, did he leave medicine and go to England to study his real interests, philosophy and social sciences.

He had made many friends at the various universities, but his belief that he was likely to be dead by the time he was fifty had been hidden from them. Moreover, he had observed that people treated him differently if they knew he had diabetes so he only told a few close friends. So a huge section of his emotional life was closed to his friends. In Germany, when on the dialysis ward during grand rounds, he had identified with the renal patients as he stood over them. Thus his fear of renal failure, his age, and his belief in the

nearness of death separated him from his fellow students.

His parents queried his continuous studies, but he enjoyed learning and wanted to avoid the chores of teaching and the mundane life of the working man. His continuous studies, he had felt, gave him the highest quality in a life that was bound to be short.

4.1.3 *Interview Time*

4.1.3.1 *Illness and adaptation*

Four years before, in England, he had taken ill with a rare form of vasculitis. Despite his insistence that his illness seemed to be a form of autoimmune disease the doctor waited several weeks before ordering the proper tests. Death had always seemed preferable to dialysis, but since kidney function was likely to return, he agreed to dialysis as a temporary therapy. Released after several months in hospital, he decided to come to Canada for better medical care.

As mentioned above, Wayne had always feared renal failure. Although he had tried a variety of medications in the hopes of preventing renal failure, he had never had any tests for renal function as he feared learning that his kidneys were failing. Since he had determined not to go on dialysis, such a diagnosis would be a death sentence. Now ironically, not diabetes, but a rare disease had got him. He wondered whether there was some connection between his fixation on kidney failure and the fact that he eventually did suffer from kidney failure, even if not of the type that had haunted his life.

Realizing his kidney failure was permanent, Wayne decided to kill himself, rather than continue living on dialysis. He obtained poison from a friend and made preparations for death. But he kept postponing suicide. He described this period— indeed much of his

life on dialysis— as being like a prolonged version of Hamlet's soliloquy ("To be or not to be, that is the question"). Eventually time slipped away, and now, he told me, he was held back at least partly by his concerns for his wife and his parents.

Before dialysis, he had rejected the idea of a transplant because of the short survival time of the transplanted organ and the increased possibilities of cancer. Now, however, he was persuaded to reconsider the matter; the survival time has greatly increased, and the possibilities of more permanent solutions seemed on the horizon. However, without relatives willing to donate a kidney the waiting time for a transplant could be many years. He investigated going to the United States for a transplant. (He had dual citizenship.) However a number of his initiatives towards this end fell through.

Having received his doctorate before his illness, Wayne explored the possibility of university teaching, but his field was too specialized for a Canadian position, and the American medical system made working there impossible for him. Gradually his health deteriorated with weakness, nausea, a heart attack and serious line infections; he could no longer think of a job. Now he worked on his research, taking endless neat notes without the strength to write the papers to publish his findings. He went to libraries, often with bags to vomit in, and brought his books and papers to the dialysis room.

He liked to talk to people about intellectual matters. During his interview he spoke of his pessimistic views of life and his approaching death, but in more casual conversation Wayne did not reveal such despair.

4.1.3.2 *Identity*

Wayne saw himself as a thoughtful person, very pessimistic in his outlook throughout his life. His preoccupation with death had begun with the onset of diabetes in his mid-teens. While his peers worried about their "acne and social lives", he considered his own death. This experience had made him a deeper person than he might otherwise have been. He had been, he thought, "on my way to being a very superficial, ambitious, success-oriented, type A personality", until his illness made him very thoughtful.

Wayne saw himself as a renal patient. His life was peculiar: as a student he had lived like a 19 year-old until his mid-forties; then he went into retirement, missing the "great middle period" of career. Now he was like an 80-year-old man in his low energy level, his walking pace, his life style, and his life expectancy. He saw himself as not really living but existing in a kind of zombie-like state, observing and reflecting on the meaning of life, but not really participating in it:

> I thought it was something like being a ghost— as if I had **died** at the onset of renal failure— and then I was somehow magically able to continue going on through my life and looking at it, seeing the familiar people and rethinking things that had happened over the years.

4.1.3.3 *Social relations, including family*

Wayne seemed to be a sociable person. He liked to spend time chatting with me in my capacity of chaplain, when we discussed his research and our religious beliefs. He spoke of his many friends in different countries.

His relationship with his wife was important to him. She picked him up after dialysis and could be relied on to give him the care he needed. He spoke of her work with pride and referred to his love for her. Although his relationship with his parents seemed to

have been tense when they questioned his continuous studies, he obviously was concerned for their happiness. One reason for not committing suicide was his desire not to bring grief to their final years, especially as his mother was herself dying.

4.1.3.4 *Values*

Wayne's values were expressed in terms drawn from his studies in philosophy. He often cited eighteenth and nineteenth century philosophers such as Hegel and Hume. Self-transcendence was an important central theme. Seeing his life as ending, he considered its value and found worth in his interactions with others: "things I had done for other people bringing a more intelligent perspective to discussions or bringing a sense of humor into situations where it might have been missing."

The importance of self-transcendence led to consideration of the value of moral decision-making. And here his horrible illness gave opportunity for great moral decisions. Those cousins who had refused to make available kidneys for transplant had made major moral decisions, albeit negative ones. He considered too that his rare illness was a kind of chance that **he**, rather than someone else, had to endure. He thought that if he had been given a choice of it being him or someone he loved getting the illness, he hoped that he would have had the courage to make the right moral decision. Thus he saw his illness as a focus for moral decision-making, the supreme acts of human existence.

4.1.3.5 *Religion and hope*

Although Wayne had no religious beliefs and had rejected the idea of God, he held to a humanistic philosophy. He found spiritual value— although he never used the word

"spiritual"— in reflecting on the meaning of life. Death was the end, but a kind of immortality lay in self-transcendence, in the qualities that live on— in the ways people touch each other. The value of a life lay not in happiness, but in duty to others. And indeed the approach of death might have value if it freed him to participate in particularly dangerous medical experiments.

The failure of Wayne's efforts to arrange for transplant in the U.S.A. seemed to have removed his hope for a successful kidney transplant or any other hope. The life he was living was "meaningless and vacant and just sort of a punishment."

4.1.3.6 *Support*

Wayne found support in his relationships with people, especially his wife, and in his philosophical reflections.

4.1.4 *Changes*

Wayne had rejected the idea of life on dialysis, preferring death to this restricted routine. In fact the horror of that possibility had been a major motivating factor in his life. When he was first told he had to be dialyzed, he only agreed because he hoped it was to be a temporary measure until his own kidney functioning returned. However when it came time to actually commit suicide, he was never able to do so. Then he was persuaded that a newer transplant procedures and anti-rejection drugs might make kidney transplant a viable alternative, providing the life-saving bridge until the day when a better solution to kidney failure was found. This provided a measure of hope to carry him for some time. But by the time I met him this alternative seemed to be unlikely but he had become more accepting of

his life on dialysis, taking pleasure in reading, studying, philosophical reflection, and the small pleasures of the moment. But he still regarded dialysis as a kind of torture.

4.2 DAVID

4.2.1 *Introduction*

David, a Canadian of British ancestry, was in his mid forties. He was married with two children. He had custody of his son, by an earlier marriage, who was in senior elementary school. He and his second wife had an infant, about a year old at the time of this interview. His mother, a widow, lived in Ottawa, and he had two sisters. He was a stay-at-home father, while his wife went out to her position with a high tech firm.

David had suffered from kidney disease for many years. Finally, about twenty months before, he had gone onto dialysis. He had been a successful professional and continued to work for about a year. However, his health was not good enough for him to perform all aspects of his position and so he had gone onto disability insurance.

He was an outgoing person who liked to talk to people. He chose to be interviewed in his own home. The interview took almost two hours.

4.2.2 *Premorbid Personality*

David said that he had been a "very aggressive, type A" personality before he went on dialysis. Although the type of work he had chosen indicated a strong social conscience, at least one aspect of his work brought out his dark side as he strove to get people to do what he wanted. Outside of his work he was chatty and friendly, but on the job he put on a

very aggressive, unemotional façade; co-workers often referred to him as "the iceman." Moreover, he got irritated over little things, even throwing his golf club when he lost a ball!

As a renal patient for many years, he had consulted a dietitian about the best diet to follow in the circumstances and fought going on dialysis as long as possible. His kidney specialist had wanted him to go on dialysis at least two years before he finally did. He had had a fistula created so that when he decided that it was necessary he would be ready, but he refused to start dialysis until it was unavoidable.

4.2.3 *Interview Time*

4.2.3.1 *Illness and adaptation*

About two years before our interview, David's health deteriorated. Finally his colour became bad, his mind somewhat confused, and his speed slow. One evening at a children's soccer game he met his former nephrologist who recommended that he not postpone going on dialysis any longer. So the next day he began dialysis. A caring nurse helped him through the stresses of the first week or so on dialysis.

At first dialysis really made a huge difference, but over time he found he could not do all that he had formerly done. One aspect of his job, particularly, was impossible for him to perform. Thus, after eleven months on dialysis, he went on long-term disability. In some ways David felt that dialysis had failed to live up to its promises.

David did not allow the time spent on dialysis to be a great hardship. He adapted to the procedure, bringing a phone with him, and spent time talking to friends and family. He went to a hospital clinic, rather than an off-site clinic, because having dinner with his family was important, and he wanted to start dialysis later than was possible at the clinic.

David's attitude and character helped him adapt. He felt that being externally motivated made him want to please the nurses so he strove to come in without excess liquid and to make their lives easier. This, in turn, made his dialysis go better. He had also used his competitive streak to help him to keep his liquid intake down. His humour also helped; it put things in perspective. He said of dialysis:

> So I tell people dialysis and kidney failure is the perfect guy disease. I got a lazy boy chair. I got a TV. I got a clicker. I got a wonderful nurse who will come running at my beck and call and even line up my chair so I'm directly in front of a TV. If I asked my wife to line up my chair at home, she would quite properly slap me on the head.

Physically he had changed. He was not able to jog as he had before; the Baby Jogger he had purchased to go for runs with his infant was used as a stroller. However adaptation was made easier by the fact that he had already begun to slow down before going onto dialysis; where once he had run marathons, in the year before going on dialysis he had only tried to run a few kilometers a day. Also instead of sleeping only six hours a night, as he had previously, he now needed eight to ten hours.

Usually dialysis went well, but sometimes he felt uncomfortable. He suffered from mild anxieties and occasionally, had anxiety attacks, especially while on dialysis.

4.2.3.2 *Identity*

David felt he had changed. He had learned to listen more to his body and his emotions, only jogging when he felt up to it. However, this listening was not perfect; only that morning he had persisted in exercising to the point where he had become dizzy.

He did not want to go back to the profession in which he had been so successful. He did not want to try to control people as he had before or deal with people in the midst of

their quarrels. He had learned to be less stressed and more philosophical; no longer did he get angry about unimportant things, like a leaky roof or an awkward tenant.

He had observed that in stressful situations, people either got angry and took their anger out on their spouses or families grew closer; he and his wife had grown closer since he went onto dialysis. Part of this was due to his desire not to feel like a victim, but to look for the "silver lining in the cloud" that had come over his life.

David found "silver linings" in dialysis. It had forced him to slow down, to enjoy beauty in nature. It gave him the opportunity to get to know many different people in the dialysis clinic— brave patients and devoted family members. And— especially important— it gave him the chance to spend lots of time with the baby and his older child. He especially appreciated being a stay-at-home father at this crucial point in the baby's life, "to mold and create a one year old... (in his or her) formative years." Dialysis had, he said, "made me more aware of the important things in life."

Why he was so happy to be a homemaker? He thought it had to do with the way he could nurture his children, but also with his feelings about his old profession. He had been successful, he believed, in contributing to our society and he had been on his way to the top. But he had grown tired of his profession; it offered no new challenges.

David's understanding of people had been the basis of his professional success. Now his self-knowledge and his acceptance of others were growing. For him restricting his liquid intake and keeping his weight down were important, but this was not so easy for others; in fact the prohibition on liquid consumption might even play a role in their excess drinking.

Nevertheless David did recognize the bad things. His illness had made him older than his years. Dialysis patients have much greater chances of developing heart conditions than their peers. Sometimes he got "down" and became "grumpy", not as patient as he wanted to be with his son; then his wife said something and he "shook (himself) out of it." Occasionally some bitterness came through; he felt that he had been misled about the effectiveness of dialysis. Still he wanted to focus on "the silver linings."

4.2.3.3 *Social relations including family*

David's relationships with others were very important to him. He was outgoing and loved to spend time with others. Perhaps he was shifting the focus of his social awareness from the desire to change society that his former profession had involved to his present desire for personal intimacy.

His family too was important. When I first met him, his wife was on maternity leave. He was dialyzed in the afternoon, and she brought the baby every day for a while. Now she was working and he was dialyzed in the evening and she did not have time to come to the clinic. However they spoke on the phone and even watched television together, he in his chair at the clinic and she at home. She also made sure he realized how appreciative she was of his care of the children. She told how, in a discussion about childcare arrangements, she was the only mother who went to work without a worry about her baby. David strove not to burden his wife with his troubles; when dialysis had been hard, he would slip quietly into bed beside her, pleased not to worry her. As we saw earlier, one of the "silver linings" David found in dialysis was the way this time had brought them closer together.

David also kept in contact with his son while on dialysis. On occasion he helped with homework over the phone. Moreover during school breaks, his son would come with a video or games and they would pass the time together.

His relationships with his mother and sisters were not so close. They did not like to talk of illness and would not come and visit him at the clinic as he wanted. His mother had come when he had pressured her, but he had decided to accept the way his family felt about illness. Years before one sister had offered to give him a kidney for transplant if that ever became necessary; when the time came and he spoke of her offer, the occasion was "one of the most difficult conversations of (his) life" as she refused his request. Despite that, his relationship with them was, he said, the same as ever.

Dialysis seemed to have changed a number of other relationships in David's life. The people in the organization where he worked did not keep in touch with him but his relationships with other professionals he had dealt with became warmer. Formerly they had been polite, but distant; now they became warm and more intimate. Also he had new friends on dialysis, friends whose strength, courage, and devotion he admired. They helped each other pass the time and provided support on the bad nights.

David thought that those who had known him for years would still describe him as aggressive and ambitious but those who had only got to know recently him would probably describe him as nurturing and compassionate.

4.2.3.4 *Values*

Dialysis had helped David to discover what values were really important. Family was important, but he valued others, observing them with care and compassion, in order to

understand them. He also observed himself to understand his own feelings and reactions. He valued strength and caring in others and strove to be thoughtful himself. He had rejected his old aggressiveness with people as indicative of a lack of caring.

As we have already seen, really important to David was looking on the positive side of things. He was basically happy, but part of this grew out of his desire to make the best of his situation; looking for the good in each situation as being a self-fulfilling prophecy. He acted so people would not see him as a victim; he wore two small band-aids, rather than a gauze strip, on his arm as he left dialysis. Moreover he did not look on dialysis as a burden, but rather emphasized its life-sustaining quality.

4.2.3.5 *Religion and hope*

David was an Anglican, by upbringing and by choice. He mentioned going to church, but otherwise did not discuss the content or meaning of his faith with me.

He was awaiting a transplant, and at first he had jumped every time the pager rang, but now he tried not to think of it, making the most of the time that was. Although he did refer to the physical toll of being on dialysis and to the patients he had seen die, he never spoke of his own fears of death; however those anxieties must have been present.

4.2.3.6 *Support*

As is obvious from what we have seen, David felt supported by his wife and friends and by his optimistic outlook on life. Particularly important was his wife's willingness to work with him to make his life meaningful. However, in the initial stage of dialysis, the most important person had been the nurse who looked after him on his initial dialysis runs.

She had explained things and reassured him. He had found her kindness and the continuity of her care particularly helpful.

David's advice to those wanting to be supportive was not to feel sorry for people coming onto dialysis but to encourage them, to visit them at the clinic if they want it, and to recognize that "This is their life."

He was pleased when nurses brought new patients to him for support and encouragement. He told such people to regard the dialyzer as their "magic machine" and to make the time on dialysis their own, creating a cocoon of peace for themselves.

4.1.4 *Changes*

David had been reluctant to go on dialysis, postponing it as long as possible. When finally forced to go onto it, he had been rather nervous about the procedure, but a kind nurse provided guidance for the first few treatments. So dialysis became an inconvenience, something to be fitted into his daily life. At first he felt much better than he had for some time, but after a while he realized he was no longer able to keep up the pace of his old life. He had to give up his job and to learn to adapt to a weakened body.

David's positive attitude to life, looking for the "silver lining in every cloud" helped him. Despite real concerns about his health— partly the cause of the anxiety attack he had one night— David looked for positive aspects in dialysis. Moreover the pattern his life had followed facilitated adjustment. He and his wife had grown closer working together, not fighting over the bad spots. He had already learned about slowing down as he got older. His old profession had lost its challenge for him. He was happy spending time with his

new baby; child rearing was the most important job of all. He had made wonderful friends on dialysis. And most of the time he could joke away his frustrations and fears.

4.3 Implications

The case studies of these men show different change processes than the three men whose stories were examined in Chapter Three. The life meanings of the men in Chapter Three were changing as they became accustomed to life on dialysis. This second group had undergone changes over longer time periods. And as they had grown more aware of the ramifications of life on dialysis, putting aside hopes that did not materialize quickly, they learned to find ways to live with the disease.

Wayne went through a number of different reactions— whether they can be referred to as stages is unclear as they may well have overlapped. Initially he hoped that dialysis would be only a temporary measure. Then realizing kidney functioning would never return, he made plans to commit suicide— a step he hesitated to take— until finally he realized that was not what he wanted to do. He considered how he could normalize his life on dialysis by getting a teaching job, but, after some investigation, rejected that as impractical. He was persuaded to consider getting a transplant, and made a series of efforts to obtain a transplant— asking some cousins to consider being donors, applying to various sites in the U.S.A. where he might join a program of experimentation— but these all fell through and these hopes were denied. Meanwhile his health deteriorated and he became weaker and subject to a number of unpleasant symptoms.

By the time I met him he had come to think of himself as a person who is preparing to die. He saw himself as no longer really alive and had reflected on the meaning of his life, meaning he saw in philosophical terms. Contributing to a study too added meaning to this end time of his life. Still, despite his underlying pessimism, he enjoyed engaging with people who would talk about philosophy and history with him. He focused on his love of learning and had learned something of living in the moment. Thus in the midst of his "horrible" life, he still found small pleasures in his reading and studies, in conversations with others, and in his relationship with his wife.

David too had gone through several stages. He had attempted to continue working for about a year and had eventually come to the conclusion that he could no longer handle his job. Just about this time David's wife had a baby and the pleasure he took in the new life seems to have helped him through the upset of having to give up his job. At first too the hope of a transplant was important; however his sister's refusal to consider giving him her kidney and the realization that a cadaveral kidney might not come for a long time led him to put this hope to the back of his mind.

Now he had come to another acceptance of his illness. He still hoped for a transplant, but that might be a while in coming. Meanwhile he had come to find pleasure in the present— in closer relationships, in the time to enjoy parenting, in new understanding of himself and others, in a life when he had time to enjoy a beautiful scene. David had found new goals in his life, goals that were consistent with his new circumstances

Thus the processes Wayne and David had gone through were in response to changes in their circumstances, and the learnings they acquired led to new meanings in their lives.

Their diseases are not static and other circumstances altered; such changes led to changes in their meaning making.

CHAPTER FIVE

DISCUSSION

A certain commonality of themes and approaches can be seen in the meaning making of these five men as they experienced the changes that came in life on dialysis, as well as in the advice they offered to help others through similar circumstances. Common themes include making meaning of illness; developing new senses of the body; changes and continuities in relationships with others in ways that strove to balance new dependencies with ways to maintain self esteem; and processes of adapting, including the role of religion.

5.1 Illness

All five men developed quite extensive illness narratives, telling the stories of their sicknesses and how they came to adapt to life on dialysis. Their illnesses were obviously important parts of their life stories. And the origins or roles of the onset of their illnesses were especially significant.

Initially going onto dialysis was very stressful. For the three men who are the primary focus of the study going on dialysis was traumatic. Abdul and Vivian were shocked about being hospitalized and requiring regular dialysis to survive. Despite advance warnings, neither had comprehended or accepted the severity of his medical problems. Abdul had not fully understood notice that his kidneys were failing and had not gone to the Kidney Clinic to be given the proper preparation. Vivian had failed to absorb

the warning about the damage high blood pressure was doing to his kidneys and had discontinued his medication. Perhaps their inability to absorb the prophecies was a function of their youth. John too had had some advance warning of physical problems, but had failed to change his life. After his stroke, he had resumed his old pace of life fairly quickly until he developed symptoms of Wegener's disease. (This is not to suggest that there is any connection between John's lack of self care and developing Wegener's—NIAID, 1997, maintains that the causes of this disease are unknown.) Thus the total breakdown of his body, of which ESRD was only a part, came as a great shock.

None of these men appear to have recognized what was going on. Many observers would label this as 'denial'. Different approaches to understanding how patients perceive their illnesses may be more helpful in explaining these failures. In their study of the application of different social cognition models of illness to renal disease, Horne and Weinman (1994) argue that illness is a problem a patient's behaviour is an attempt to solve; the patient finds meaning in the illness through identifying its health threat, develops a coping strategy, and finally assesses the outcome. Park (2000) too argues that appraising the meaning of a stressor is the basic element in a person's coping process. Thus denial may be an indication that these men were not ready to see themselves as really ill. Perhaps more support at the time of receipt of the news might have enabled them to fully absorb these diagnoses.

For David and Wayne, going on dialysis was not so much shocking as stressful. Wayne went onto to a hated procedure only because he saw it not as permanent condition but as a temporary, life-saving procedure until his own body recovered from the acute form of vasculitis from which he was suffering. David had fought going on dialysis for several

years, defying his doctor's advice as long as he could (a move that he now felt was right since dialysis did not turn out to be as effective as he had been led to believe).

All the men, except David, wondered about the roots of their illnesses. Abdul questioned if his kidney failure grew out of the serious infection he had had years before or out of his coronary problem. Vivian saw his failure to follow medical advice as the root of his problem. Wayne commented on the irony of being saved from his life-long horror, ESRD as a result of diabetes, only to lose his kidney function through such a rare form of vasculitis; he wondered if there was a connection between his perennial fear and his illness. John, probably encouraged by Melissa, saw the breakdown of his body as a catharsis, burning all the bad old ways out of his system.

The loss of control of their lives and the limitations of life with ESRD came out clearly in the stories of all the men. Abdul particularly commented on the reduction in time with his daughter. Vivian spoke of losses too, especially of his freedom.

Like these men, the cancer patients interviewed by Angen (2000) struggled to find meaning in their illnesses, accepting responsibility without self-blame. (Our society, with its myth that we control our own destinies, often blames the victims for their illnesses.)

Transplantation and the men's attitudes to it differed. Abdul saw a transplant as the road to the return to his old way of life; he knew there would be changes, but transplantation would be like having a baby, the beginning of a new life, like the old but even more appreciated. Vivian saw a transplant as offering him new chances, among them the opportunity to spend time in the "environment", a reminder of his boyhood freedom. John's focus was not yet on the possibility of a transplant; his Wegener's disease had to go into remission and he had to recover much of his strength before he could even think of it.

For Abdul and Vivian, and to a lesser extent for John, this was a time of waiting. Abdul and Vivian waited for transplants to return them to lives as young men, and John waited for his disease to go into remission and his strength to return.

For Wayne and David the present was different. For Wayne this was the time he had as he waited to die. David enjoyed much of his present life, choosing not to focus on its unpleasant aspects. Thus neither felt the present was a time in between their real lives.

For all these men then the ways they perceived living with dialysis was part of the meaning they made of it, either really part of stories or unpleasant side roads. Nowhere in the material I read on renal disease did I come across any studies that focused on the sense of time in this way.

5.2 Body Sense

ESRD and dialysis changed these men's senses of their bodies, changes which each experienced differently. Abdul, Vivian, and John had all been able to ignore the effects of earlier illnesses; ESRD brought whole new perceptions. Abdul had enjoyed sports previously, and his willingness to work overtime suggests a fair amount of energy. Thus he felt himself a normal active young man. Now he no longer participated in sports or worked overtime. Without functioning kidneys he thought of himself as incomplete; his body had to some measure failed him. Even after a transplant, he anticipated, he would have to take special care of his health.

Vivian too had enjoyed sports, often playing basketball with his friends. His body appears to have been something to enjoy, even a source of pride (consider his consciousness of his appearance), not a source of worry. He had dismissed his headaches

and nausea as unimportant and had even gone to work when simply walking was really difficult. His ability to ignore signs of trouble probably grew out of a young person's unconscious belief in his body and its ability to recover. Now his body was different—thinner, weaker. Even after his discovery of the wonderful cookbook and regaining some weight, he was still conscious of his weakness. Moreover, like Abdul, he saw himself as incomplete without functioning kidneys. Despite feeling much better– dialysis "really worked"— he was conscious of the need to take care of his body. He followed medical advice carefully, going regularly for dialysis and sticking to his diet. At first he had to protect his permacath. Later even a fistula would have to be protected from injury. The altered sense of his body led to major lifestyle changes, no more basketball with his friends or going out "clubbing."

From being an active, normally healthy, middle-aged man who had even come through a stroke with little damage, John had been struck low, not just physically but psychologically, by the ravages of his illness. His whole body had seemed to be failing, and his sense of himself seemed to go too. The return of strength helped, but he was still weak, not even allowed to walk the dog. He spoke of the new sense of himself: formerly healthy, subject only to minor temporary ailments; later an invalid; now still frail, unable to work. He now placed a special emphasis on self-care. This clearly meant more than just physical health; self-care involved, according to Melissa, loving himself enough to take time and energy for himself, and saying no to others. Thus self-care meant looking after his physical, emotional and spiritual well-being, even initially helping him know who he was.

As a young man David had been very athletic, running marathons, skiing, playing golf. He had begun to slow down before he went onto dialysis. Perhaps this was simply a

function of age or one of the effects of the chronic kidney problem he had suffered from for years. But ESRD hastened the slowing down. Moreover he had had a heart attack, a condition that dialysis patients were often subject to. Now he could not use the Baby Jogger he had purchased before the baby's birth, except as a stroller. And when he played golf he now used a motorized cart to get around. Illness had aged him. Still David wanted to appear normal, opting to wear only two small bandages over his fistula as he left dialysis.

Wayne too spoke of how illness had aged him. He walked like an 80-year-old man and had the life expectancy of one. His body was a constant source of discomfort to him, as he rarely escaped from nausea. Previously he had been a man of great energy, managing the studies for several degrees simultaneously, reading and studying on the train as he moved from one university centre to another. Now he did not have the energy to write up the results of all the reading and studying he did.

The role of the dialysis machine in the lives of all these men loomed large. Abdul spoke of thanking God for its invention. John joked about taking it camping, a possibility precluded by its size and need for sterile water. Part of the reason for going on peritoneal dialysis may have been to get away from this machine, which like the wheelchair that he had been so happy to discard, reminded him of his dependence. Similarly David too used humour in describing this machine, referring to it as his "magic machine." Thus the sense of their bodies were parts of their changing senses of themselves.

Among the various writers on patients' perceptions of their illnesses, the comments by Lindquist et al. (2000) and the work by Charmaz (1995) seem most helpful. The first study points out how patients, in their desire for normalcy, often strive to live as usual, like Abdul, or to appear normal like David with his small bandages. Charmaz examines the

ways the experience of altered bodies changes people's sense of identity. She notes how people usually take their bodies for granted. Some people with chronic illnesses treat the illnesses as separate to be fought against while others accept them more as part of who they are, seeking ways to be as normal as possible with their illnesses. Clearly Abdul was experiencing his illness and his body in the former way. Eventually, Charmaz says, some people accept their bodies as fragile and familiar. Wayne and David clearly fit this pattern. David even felt really comfortable in his altered body, often "attending to the cues...(it) provided" (p. 663). Wayne's nausea and concern about maintaining his limited health left made it impossible for him to ever feel comfortable in his body, but he certainly "attended to all the cues (it) provided" (p. 663).

Changes in their health status and changes in their understandings of their health situations brought changes in meaning making as we have seen. Gregory et al. (1998) also comment on how varying illness developments affect patients' images of themselves. Moreover Charmaz's image of life with chronic illness seems really apt; such a life is an "odyssey", a journey in which the patient's concept of self changes, particularly in relationship to his/her body and in identity goals.

5.3 Relations with Others

In the stories of these men's relationships several themes emerge: dependence, interdependence, and autonomy; relationships with people outside their families; and caring for others. All these were parts of the meanings these men made of their lives.

5.3.1 *Dependence, Interdependence, and Autonomy*

The themes of dependency, autonomy, and interdependence are signs of the changes in each of these men. Writers like O' Brien (1983) comment on the role of dependency in the lives of renal patients, particularly on their involvement with dialysis. She notes the role families play in encouraging patients to go to dialysis and in providing support with diet and adjustment. Gregory et al. (1998) emphasize the role of quality of support patients receive in their redefinition of themselves.

All these men relied on family members for support during their illnesses and as they coped with living on dialysis. All needed help, at one time or another, of the types indicated in O'Brien's study. Abdul mentioned how his wife and mother took care of his dietary requirements and how these women, later joined by his daughter, encouraged him to keep up his spirits. Vivian's brother drove him to the hospital, his girl friend prepared his food, and the whole family encouraged him to maintain his dialysis and keep up his spirits. At first, John's dependence on Melissa was enormous because of his great weakness; at times she had to act as his protector and intermediary to the world and even help him find who he was. Although he did not discuss her in any detail, it was clear Wayne relied on his wife for care and support. Thus their familial roles had changed.

However the desire to maintain autonomy continued. They attempted to maintain emotional autonomy so they could accept necessary support without feeling infantilized. The dichotomy between dependency and independence and the theme of intimacy appear in several stories. Abdul was pleased that his wife no longer had to help him bathe after he got his fistula. Vivian lived with his brother in order to avoid the kind of babying he felt from his family. His distress about not being able to pay child support was a reflection of

his desire to continue his adult responsibilities. John's dependence on Melissa grew less as his health improved, a move she encouraged as she wanted to avoid the dependence her first husband had demanded. Moreover, John's desire to be able to contribute again was a form of independence. This theme also appeared in David's desire to protect his wife from worry on evenings when dialysis had not gone well. His satisfaction with being a stay-at-home father lay in regarding his caregiving role as important.

These men found ways to accept their dependence, without feeling they had to give up their identities as adults. Abdul's ideas of teamwork allowed him to accept help. The closeness of his relationship to his family is especially noteworthy; more than any of the other men he saw his identity in terms of his family. He relied on his family for psychological, social, emotional, and spiritual support— essential to his recovery.

Vivian achieved the closeness he wanted with his family by learning how to be more open about his feelings. With the aid of a social worker, he learned to set boundaries for relatives so that he could allow them to become more intimate.

Perhaps Wayne's continuation of his studies was a way not just to fill time but also to maintain a sense of himself as continuing to learn. Moreover, on occasion others in the dialysis unit consulted him as a source of learning and knowledge.

Living with stress could bring conflict into family relationships, David knew, but instead ESRD had brought a greater closeness to his wife. David's desire to have his mother visit him in the clinic may have been to achieve a greater intimacy, but eventually he had decided not to fight against her discomfort in the hospital, but to understand it.

Changes in how roles and relationships are perceived are important to changing self-images, as we have seen Charmaz (1995) and Gregory et al. (1998) emphasize.

5.3.2 *Relationships with People outside the Family*

Continuity and change come in relationships outside the family. Abdul's friends at work reinforced his self-esteem through their concern and assistance. Vivian's relationship with most of his friends seemed to be breaking down; when they visited him in the hospital, he had hidden his upset and the seriousness of his illness from them behind a curtain of jokes; later he spent less time out at clubs with them. However one friend still was important, maintaining regular contact, and the concern shown by work mates was part of the sense of loss he felt being cut off from his job.

John was hurt by the failure of some of the people he thought were friends to come to his support; even the youth group had rejected him although he blamed this betrayal on another leader. The people he worked with had made no effort to contact him except to get back their computer. However, as we have seen, he chose not to brood over such rejections. David valued friends, not only old ones, but also people to whom he had never previously been close; in the past their roles had kept distance between them, but such barriers were removed by his new status. He had shifted his focus from professional competence to building close relationships with friends and family. Thus old friendships sometimes passed away while new ones developed and the men changed.

Both Abdul and John, the two who most valued friendships, mentioned the roles of people in the clinic, especially other patients and their families, as important to them. Abdul described the group of men in his small regular section as being a kind of family and showed his caring in the empathy he showed for them. David spoke of his appreciation of the patients and their families, their kindnesses, their courage, and their willingness to share

as being part of the "silver lining" of life on dialysis. The maintenance of old relationships and the building of new, are ways of sustaining self-esteem. O'Brien (1983) and Gregory et al. (1998) also note the important role of people on the dialysis unit in patients' lives. Gregory et al. (1998) discuss the roles of relationships as sources of support without considering the possible role of relationships in maintaining ego strength and the attempts by patients to use relationships to continue to see themselves as contributing members of society.

5.3.3 *Caring for Others*

The theme of caring for others may be seen not just as the continuation of long-established values, but also as a way these men tried to maintain their identities as independent adults. The theme of caring for others comes out clearly in their relationships to their children. Abdul, Vivian, and David found special meaning for their lives in their responsibilities for their children. Abdul saw his daughter as a special responsibility, the most important one in the family, the reason why getting a transplant was so important for him. Vivian saw his care for his daughter as special so that she would not have to grow up without proper parental care, as he and his brother had. As we saw earlier, David too viewed his role in molding his infant as a special responsibility. But it was not only their responsibilities for these children that gave meaning to these men's lives, they were also sources of great pleasure, part of the joys of intimacy. John's willingness to let his sons go until they were ready to reengage is a mark of his recognition of them as nearly adult.

Caring for people other than family was also important. Abdul was empathetic towards others on the unit, and provided help for other immigrants. Vivian did not

specifically refer to assisting others, but in speaking of supporting people coming onto dialysis, he seemed interested in aiding them. John wanted to go back to "making a contribution", with Scouts, even if on a lesser scale, and even saw the interview process as being a way of making a contribution. Wayne found value in his life in the contributions he made to others' well-being. In his idea of self-transcendence and his effects on others he even found a kind of immortality, a strange concept for such a conscious atheist. David's professional work had involved justice issues, and now he took pride and pleasure in ways he could assist others coming onto dialysis. Concern for others may be a way to maintain the sense of self as an autonomous adult, despite the dependency disease created.

Gregory et al. (1998) do refer to older studies that reveal that patients often want to protect their families from too much concern about their illnesses and Weis (2000) refers to patients' hopes for others. However none of the studies of dialysis patients I have read explore the theme of caring for others as a means of maintaining self-esteem.

5.4 Adapting

As previously noted, Symister and Friend (1996) argue that the subjective quality of life is related to the adoption of suitable life goals; Charmaz (1995) says that adapting to serious chronic illness changes the concept of self; and Gregory et al. (1998) find the redefinition of self, quality of support, and the meanings of illness and treatment to be the dominant constructs. King et al. (2002) argue that patients, with varying degrees of renal insufficiency, struggled to cope with their illnesses and the treatment regimens required, and with changing outlooks for the future. All of these themes appeared in these men's stories. Another important point revealed in a number of studies in the last decade,

according to Somerville and McCrae (2000), is the influence of individual characteristics on the adaptation processes.

5.4.1 *Adaptation over the Short Term*

Abdul had been very satisfied with his life. He was a good person, a member of a good family, all of whose members fit their roles perfectly. The family had successfully adapted to life in Canada, in a few short years managing to buy their own home. His long-range hope too was tied to his family— in its continuation, as represented by his daughter. His job was satisfying and he worked for a good company. He was well appreciated there, even by the president.

Abdul had always come well through bad times. Now he strove to maintain a "normal" life, as much like the one before as possible. He tried to understand what was happening to regain a sense of control at a time when his illness seemed beyond his control. He used self-talk to get him through the "down" times and he drew on his mother's optimism and on the strength of his people, people of a land torn by war. The memories of the success of his earlier operation carried him past his fears of the operation for a transplant. His prayers and those of his mother would be answered in a return to the satisfactory old life. A transplant would bring him again to "normalcy." The present was a time to get through as he had other difficulties. **He** had not changed, only his circumstances. He fought to maintain an active, "normal" life. The fear that he would not get a transplant, although never acknowledged, occasionally cast its shadow in the questions he asked himself about all these tests and how long they were taking.

Vivian was very conscious of the changes in his body and mourned his losses. However he drew on the strategies he had developed during earlier times of trauma to establish a stoical acceptance of his loss of freedom. He used humor and an attempt to live life one day at a time to get through what he hoped would be a time of waiting. He prayed regularly and trusted in God to bring him to healing, prayers that seemed to be answered as he regained some of his old strength. His brother and girl friend were important sources of support, physical, emotional, and social. After he learned to express his feelings, the rest of his family could take their proper roles in supporting him. This seemed to give him special satisfaction as the importance of his family was indicated by his sense of being part of a large family and the frequency of his visits to extended family in New York.

Although Vivian felt he had altered, especially in the way he was able to express his emotions, he was ambiguous about this change; he still liked the image of himself as a silent man. He lived a quieter life than before, but this was, he thought, part of the maturing process that had begun with the birth of his daughter. The significance of the birth of his daughter is clearly related to his sense of being abandoned after the deaths of his grandparents.

Vivian's concern about the change in his appearance is an obvious indicator of its importance to him, an importance borne out by his continuation of a style of clothing and hair that had obviously on occasion led to people misjudging him.

Melissa's support and his will to live had bought John through the worst of his illness. Now the process of regaining strength and relearning old skills, such as walking, encouraged him to believe that things would get better. Eventually he decided that he would prefer peritoneal dialysis, a procedure which would allow him greater control over

his life and make him less dependent on the hospital, where some of the medical staff irritated him with their failure to treat him as a whole person

John felt that he had undergone several changes. He hoped that as he grew stronger, he would be able to contribute in a more balanced way than before; he would no longer strive to "give 150 per cent." He would not again take up smoking a pipe and all that symbolized. He would be better able to express his feelings than he had in the past. But these changes were part of the change process of which the decision to live with Melissa was a part. Thus they saw his illness as a fire burning out the old to allow the new to flourish more richly. Disease, Melissa said, had sent John to places in himself he had not known existed.

The failure of many of those he felt he had supported in their times of trouble to support him in turn was a source of some pain to John, but he did not want to become angry or bitter. As he had done in the past, he tried to understand them. He planned to speak to some of these people about his upset and then to put away his hurt. He had used this pattern in the past and it had worked for him then.

5.4.2 *Longer Term Adaptation*

Wayne and David also drew on long-standing practices and traits to adapt to ESRD. Wayne had always tried through study and knowledge to control his life, even going to the extent of studying medicine for a number of years in an attempt to find ways to prevent diabetes-based kidney disease. He kept postponing his planned-for suicide, gradually finding reasons to go on living, even though he found his life horrible. He passed the time doing the reading and research he so loved. He drew on his cognitive resources to find a

purpose to live in his stoical philosophy. Also he had come to find pleasure in the small things of life, the living in the moment that Vivian spoke of.

David used a conscious optimism and looked for ways to build his life around dialysis. It allowed him to be a stay-at-home father with his two sons, and he was able to manipulate his schedule to find time for family dinners. He used the time on dialysis to develop warm friendships with other patients and to build and maintain relationships with people outside the hospital, family and friends, using the phone he brought with him every night. Thus his love of his family and his concern for others were refocused to take new forms and meaning in his altered circumstances.

Part of his ease in adapting to life on dialysis was that he had already begun to slow down before he had gone onto dialysis so the fatigue dialysis patients often feel became an extension of that process. His profession had lost some of its old challenges for him so he did not feel great unhappiness in giving it up. In fact if he got a transplant and was able to resume a more active life, he planned to study for another profession, one involving less aggression then his old one.

5.4.3 *Religion and Adaptation*

Fairly extensive work is being done on the role of religion in coping with major problems. Pargament(1997) and Ellison and Levin (1998) surveyed the literature in this field and outlined 16 methods of religious coping; seven of these methods appear in the stories of these men, albeit sometimes not quite in standard terms, since my definition of religion is broader than theirs: (a) reappraisal of God's powers to influence stressful situations; (b) collaborative religious coping, that is seeking control through a partnership

with God in problem solving; (c) deferred religious coping in which God is expected to control the situation; (d) seeking spiritual support through God's love and care; (e) seeking a sense of connectedness with transcendent forces; (f) searching for or finding support in the love and care of congregational members and clergy; and (g) religious helping, through attempting to provide spiritual support and comfort for others (p. 711).

Abdul's prayers to God involved (c) deferred religious coping, with his emphasis on God as all-powerful. Vivian's prayers involved (b) collaborative religious coping in that he saw his self-care as playing a major role for his healing. Although Vivian had not asked for the prayers of others, his gratitude that relatives' church communities were praying for him involves (f) finding support in a religious community. David's church going, his social conscience, and his desire to help others to maintain their spirits as they came onto dialysis seems to be a form of (g) religious helping although he himself never expressed matters in that way.

Although Wayne and John would not define themselves as religious in any way, a number of their cognitions and behaviors seem to spring from the same kinds of motivations that are part of religion. Stoker (1996) discusses how modern humanistic meaning making serves some of the same purposes as religion; moreover Dyson et al. (1997) broaden the definition of God to include any matter of ultimate concern to the individual. For John, the Scouts Canada organization served many of the roles of a religious community. It provided a code of behavior to which he subscribed. He even accepted its belief in a Supreme Being. It provided a community of people of various ages, like a church. Thus he could find a type of (e) transcendent connection in it and he sought for (f) support from its members. I wonder if the failure to many Scouting friends to

support him would eventually lead him, with Melissa's encouragement, to extend his search for the transcendent.

Wayne found support in his philosophical reflections, finding in Hegel's idea of moral decision-making a kind of transcendence. This is a type of (e) connection with the transcendent. Thus the variation in religious responses— part of their ways of finding meaning— depended on each man's individuality and history.

5.5 Optimism or Pessimism

All the men, but Wayne, strove to be positive, uncomplaining, optimistic in the face of trouble. Abdul focused optimistically on a return to "normalcy." Vivian refused to focus on the unfairness life and people. He looked for the good in circumstances, just as he had used the year in ESL to learn to play basketball. In addition, when things became too worrisome, he joked to put things "in perspective." John saw his illness as part of a life-transition, giving a positive spin to a terrible time. He tried to show understanding of those people who had failed him, not supporting him as he had supported them. David looked for the "silver lining" in his life; ESRD had given him the chance to be a stay-at-home father, to spend time with his children, especially the baby. The kind of life satisfaction that David seemed to have found and for which the others were searching is consistent with the degree of life satisfaction that Symister and Friend (1996) found in their examination of major quality of life studies of renal patients, a quality of life based on new life goals.

In his quiet, uncomplaining pessimism, Wayne exhibited a stoical acceptance such as Nigel King et al. (2000) found in their study. Moreover the conscious optimism of the other four men is very similar to stoical acceptance. The way these men were so deliberate

in their optimism suggests that they were trying to stave off the depression so common in renal patients (O'Brien, 1983). Each man was trying to make himself as he wanted to be—not always successfully as we saw with David's anxiety attacks— but at least most of the time.

5.6 "Taking the Lead in Dancing with Chronic Illness"

These men attempted to control who they were despite their illnesses and the changes these had brought in their lives. One wanted to remain unchanged; another did not want to perceive himself as a victim; several wanted to understand their illnesses and the behaviour of people. The ways they tried to control their identities as they "redefined themselves"— to use a phrase from Gregory et al. (1998)— followed on from the identities they had created for themselves throughout their lives. They had patterns of coping, they had ways they wished others to see them, and they had ways they wished to see themselves. And these patterns guided them on their journeys to new identities. Perhaps they had little control over their lives and their treatments, but they hoped they could control who they were in those circumstances. Of course they were not always successful. Fear lay as a shadow behind Abdul's positive thinking. Bitterness occasionally broke through Vivian's attempts to cope with troubles through finding the good things in any circumstance and when he could not, make a joke of it. David had an anxiety attack one evening and left dialysis immediately, much to the distress of the nursing staff. Nevertheless most of the time they seemed to be able to be the kind of men they had chosen to be. And in Giroux's words, they tried to "take the lead" in their "dance with their chronic illness" (1998).

5.7 Support

The questions about support had two foci, the first on those the patient himself had found helpful and the second on advice they would offer to others. The answers provided reflect the supports each man found particularly helpful and are similar to the kinds of supports mentioned by writers like O'Brien (1983) and Gregory (1998).

All patients had relied on their families for support of one kind or another. Abdul's wife and mother provided encouragement as well as practical support; moreover as time went on, his daughter joined the older women in offering hope. Vivian looked to his brother and girl friend for practical support, and later, to the family for emotional support, especially in trips to the doctor. His daughter too gave support as a source of pleasure and a focus for life meaning

The care of friends and acquaintances was important to most of these men. All except Wayne, mentioned friends who called and people who listened. Such friends provided emotional support and helped maintain a sense of normal life continuing.

The skill and care of medical personnel were important as sources of information and reassurance. Over-optimism in talking of the benefits of dialysis could, however, lead to some feelings of betrayal, as we saw with David. David was particularly affected, though by a caring nurse who had supported him through the stressful first days on dialysis. Vivian mentioned a dietitian's advice about a cookbook and a social worker who assisted him to learn how to improve relationships with his family.

The support and caring of other patients and their families were mentioned by the two men who were most social in their outlooks, Abdul and David. Perhaps John' heavy

reliance on Melissa had kept him from developing relationships with other patients and their families.

The role of humour in helping get through the tough spots was important, and both John and David particularly joked about the dialyzer.

Advice for others varied. Most recommended following medical advice and attending dialysis regularly as vital to well-being. The value of keeping up hope and being positive were also seen as necessary. Vivian particularly spoke of learning to live one day at a time. David spoke of not wanting people to feel sorry for them. Abdul especially mentioned using self-talk for this purpose. Implied was the importance of having family and friends to assist with practical as well as psychological support. Sometimes these men had been so ill they had really been incapable of looking after themselves; Wayne and John particularly had obviously been very dependent on others for practical care.

Advice on how to assist others was consistent with these ideas. Family should not feel sorry for people on dialysis. The importance of having support from those who had been through this experience and so could give an insider's point of view was mentioned by Abdul and Vivian. John emphasized how caregivers need tolerance and understanding in dealing with patients who become bad tempered. (David too spoke in another context of his wife's role in encouraging him not to be hard to get along with.) Thus caregivers should recognize the need for their own self-care.

Thus we have seen how the on-going process of living with dialysis for these men involved making sense of illness and developing a new sense of the body. Relationships too changed as these men became more dependent on others. To cope with the ego threats

of such dependency, these men emphasized interdependence in their social relations and their roles in helping others. They used a variety of methods to adapt to life on dialysis, methods consistent with who they were and their previous life experience. Particularly noteworthy are the ways in which they attempted to be who they wanted to be in their situations, a process that may be described as "taking the lead in the dance with dialysis." Out of their experiences these men recommended a number of ways to support others going through similar health crises.

CONCLUSIONS

This section consists of a summary of the study, observations on the processes involved in the study, comments on the implications of the study, suggestions for future research, and applied usage.

00.1 Summary

In recent years there have been numerous studies done on religion and health (Ellison & Levin, 1998; Koenig et al., 2001) and on coping with stressful events (Pargament, 1997; Park, 2000; Somerville & McCrare, 2000), including religious coping (Pargament et al., 1998; Radley, 1997). These studies indicate that religion is important in enabling patients to live in mentally healthy ways with illness.

Chronic illnesses provide on-going stress to which people continually have to adapt (Charmaz, 1995), and ESRD is one such chronic condition. Using a collective case study approach (Stake, 2000), this study examines the meanings people make of their lives as they become accustomed to life on dialysis. Meaning making has been shown to be an important method of coping with major illness (Angen, 2000; Barkwell, 1991). Meaning making is taken as a spiritual process within closely related definitions of spirituality and religion that emphasize "the search for significance" (Zinnbauer et al., 2000). Little work has been done on the connection between religion/spirituality and ESRD (O'Brien, 1983;

Weil, 2000), although one study (Gregory et al., 1998) does focus on meaning making as a method of adapting to dialysis.

The meaning making processes of five men (three newly on dialysis and two more experienced patients) were examined with the following results. Adaptation, through meaning making, varied depending on the life long meaning making processes, the personal characteristics, and the illness trajectories of the participants. Younger men undergoing short term adaptation tended to regard the present as a time of waiting for relief to be brought by transplantation, which was seen as near panacea for the losses imposed by ESRD. In the longer term men came to see their illnesses as integral parts of their lives.

The most important themes in the narratives of the men included making meaning of the illness itself (Angen, 2000; Horne &Weiman, 1994), the losses it imposes and its causes. They developed new senses of their bodies as fallible, as they went through various stages in their illnesses and adjustment (Charmaz, 1995), using a variety of coping mechanisms. Coping may be seen, at least in part, as making new meanings of their illnesses and of relating to their illnesses and bodies in new ways. In some cases, it also involved developing new life goals. The men clearly looked to their past experiences to find the strengths and ways of revising their views of their lives. Most participants consciously chose to avoid bitterness and despondency through optimism, using humour to put "things in perspective", looking for the "silver lining", and putting anger and unhappiness out of their minds. In most cases these processes resulted in new identities.

Some of the men struggled to find the balance between varying levels of dependency and the struggle to maintain autonomy. They often tried to maintain self esteem through developing new or different senses of interdependency and caring for

others; in this they were often assisted by the caring shown by family and friends. Thus relationships and roles changed.

In religion, that is in their focuses on matters of "ultimate concern" (Emmons, 1999)— the matters that are "God" to them (Dyson et al., 1997)— these men found strength and even different focuses for their lives. The older men showed this more clearly then did the younger, perhaps because the younger men saw living on dialysis as temporary. Thus meaning making processes occurred in the lives of all the men through the development of new identities, the changes in relationships and life goals, through consciously chosen attitudes, and through the use of coping measures. These men chose to "take the lead in dancing" with ESRD.

One of the things that struck me is how for some this process brought deepening to their spiritual life, richer understandings of themselves, closer relations with some individuals, and new meanings to their understandings of what it means to be human. Several seemed to be learning the old lesson from so many religions that life should be lived in the present and that the richest joys come from relationships and small pleasures.

As to support, the roles of families and friends were very important in providing practical help and emotional support. The role of the people in the clinic as a kind of family was especially important for the more outgoing of these men.

Knowledgeable persons, both medical staff and well informed patients, were important in providing the physical care these men required and the information they needed to enable them to feel better control of their lives.

The importance of adhering to the prescribed regimen was emphasized, although several men mentioned how they did, on occasion, deviate from it in small ways. Also several of the men argued that a positive attitude was very important.

00.2 Observations

The process of psychospiritual change that is meaning making is not one with a clear beginning and end, but rather is part of a continuing process; thus a study that focuses on short term adjustment has serious inadequacies.

I wondered why most of the men who agreed to be interviewed were so positive in their outlooks. Is this perhaps because those who were feeling despondent found it difficult to share these feelings? Can this drawback be overcome in future studies? If so, how?

Despite the high rate of loss of libido and impotence among men on dialysis (Czarczkes and De-Nour, 1978, p. 96 and O'Brien, 1983, p. 59), none of the men I interviewed mentioned this problem in their interviews. I wonder if this was due to the fact that they were being interviewed by a woman in late middle age with whom they were uncomfortable talking about such matters. However, I note that Gregory et al. (1998) make no mention of this problem either. Their research team consisted of two women and three men, four nephrologists and a professor of nursing, but no mention is made of who did the actual interviewing.

In considering my study design, I noted that my assumption that patients are often persons with little power in a hierarchical system was born out in three of these men's stories. David felt he had been mislead about the efficacy of dialysis; John and Melissa had to fight to have specialists consider John's whole body; Wayne's argument that his original

illness seemed to be an autoimmune disease was ignored. I also found that all the headings I had looked at originally were helpful, except for the one on anthropology. The methodology seemed to be effective within the limitations outlined in Chapter Three. Since I wanted to hear the narratives as the participants themselves created them I rarely challenged or confronted my subjects. This method has limitations but it did allow these men to express their preferred selves.

00.3 Implications and Theoretical Uses

The implications that grow out of this paper are the need for further research of this kind, with its focus on individuals. For example, other types of people might be investigated, including women, older persons, diabetics and others with long-term warnings of the possibility or probability of renal failure.

The need for work that covers longer terms is also indicated by the ways that Wayne and David's heath had deteriorated since going onto dialysis. How do such changes affect people? Charmaz (1995) argues that adaptation to serious chronic illness is an on-going process, changing as the disease affects the system. Thus it follows that the meanings people make of their lives will also continue to change.

Wayne also suggested that there is a place for studies of family members and of clinic medical staff, a suggestion with which I agree. Such studies would give a fuller picture of life in a dialysis clinic, and they would allow for improvements in these places that truly become small communities in their own right.

Similarly studies should be done of persons undergoing other kinds of life-changing health crises. A short examination of the literature would suggest that some have been

done, but most have been by nurses and social workers with the interests of their professions in mind (Thorne et al., 2002).

As we saw the personality of the interviewer may be a factor in the shared activity, which is the meaning created in an interview. Thus the identities of interviewers should always be clarified in reporting on research involving interviews. Moreover the effect of the interviewer in shaping the interview and the nature of topics raised might well be examined by another researcher.

00.4 Applied Usage

Practical implications arise primarily out of the section on support. The first is the importance of putting each patient's total needs first, considering his or her own story in determining a treatment plan. It should be noted that staff on the dialysis unit often show interest in their patients as whole persons. The concern about impersonal treatment seems rarer on dialysis units where the staff and the patients get to know each other better than on other units where patient turn-over is so high.

A specific suggestion that arose might be to consider using "experienced patients" as guides for new patients. Carefully selected and trained patients might help new patients to understand the process and provide role models for adjustment to dialysis.

The role of pastoral caregivers with dialysis patients may be focused by some of the learnings from this study. The role as supporter— fellow travelers on the road in the hard times— is especially important during the anxious times of initiating dialysis, waiting for operations, and living with the stresses of dialysis when it does not go well. Pastoral caregivers may assist patients in making sense of their illnesses and as they come to new

senses of their bodies. Patients may need help as they struggle to cope with the losses that life on dialysis brings; in such times caregivers can help patients get in touch with their strengths and past successes with stress.

Pastoral caregivers are often skilled in assisting patients to find new identities and to learn new ways to relate to family and friends. They can also help patients open to the possibilities of new friends on the dialysis unit. Patients may need assistance in finding new life goals, appropriate to their new lives. They can listen to patients' stories and help as editors as patients try to find new meanings for their lives. And last but not least they can help patients find the sources of "ultimate concern" in their lives, especially when the old ones do not work any more. They can be the dancing instructors as patients "learn to take the lead in dancing" with dialysis.

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APPENDIX I: KIDNEY DISEASE AND DIALYSIS

Kidney functions include (a) elimination of metabolic wastes and other toxic materials; (b) maintenance of the body's volume and composition of fluids, including endocrine maintenance of blood pressure; and (c) some other endocrine functions. End Stage Renal Disease (ESRD) occurs when the kidneys are only performing 10 to 15 per cent of their normal functions. This is determined by blood tests, especially for creatinine, a waste product from muscle tissue (Ulrich, 1989 and Gutch et al., 1999).

Once their kidneys fail, people require dialysis or kidney transplant to replace renal functioning. There are two types of dialysis: hemodialysis and peritoneal dialysis. In Ontario, approximately three times as many people are on hemodialysis as are on peritoneal dialysis.

Hemodialysis is a process whereby the patient's blood is passed through a device called a dialyzer to remove the toxins and excess fluids from the blood. Since only a small portion of the blood is removed at a time, the process takes three to four hours and must be done three, and occasionally four, times per week. Access to the body's blood supply is obtained either through a catheter or a fistula. Catheters are tubes inserted into blood vessels from the outside the body. Temporary catheters may be inserted in emergencies or, on a more permanent basis, soft tubes, called permacaths, may be permanently inserted into large blood vessels. Otherwise a fistula may be created. A fistula internally connects a vein and an artery. After an operation to connect an artery and a vein, a fistula takes six weeks or more to mature since the arterial blood pressure must work to enlarge the vein. Alternatively a graft may be used to connect the two blood vessels. A needle must then be inserted into the fistula to gain access to the blood supply, but the access is less liable to

infection than a catheter. Access sites eventually become clogged and have to be changed (Ulrich, 1989, p. 113-151).

While dialysis is often not painful, except for the insertion of needles into the fistula, discomfort may occur during the process. Cramping and changes in blood pressure may result, as well as less painful or serious sensations. Cramping is most common among those patients who do not maintain their restrictions on fluid intake.

Hemodialysis patients must follow a strict diet and should gain no more than one kilogram per day (the result of drinking one liter of liquid). Although a few patients have dialyzers installed in their own homes, most go to a clinic for dialysis. Other patients may obtain dialysis by using the lining of the abdomen as the filter. This process, called peritoneal dialysis, is managed by the patient and his/her family at home.

Hemodialysis is not a perfect substitute for healthy kidneys. In addition to the inconvenience and discomfort of dialysis, the mortality rate of such patients is significantly higher than their age cohorts. A study by the Canadian Institute for Heath Information indicates that non-diabetic Caucasian patients, aged 18 to 44, from 1989- 1998, in Ontario, had a survival rate, in the ninth year on dialysis, of 79.8 per cent (CIHI, 2000a, p. 12-13).

APPENDIX II: QUESTIONNAIRE

First Interview:

I shall begin the interview by introducing myself and by explaining what I am doing and the purpose of the study in the following way.

I am studying a group of people, like you, all of whom have recently undergone renal failure, a major life-changing health event. My aim is to learn what differences this event has made in your lives. Let me describe for you the process for this study.

The first interview will be fairly lengthy in order that I may get to know you and something of your life and how you see the changes in it. I will do this interview, and the subsequent interviews, in parts, if this is easier for you.

In six weeks I will meet you again to learn if and how things have changed for you since the first interview.

Two months later, that is approximately three and a half months from now, I will meet you again to learn how you are finding this new phase in your life that began with your health crisis.

You will choose a comfortable place to conduct the interviews. Possible sites include a conference room at the hospital, a room at St. Paul University, or your home as you choose.

Here is a letter that outlines the project and two copies of a consent form. (See Appendix II.) Please note that I will make audiotapes of our interviews and they will be transcribed. All tape recordings and transcriptions will be kept in a locked cabinet at St. Paul University. The information that is provided will be kept confidential; only four people will have access to this information. These people are my assistant and I, and the two co- investigators, Prof. Pierrette Daviau, who is my university supervisor, and Marguerite Mondor, the Director of Pastoral Care Services for the Ottawa Hospital.

Quotations from your interviews will be used in my final report, but your name and other identifying information will be omitted.

If at any time you wish to withdraw, you may do so and I will erase any tapes of our interview(s) and shred any transcriptions already prepared. If you

encounter any distress in the process of this time of change, I will assist you to find appropriate counseling through the Pastoral Care Services of the Civic Campus of the Ottawa Hospital.

Your co-operation will assist me to produce a piece of research that might allow Health Care providers to learn something of what it is like to go through a life-changing health-event. Such understanding might enable them to better support others going through such crises.

I will take biographical information in writing, partly to assist the participant to relax. Then I will turn on the tape recorder and begin the tape by recording time, place and an identifying letter corresponding to the letter on the sheet of biographical information.

Then I will ask the following question: "Tell me about yourself and what has been going on in your life." Subsequent questions will be designed to grow out of the participant's talk. If he/she has difficulty with such a general question, I will use the following questions to assist me.

1. What has happened to you?

Back up questions:

What did you first notice about the onset of your illness?

What brought you to your doctor?

How would you describe your experiences as you went through testing, diagnosis and the beginning of treatment?

How were you feeling through this time?

2. Tell me about your life before your illness.

Back up questions:

What was your primary occupation?

Tell me about your family and friends and your relationships with them.

What kinds of activities were you involved in: hobbies, sports, social activities, cultural activities, volunteer work, clubs, church, etc.?

How would you have described your life as it was then: busy, happy, full, relaxed, etc.?

Tell me about your religious beliefs or philosophy of life.

What were your hopes for the future?

3. What were the most important things in your life in the time before your illness?

Back up questions:
What gave your life meaning?
Was your work or other activities really important to you?
Did your life focus on your family and friends?
Was your religion important in your life? How?
How would you have described yourself?
How do you think would others have described you?

4. In what ways has your illness changed your life?

Back up questions:
How has it changed your life physically?
How has it changed your life socially,---emotionally, ---spiritually?

5. Do you think you are any different as a person since the onset of your illness?

Back up questions:
Have your moods changed?
Do you have any regrets about your life before?
Has your outlook for the future changed? If so, how?
Do you regard the same things as important now as compared to before your illness?
If your illness prevents you from carrying on life as you used to, have you any ideas of what you may do with your time now?

6. What or who has been of most help to you? How?

Back up questions:
What part has each of the following people played helping or hindering you in facing the challenges of this time: family, friends, doctor, social worker, minister, others who have faced the same problems, church, etc.?
What role have your religious or philosophical beliefs played at this time?
What advice would you give someone else facing this difficulty? What advice would you give to someone wishing to be supportive of a person facing this difficulty?

7. Is there anything else you would like to mention?

Second Interview:

I will begin by summarizing what we talked about at the first interview. I will ask the participant for any further thoughts about the first interview.

Then I will ask about changes since we last spoke. The following questions may be used as a guide to prompt a participant.

1. How do you now feel about your health and illness?
2. What is your everyday life like (activities, job, entertainment, pace, etc.)?
3. Describe your relationships with your family and friends. How do they compare with these the last time I saw you? to the time before your illness? Tell me about any new relationships that may have developed.
4. What are the most important things in your life now? How are they different from before?
5. What new understandings or beliefs have you developed?
6. How has your attitude to life and to your illness changed, if at all?
7. How would you describe yourself now? How do you think others would describe you? Is this different from before your illness?
8. What advice would you give someone else facing this difficulty? What advice would you give to someone wishing to be supportive of a person facing this difficulty?
9. Is there anything else you wish to mention?

Third interview:

This will be like the second.

APPENDIX III: PERMISSION FORM AND LETTER

Pastoral Care,
Civic Campus,
And
St. Paul University
Faculty of Human Sciences

PROJECT TIILE: "The Effects of a Major Health Crisis on Meaning-Making in People's Lives"
SUPERVISORS: Prof. Pierrette Daviau, St. Paul University (613) 236-1393
and Marguerite Mondor, Director of Pastoral Care (613) 761-4587
INVESTIGATOR: Helen G. Smith, candidate for Master of Arts (Pastoral Studies-Health Care) and Chaplain Intern, Hemodialysis Unit, Civic Campus, Ottawa Hospital (613) 761-4587

The purpose of this study is to learn how a group of people, all of whom have recently undergone renal failure, are experiencing this major health crisis. The aim of this study is to learn what differences this event has made in their lives so that Health Care providers may more fully empathize with those undergoing such experiences. A fuller understanding of the changes in meaning-making that patients go through during a major health crisis should enable us, as Health Care providers, to enhance our support of patients in their journey to healthy psycho-spiritual adaptation to their new life circumstances.

If you agree to participate in this study you will be interviewed three times. The purpose of these interviews with you is to get to know you and how you see the changes in your life. The total duration of the first interview may be up to three hours. However this interview may be spread out over two or three sessions to make it easier for you. The second interview, in six weeks, is designed to reveal what changes have taken place since the first interview. The final interview, two months later, (that is about three and a half months from now) is designed to learn how you are finding this new phase of your life since your health crisis. The second and third interviews may take up to three hours each. Like the first interview, the second and third interviews may be spread over two or three sessions.

These interviews may take place in a conference room at the hospital or at St. Paul University or in your own home, at your choice.

These interviews will be audiotaped and transcribed. Your name will not appear on the tape or the transcription. Your name and address will be recorded on separate paper and stored at the hospital, in accordance with the policy of the Research Ethics Board of the Ottawa Hospital that requires that no records with patients' names may leave the hospital. (The purpose of this policy is to protect the privacy of participants.) Any information provided will be kept confidential; only the investigator, her supervisors, and her assistant will have access to it. The tapes will be erased upon completion of the transcriptions. The transcription will be retained in a locked cabinet at St. Paul University for five years, at which time the investigator will supervise their destruction.

Quotations from your interview will be used in the final report, but your name and other identifying information will be eliminated.

If at any point you wish to withdraw from the study, you may do so and your care will not be affected in any way. Moreover the investigator will erase any tapes of your interview(s). If you experience any distress in the process of this change, the investigator will assist you to find appropriate counseling.

Your co-operation will assist this investigator in producing a piece of research that will allow Health Care providers to learn something of what it is like to go through a life-changing health-event. Such understanding will enable them to better support other persons going through such crises.

This study has been approved by the Ottawa Research Ethics Board. The chairperson of this committee may be contacted at 761-4902 if you have any ethical concerns about this study.

THIS IS TO CERTIFY THAT I _____ HEREBY AGREE TO PARTICIPATE IN THE PROJECT: "The Effects of a Major Health Crisis on Meaning-Making in People's Lives"

I have read the attached patient information sheet.

I have been given the opportunity to ask any questions I desire and my questions have been answered to my satisfaction. I have received a copy should I want to review the information at a later date or if I need to contact someone about the study.

I understand that my participation is purely voluntary and that I may withdraw at any point. I hereby grant permission to be interviewed, to have these interviews audiotaped and transcribed. I understand that every effort will be made to keep my participation and any information I supply confidential. Information and quotations from my interviews will be used in the final report; however my name and identifying information will be omitted.

When the audiotapes have been transcribed they will be erased. The transcriptions will be retained for five years and then shredded.

I understand I am free to refuse to answer any questions and I may withdraw my participation at any time.

Participant's signature_____

Researcher's signature_____ **Date**_____

Pastoral Care
Civic Campus
And
Faculty of Human Sciences of
St. Paul University

Hemodialysis Unit
Civic Campus
Ottawa Hospital

Dear

I am glad to have returned to the Hemodialysis Unit to work with you to enhance the lives of our patients. I am a student in the Masters of Arts in Pastoral Care (Health Care) program at St. Paul University. To meet the requirements for this degree I will be doing a research project entitled "The Effect of a Major Health Problem on Meaning-Making in People's Lives."

The purpose of this study is to learn how a group of people, all of whom have recently undergone renal failure, are experiencing this major health crisis. Its aim is to learn what differences this event has made in their lives so that Health Care providers may more fully empathize with those undergoing such experiences. A fuller understanding of the changes in meaning-making that patients go through during a major health crisis should enable health care providers to better support patients in their journey to healthy psycho-spiritual adaptation to their new life circumstances.

The particpants will be selected from patients who are just coming onto the service. Suitable participants will be persons from 18-65 years who, with little or no advanced warning, have gone into renal failure and require dialysis.

I will ask participants to tell me what it is like for them to suddenly find they have a major life-changing health problem. I will ask them what changes this has made in their lives socially, psychologically and spiritually. Each patient will be interviewed three times: first a month or six weeks after the diagnosis, second approximately six weeks later and third about two months later still. Interviews will vary in length but they may last up to three hours. Long interviews may be divided into several parts depending on the needs of the participant.

Since I will be focusing on the experiences of individuals in a life-history type of approach, I will only be interviewing six people. Patients will all freely consent to their participation and may withdraw at any point. The regular hospital chaplains will provide pastoral care for these individuals.

Your part in this project will involve several steps:
1.to recommend possible participants to me;
2. to speak to potential participants about the study and ask if they are interested in participating; and
3. to introduce me to potential particpants who have agreed to meet me.

I am looking for persons who have recently undergone renal failure and who are just starting dialysis. Possible participants will be persons from 18-65 years who, with little or no

advanced warning, have gone into renal failure. Persons who have previously undergone another major debilitating or life-changing health crisis such as diabetes, amputation, and major heart attack, will be excluded.

If you have any further questions I would be pleased to answer them. Please feel free to leave me a note with the ward clerk letting me know about any questions and/or concerns you may have. Or if you prefer you may leave a message for me at the Pastoral Care office, 761-4587.

Yours truly,

Helen G. Smith
Chaplain Intern

P.S. This project has received approval from the Research Ethics Board of the Ottawa Hospital.