RENAI2 FAILURE: A SOCIOCULTURAL INVESTIGATION OF AN ILLNESS

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ABSTRACT

People living with renal failure experience enormous challenges, yet very little is known about life with this disease. The goal of this research was to gain an integrated understanding of the lives of people with renal failure. An understanding of life with renal failure that includes cultural, institutional and historical contexts may provide health care practitioners with the kind of information and insights necessary to improve medical practice. Thus far, medical practice has been based on a biomedical model of care that focuses almost exclusively on the physical aspects of illness. From this perspective, people with kidney disease are seen as autonomous and rational individuals. In this research, a sociocultural multiple case study approach was utilized in order to gain a situated understanding of life for four people with renal disease.

This research revealed that life with renal failure is work. While it is the people living with renal failure who do the bulk of the work, friends and family also work to “live” with renal disease. Participants and their significant others learn about and become experts on life with this disease. A gap was found between practitioners’ understanding of disease and participants’ lived experience — resulting in many negative repercussions. Medical-based knowledge is lacking because it does not consider the three relevant sources of knowledge: practitioners, participants and participants’ significant others. This research argues for a bridge between the home world and the hospital world, so that a broader community of practice is created. An account of the lived experience of people with renal failure that includes these factors can inform “best practice” because it provides a richer and more authentic picture of life with this illness. It is from this perspective that health care practitioners can begin to broaden their understanding of renal failure as it is “lived”, and, so informed, can better provide the kinds of education and support that will enhance the lives of people with this illness.
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CHAPTER ONE

Introduction

The driving force behind this dissertation was a desire to provide support in a hospital context for people who have to include in their life the chronic illness of renal failure. The goal of the study was to understand the life experiences of people living with kidney failure from a social cultural perspective as opposed to the more common empirical cognitive perspective. Research from the cognitive perspective provides information on the kind of model that dominates in medical settings and, thus, is important to our understanding of the worlds of people living with this disease. However, this research is often based on faulty assumptions, gives little power to people living with renal failure and is performed in a fragmented manner, which allows only small glimpses into the lives of these people. A contextually valid understanding of people’s lives is important because individuals cannot be separated from the context in which they live. A sociocultural approach using qualitative methodologies provides the tools necessary to gain a real understanding of what it means for people to live with kidney disease and can provide guidance to health care practitioners on how best to support this population.

The process of providing support for people living with renal failure in the context of the hospital has often taken the form of educational programming. Most recent work concerned with the care of people in the hospital setting has emphasized the concept of self-management education. In a medical context, self-management education means teaching people living with illness to perform self-care, manage crises and make the lifestyle changes required to successfully adjust to their disease (Clement, 1995). Increasing people’s self-management is touted as important because it has been found to lead to improvements in both physical and psychological health, as well as increased overall life satisfaction (Clark & Zimmerman, 1990).
Further, successful self-management education has been linked to lower hospitalization rates and reduced health care costs (Clement, 1995).

Given the number of challenges that kidney disease imposes on people's lives, finding strategies for improving self-management for people living with renal failure is considered particularly critical. From this perspective, people living with renal failure must learn to manage numerous disruptions in biological, psychological and social domains (Lindsay, Burton, & Kline, 1985). Further, researchers have found that people living with renal disease often experience cognitive difficulties (Kenny, 1983; Ziesat, Logue, & McCarty, 1980). These cognitive difficulties are thought to influence people's responses to educational programming and, thus, affect the acquisition of self-management skills. The need for newer and better educational methods to improve self-management skills can be seen as one possible way to improve medical outcomes for people living with this disease. It will be argued, however, that it may be more important to understand the way in which people experience their illness, than to impose yet another curriculum derived from research on medical and educational theories.

Renal failure, along with other chronic illnesses, has altered the face of medicine over the last 100 years by changing the focus from life-threatening (acute) to chronic illnesses (Bartlett, 1983; Coates & Boore, 1995). Most of the responsibility for the care of acute illnesses lies with health care practitioners. The same may not be said for chronic illnesses, where people are often responsible for much of their own care. The recognition of the need for people living with renal failure to manage their disease on a day-to-day basis has given rise to educational programs that focus on controlling chronic health conditions (DiLorio, Hennessy, & Manteuffel, 1996; Funnell & Haas, 1995). The most effective and efficient means of improving health was seen as behavioral control (Bartlett, 1983) and, thus, educational programs focused on teaching people to control their behavior. This behavior control approach is based in, and changes with, popular
psychological theories. Current psychological theories have moved away from a behaviourist focus and now emphasize cognition. Similarly, education of people with chronic illnesses has changed from a focus on self-control and compliance to the more cognitive focus of self-management, which includes theories of self-regulation and Bandura's theory of self-efficacy (Thoresen & Kirmil-Gray, 1983). This interest in self-management is an attempt to improve on the traditional view, which perceives people with illnesses as passive and submissive recipients of care (Coates & Boore, 1995; Strowig, 1982). There has been an overall societal push for people living with illness to become more involved in their care and take responsibility for their health (Coates & Boore, 1995). Thus, the focus on improving self-management skills in the medical context stems from the goal of increasing the agency of people living with chronic illnesses (Bartlett, 1983) and from the concern that other types of educational programming were not working to improve people's health (Clark, 1989).

A retrospective review of research on educational programming for people living with illness has revealed that a large majority of educational programs do garner benefits (McCain & Lynn, 1990; Tabac, Mullen, Simons-Morton, Green, Mains, Eilat-Greenberg, Frankowshi, & Glenday, 1991; Wilson-Barnett & Osborne, 1983). These benefits include: improved disease-related knowledge (Kozak & Yura, 1989; Ozbolt-Goodwin, 1979; Pommier, 1992), improved compliance (Hecht, 1974; Reibel, 1969; Tirrell & Hart, 1980), reduced stress and improved recovery time after surgery (Fortin & Kirovac, 1976; Klos, Cummings, Joyce, Graichen, & Quigley, 1980; Linderman & Van Aernam, 1971; Midgley & Osterhage, 1973), and improved self-care (Bowen, Rich, & Schlotfeldt, 1961; Levine & Britten, 1973; Richmond & Peacock, 1989). The goals of these educational programs are improvements in knowledge and stem from a medical model of health-care. It is assumed that knowledge improvements will affect people's behaviors (resulting in improved compliance, self-care, etc.) which, in turn, will improve
people’s health outcomes. This, however, has often not been found to be the case; changes in health behaviors do not necessarily improve health outcomes — especially long-term health outcomes (Lorig & Holman, 1993).

Research conducted to date has focused on teaching people with chronic illness to recognize and manage physical symptoms and medical regimes and, as such, is based on a medical model of illness and focuses on the causes and the symptoms of a disease. Self-management programs attempt to go beyond the medical model to include other aspects of people’s lives such as social and psychological well-being. To this end, the model of self-management includes a number of personal and environmental factors that can have an influence on the well-being of people living with illness. These influences include: personal characteristics such as age and education level (Brown, 1992; Clark & Zimmerman, 1990; Pommier, 1992), people’s beliefs (Bandura, 1982; Rosenstock, 1974), social supports/stresses (Bandura, 1993; Burton, Lindsay, Kline, & Heidenheim, 1989; Korniewicz & O’Brien, 1994), and various outside influences (Coates & Boore, 1995; Tirrell & Hart, 1980).

Despite these clearly important additions and improvements to self-management educational programs, little has changed in terms of the type of curriculum that is created for people living with illness. Self-management educational programs would more aptly be called self-management training programs. In these programs, the goals are specified in advance and the people for whom these programs are made have no say in setting the goals or determining content. Thus, the people living with chronic illness who take these types of training programs have little power (even though empowerment is one of self-management’s original goals); people living with illness are seen as needing knowledge and the educational programmers decide what types of knowledge are needed. Further, self-management educational programs assume that the model of human competence that dominates the context of the hospital is universal. That is,
people living with chronic illness are viewed as autonomous rational beings who will act in predictable ways. Thus, it is assumed that if these people are given the proper information, they will use this information to improve their health. This view at best denies that other worldviews do exist, and at worst attempts to coerce people into accepting this worldview. Other, equally valid worldviews such as the feminist social-based model (Smith, 1987) or a First Nations' model that focuses on group, balance and harmony cannot be integrated into this cognitive model. While the self-management model seems to be cognitively based, the stress on medical outcomes results in a type of cognitive behaviourism, whereby the beliefs of people living with illness are shaped until they accord with those of the model's. In this way, self-management focuses on training people living with illness to subscribe to the worldview that holds that physical health is the ultimate goal no matter what the cost to their lives.

Self-management is currently the most commonly used model for developing an educational curriculum for people living with renal failure, and, therefore, it is important to understand and delineate the properties of this model. However, this model is based on constructs that are culturally specific, and does not allow for democratic involvement of people living with this disease. The model of self-management needs to be challenged and transformed by the experiences of people living with renal failure. What is important in and for the lives of people living with chronic renal failure must be determined not by health care practitioners or researchers but by the people living with this illness. The needs of people with renal failure should determine the curriculum of an educational program meant to serve them. In this way, people living with renal failure can be the agents who determine the hallmarks of success and how best to achieve that success. A sociocultural look at the lives of people with renal failure will provide a window on how health care practitioners can provide the kind of educational programming and support that people with this disease desire.
In the sections that follow in this chapter, I begin by describing the typical symptoms and difficulties that are associated with renal failure. Based on the research literature, I will then describe the self-management model, including its components and success indicators for people with renal failure. This model, while useful in understanding the medical perspective of chronic renal failure and medical outcomes, does not adequately address the context in which people with this disease live. In the final section, I describe how a qualitative study based on a sociocultural model has the potential to bring new understanding to what life is like for people with renal failure and how this understanding can assist health care practitioners in the provision of necessary support for this population.

Living with Renal Failure

Research has revealed that numerous difficulties are associated with kidney disease (Burton et al., 1989; Corkadel & McGlashan, 1983; Charmaz, 1983; Fife, 1994; Fraser & Arief, 1985; Lindsay et al., 1985; Speers, 1989). Some of these are certainly physical, but others can have an effect on all aspects of people’s lives. Chronic renal failure is a disease which is associated with multiple stresses and a myriad of losses (Lindsay et al., 1985). In this section, the ranges of difficulties that have been associated with kidney disease are described. These difficulties demonstrate the kinds of life-changes that people living with kidney failure may experience.

Physical Requirements

People living with kidney disease are often confronted with physical difficulties associated with their disease. In this section, I provide a brief overview of how kidneys function, problems of unhealthy kidneys, and salient characteristics of common interventions. I then summarize some of the more typical physical problems resulting from kidney disease.
Normally functioning kidneys have many vital tasks. Within our bodies, kidneys regulate sodium and water, remove wastes, and produce hormones (Kidney Foundation of Canada, 1990). If the kidneys are not operating properly, a number of problems may occur. Very often there is an elevation in wastes in the blood such as urea (protein wastes from foods such as meat), creatinine (waste products from muscles), and potassium. In addition, problems in kidney function lead to changes in hormone levels that control blood pressure, the making of red blood cells, and the uptake of calcium. Finally, when the kidneys fail, the body often must contend with a large fluid overload. Thus, from a physiological/medical perspective, the goal of interventions has often been directed at helping people with renal failure learn to manage their health so that there will be a reduction in excess fluid and wastes, and so that hormones will be controlled. The most common form of intervention requires that people living with renal failure monitor their diet and fluid intake and give up a number of hours per week for dialysis treatment. Dialysis treatments begin when the kidneys are functioning at less than 10% of their normal rate and are thus, no longer able to clean the blood adequately (Kidney Foundation of Canada, 1990).

Dialysis therapies necessitate that people living with renal failure limit their intake of sodium, potassium, protein, and fluids. Treatment protocols often lead to a loss of freedom as restrictions are placed on this population’s movement, diet and independence (Baldree, Murphy, & Powers, 1982). People living with renal failure may experience a loss of overall physical well-being because of their chronic condition, and pain and discomfort may become a part of everyday life (Speers, 1989). Very common somatic complaints include pain, itchiness, burning sensations, tingling, fatigue, weakness and headaches (Burton et al., 1989; Corkadel & McGlashan, 1983; Wolcott, Marsh, La Rue, Carr, & Nissenson, 1989). The medical model requires that people living with renal failure learn about their kidneys and their dietary
requirements. Further, this model requires that people living with renal failure manage their pain and discomfort, deal with the loss of control over their lives, as well as manage the time allocated to dialysis therapy. This focus on the medical model, however, does not assess the importance of these physical symptoms or the kinds of impacts that they will have on people’s lives, nor does it give people living with illness the option to subscribe to other models. The effects of culture, environment and other factors important in people’s lives are not considered. It is assumed that all people living with chronic illness want to improve their health and will act in a rational manner to attain this goal.

Cognitive Functioning

Kidney failure is different from most other illnesses because it not only affects a person’s physiological well-being, but it also affects cognitive abilities. It has long been recognized that people with chronic renal failure have significantly impaired cognitive functions prior to treatment (English, Savage, & Britton, 1978; Fraser & Arieff, 1985; Kenny, 1983; McDaniel, 1971; Osberg, Meares, & McKee, 1982; Shea, Bogdan, Freeman, & Schreiner, 1965). These cognitive difficulties are thought to result from the high levels of toxins in the blood that enter into the brain and impair functioning. This body of research reveals that the cognitive difficulties are at least partially reversible with treatment through dialysis or transplantation.

Cognitive areas that are found to be impaired in people living with kidney failure include sustained attention, selective attention, speed of decision-making, short-term memory, and mental manipulation of symbols (Fraser & Arieff, 1985; Kenny, 1983). When a health care practitioner diagnoses kidney failure, people must begin dealing with the knowledge that they have a chronic disease and with all the lifestyle changes that this disease may cause. Hospital educational programs emphasize that people diagnosed with renal failure must face the difficult task of learning about different forms of dialysis treatment. Also, people diagnosed with this
illness may be asked to choose the type of dialysis they will utilize and may be required to learn how to run their dialysis machine. In educational programs, people must also learn how to alter their diet and fluid levels to maintain optimal physical health. Thus, the cognitive difficulties that people living with renal failure often experience occur at a time when they are faced with having to learn and make many life-altering decisions.

Researchers have found that once a person has commenced dialysis therapy (or has undergone transplantation) cognition does improve (Fraser & Arieff, 1985). However, it has been shown that there is a decline in cognitive functioning during a dialysis run (Churchill, Wallace, Ludwin, Beecroft, & Taylor, 1991; Massry & Sellers, 1976; Smith & Winslow, 1990). Unfortunately, dialysis is the most convenient and often the most common time for hospital-based education to take place. Although the cognitive functioning of people living with kidney failure generally improves following dialysis treatment, Ziesat et al. (1980) found that if individuals require dialysis over a long period of time the chances of developing dialysis dementia increase. Symptoms of dialysis dementia include memory disturbance, dyspraxia, paranoid ideation, speech disturbances, facial grimacing and seizures (Ziesat et al., 1980). Although much of the research focus has been on the influence of cognitive difficulties on people’s abilities to acquire knowledge about kidney disease, little attention has been paid to the effect of cognitive difficulties on other areas of people’s lives. The full extent to which cognitive difficulties interfere (or do not interfere) with the lives of people living with renal disease is not yet known.

Psychological Health

People living with renal failure may experience a large number of threats to their psychological health. Burke (1979) demonstrated that people living with renal failure scored lower on a test of psychological adjustment, the MMPI (Minnesota Multiphasic Personality
Inventory), than did other illness cohort groups. More generally, Charmaz (1983) found that many chronic illnesses have a deleterious effect on self-concept because old self-images fall away and are not replaced with equally valued ones. This “loss of self” may occur for people on dialysis because of the intrusiveness of their disease and their dependence on a machine to sustain life. People living with renal failure are often no longer able to continue with valued activities (or must do so at a severely diminished rate) and, thus, feel a loss of control over their own lives (Charmaz, 1983; Fife, 1994). When people living with renal failure are no longer able to function as usual in their everyday lives, the consequences may be far-reaching. For example, once on dialysis, people with this disease may no longer be able to work, which may result in financial strain, marital problems, social isolation and societal stigma (Charmaz, 1983). Many researchers have shown that depression, anxiety, social isolation, self depreciation, denial and a high suicide rate are all associated with renal disease (Burke, 1979; Burton, Kline, Lindsay, & Heidenheim, 1986; Kutner, 1987).

Depression was thought to be one of the most common and limiting consequences of chronic renal failure (Burton et al., 1989). The depression often associated with renal disease can be due to any number of disease-related stresses in a person’s life. Reichsman and Levy (1972) conjectured that the depression associated with renal failure may be related to the guilt people living with this disease feel when they create stress for others or fail to comply with medical routines, when they experience embarrassment over their appearance, and/or when they are forced to make general lifestyle changes. Wai, Richmond, Burton, and Lindsay (1981) found that level of depression is negatively related to the survival of people with kidney disease. However, because they also found a relationship between age and survival, there may be an important correlation between age and depression. Thus, although depression is commonly
associated with renal disease, the importance of this variable to people living with this disease has yet to be determined.

Anxiety and stress are also common problems for people with renal failure (Greene, Beaudin, & Bryan, 1991). People living with renal failure who experience difficulties due to physical or psychological problems may have increased stress (Burton et al., 1989). Lindsay et al. (1985) organized the stresses associated with chronic renal failure into three main categories: 1) stresses related to having a chronic condition, 2) treatment stresses and 3) psychosocial stresses. Chronic condition stresses arise from persistent poor health and fear of dying.

Treatment stresses arise from medical regimes that are stressful due to a loss of freedom in terms of movement, diet and autonomy (Baldree et al., 1982). As well, treatment is most often provided in a hospital and the hospital itself may be a source of stress and anxiety (Corkadel & McGlashan, 1983). Finally, psychosocial stresses arise when people living with renal failure experience financial worries, a lack of support, self-depreciation, hypochondriasis, denial and/or suicide ideation (Burke, 1979; Burton et al., 1989). The degree of influence that psychological stresses place on the lives of people living with renal failure as a whole and the importance of the different stressors on their lives have not yet been delineated.

**Social Stresses**

People with kidney disease must often face a variety of social challenges that coincide with their disease. It is not uncommon for people with renal failure to become socially introverted (Kline, Burton, & Akhtar, 1986). One of the reasons postulated for this social introversion is the limitations that dialysis therapies place on people’s social and leisure activities (Burton et al., 1989). The number of hours per week required for dialysis and the strict diet that people living with this illness are told to follow may curtail many social activities. The result is that people living with renal failure may become passive and withdrawn, and feel isolated, lonely and
ashamed (Kline et al., 1986). Charmaz (1983) focused on social isolation rather than introversion and held that isolation is the result of living a restricted life. For example, when people with renal failure are no longer able to work, much of their social world is no longer a part of their lives and, thus, they become socially isolated. Further, the considerable amount of time taken up by dialysis treatment can also be isolating. This isolation can result in a loss of self and can be seen in the symptoms of “social introversion” found by other researchers. People with kidney failure may also experience sexual functioning reduction, poor body image and a decrease in leisure activities (Burke, 1979; Burton et al., 1989; Fife, 1994; Speers, 1989). Research on kidney disease reveals that people living with this disease may experience alienation from friends, deteriorating familial relationships and loss of their usual role in these relationships (Burke, 1979; Burton et al., 1989; Speers, 1989). A high marriage breakdown rate is reported among people with chronic renal failure (Devins, Edworthy, Seland, Klein, Paul, & Mandin, 1993).

These social stressors are seen as important because they may have a negative impact on the health of people living with renal failure. A longitudinal study by Berkman and Syme (1979) found that health and mortality rates are significantly related to people's social and community relations. For example, for every age and gender grouping, people who were not married had higher mortality rates than those who were married. High mortality rates were also reported for those who reported having few friends and relatives (or who seldom saw them), as compared to those who reported having many friends and relatives (and saw them often). Finally, when comparing different types of social ties (i.e., marriage, friends and relatives, church membership, group associations), Berkman and Syme (1979) found that people with low social tie ratings have higher mortality rates than those with high ratings. Thus, we can see that this very large study (n=6928) revealed many important connections between social networks and mortality. It
is important to note, however, that despite the strength of the large sample, the data gathered were correlational and, thus, the connection between social networks and mortality may be due to other influences. Further, because the study participants were taken from the general population, it is unclear whether the correlations hold true for people living with renal failure. The relationship between the social stresses experienced by people with kidney disease and the effect of these stresses on the everyday lives of these people have not yet been investigated. Further, we do not know the importance of these social stresses, nor do we know if there are other social stresses experienced by people living with renal disease that have not yet been elucidated by research.

Summary

Research on the effects of kidney disease reveals that people with this disease often have to deal with difficulties in a number of areas. Typically, these individuals experience physical symptoms and cognitive impairments, as well as social and psychological stresses. Much of this research has been carried out from the perspectives of the health care practitioners and the focus is on how these areas will affect people’s abilities to manage their disease. Researchers have not yet illuminated how the many stresses that coincide with renal disease affect the lives of those living with it, nor have they shown the relative importance of the different stressors in people’s lives. Further, the list of stressors may not be exhaustive. That is, people living with renal disease may be experiencing stresses in their lives that have not yet been elucidated by the research.

A Cognitive Factorial Model of Kidney Disease: Self-Management

Most research on kidney disease focuses on a model of “wellness” in health care. The wellness model includes educational programming designed to help people living with disease improve their physical well-being. The program currently in use in many hospital settings is one
based on "self-management" (Coates & Boore, 1995). It is important to understand the focus and components of the self-management model because people living with illness are most often exposed to this type of training program and model of health in hospital settings. This section reviews the research on self-management for people living with renal failure.

Self-management models stipulate that people living with illness be actively involved in learning about their disease, coordinating their own health care and managing their daily lives. Active learning is a key component in models of self-regulation (Zimmerman, 1986) and, thus, self-regulation is used to explain how self-management takes place. The emphasis on "self-regulation" includes the understanding that learners set "challenging goals", use "appropriate strategies" and continually "monitor the learning process" (Pintrich, 1995; Zimmerman, 1990). When specifically applied to the health care setting, self-regulation models necessitate the use of self-care strategies for learning about and identifying threats to health. Goals must be set to maintain or promote health, behaviours must be carried out (in an attempt to achieve these goals) and the process must be monitored to evaluate the success of the strategies, behaviours and goals (Clark & Zimmerman, 1990).

"Self-regulated learners" as portrayed by cognitive theorists, are not only actively involved in the process of self-regulation, but purposefully utilize strategies to achieve their goals (Clark & Zimmerman, 1990). An important component of strategy use in this model is a learner's "self-efficacy beliefs", which are thought to affect motivation (Zimmerman, Bandura, & Martinez-Pons, 1992). The kinds of goals, strategies and beliefs concerning personal ability that people living with illness employ in their educational programs will have an important effect on their resulting "self-management skills." In their triadic model of self-regulation, Clark and Zimmerman (1990) argued that people living with illness "manage" their health by utilizing self-care strategies, establishing sensible health goals and monitoring success in achievement of these
goals. Thus, these researchers concluded that self-regulation is an essential component of health functioning.

As can be seen from above, the model of self-management is based primarily on cognitive theory. The focus is on developing educational programming that will positively influence self-management skills. It has been recognized that many factors have an effect on the self-management skills of people living with illness and, thus, a factorial model has developed. Understanding self-management for people with kidney failure requires not only a look at how self-management takes place (self-regulation), but also must include the influences on self-management, as well as the indicators of successful self-management. Research in the areas of educational psychology, hospital education and kidney disease provides information on each of these topics. The influences on self-management can be divided into two areas — personal and environmental.

Personal Influences

From the perspective of the self-management researchers, personal influences are characteristics specific to the learner and can have both direct and indirect effects on self-management skills. Some of the personal influences on self-management are characteristics such as age, education level and knowledge about the disease. Other personal influences are people’s beliefs about their personal efficacy and health (Bandura, 1982; Rosenstock, 1974). It is also important to note that the disease-related difficulties (cognitive functioning, psychological health and physical health) that are manifested by people living with illness are considered part of personal characteristics.

Characteristics of people living with illness.

In the model of self-management, a number of characteristics can have an effect on people’s health outcomes. The first two of these influences on self-management education are
age and educational background. Age has been shown to have an influence on pre-test scores (Pommier, 1992) and on people’s abilities to benefit from educational programs (Brown, 1992). Educational levels have also been shown to be related to pre-test scores (Pommier, 1992). However, because these studies were done with other illness populations, it is not clear if the results are applicable to people living with renal failure. Given that people with renal failure often have cognitive difficulties prior to treatment (Kenny, 1983; Ziesat et al., 1980), it may be that these cognitive difficulties interfere with the relationship between educational level and educational outcomes.

Other important personal characteristics in this model are the symptoms and stresses that people may experience as a result of their kidney disease. Physical symptoms are important because they present challenges to self-management abilities. Research has shown that people in very poor health, such as those whose symptoms are severe or who have other complicating diseases, may have a more difficult time managing their own health. For example, Lachman and Leff (1989) found that impaired health is associated with a decline in self-efficacy beliefs and intellectual functioning (however, other variables, such as depression, could be applied to explain this relationship). The type of physical symptoms that people experience may also affect their self-management skills. Similarly, stresses in cognitive and psychological functioning that are associated with renal disease are important in a model of self-management because they may interfere with hospital educational programming and with people’s abilities to follow medical regimens.

Disease-related knowledge.

Another important personal influence in the model of self-management is disease-related knowledge. In his analysis of self-regulated learning, Zimmerman (1989) contended that prior knowledge has a strong influence on self-regulatory skills. Further, Clark and Zimmerman
(1990) argued that both the amount and type of prior knowledge affects self-regulatory skills in health care domains. Clark and Zimmerman suggested that two types of knowledge are important: knowledge about a disease and knowledge about self-regulation. First, people living with illness require knowledge about their disease in order to identify problems, set appropriate goals, carry out behaviors and monitor their progress. Second, people living with illness must have knowledge about health strategies that will promote/maintain health, as well as knowledge of appropriate outcomes so that they can monitor their progress. For example, from this perspective, people living with renal failure must not only have knowledge about the relationship between diet and their disease, but must also have knowledge of strategies that will help them follow and monitor their diet. The above research suggests that people's disease-related knowledge can have an influence on self-management.

The beliefs of people with illness.

There are two types of beliefs included as personal influences in the model of self-management: efficacy and health-related beliefs. In his theory of self-efficacy, Bandura (1993) proposed that personal accomplishments are influenced by personal beliefs about abilities to perform and carry out skills, and by beliefs about the outcomes expected from particular behaviours. According to Bandura (1993; 1989; 1977), this is because self-efficacy beliefs and outcome expectancies influence the types of goals people set for themselves, whether they will engage in a particular behaviour, how long the individuals will persevere at a behaviour in the face of obstacles, and their chances of success.

In the self-management model self-efficacy beliefs may have an influence over people's abilities to carry out health-promoting behaviors. Further, the type of outcomes that a person expects from a particular behaviour is also important in Bandura's (1977) theory of self-efficacy. Outcome expectancies are the personal beliefs someone holds regarding the result that is likely to
occur from a particular behavior (Bandura, 1982). Researchers have linked self-efficacy and various health-related outcomes. Increases in “self-efficacy” have resulted in improved ability to take medication as prescribed (Dilorio et al., 1996), improved self-care skills (Hampson, Glasgow, & Foster, 1995), improved health status (Lachman & Leff, 1989; Lorig & Holman, 1993), and reduction in levels of anxiety (Dilorio et al., 1996). It may not be sufficient to teach people living with illness the necessary knowledge and skills to perform self-care. In self-management education, attention must also be paid to people’s beliefs in their own skills and the perceived results of performing these skills.

People’s health-related beliefs are also important in self-management education. In his Health Belief Model, Rosenstock (1974) explored personal beliefs and outcome expectancies within the medical domain, highlighting the importance of the beliefs tied to a person’s disease and/or symptomology. In this model, behavioral change is linked to three beliefs. The first is people’s belief about their level of susceptibility to illness or disease. The second belief relates to the consequences of action (or inaction). More specifically, to modify behavior, an individual must hold the belief that a behavioral change will have the effect of either improving or maintaining health. The third belief is founded on a cost-benefit analysis between possible negative outcomes and resulting health gains. Rosenstock (1974) also argued that a cue to action is required before people will perform health promoting or maintaining behavior. Cues to action can be simple or complex, and may differ for individuals depending on their related health beliefs. According to Rosenstock, the intensity of the cue required to prompt behavior performance is dependent upon individual’s beliefs about both their level of susceptibility to illness and the severity of the consequences of inaction. Examples of cues that might result in behavior change include a lecture from a doctor specifically describing a person’s susceptibility
to cancer, an efficacious educational program describing in detail the consequences of smoking, or experiences of ill health due to smoking.

In sum, it is more than just knowledge and skills that contribute to learning and functioning (Bandura, 1993). From the perspective of self-management researcher, self-efficacy theory and the Health Belief Model contribute to an understanding of how personal beliefs have an effect on self-managing behaviors for people living with renal failure. Cues to action are also considered necessary to spur a change in behaviour, and self-management educational programs are thought to provide such cues. Other personal characteristics such as age, educational background, disease-related knowledge, physiological health and psychological health all have been shown to influence self-management.

Environmental Influences

The second type of influence important in understanding the model of self-management is labelled environmental influences. Environmental influences on self-management include level of social support, the type of educational programming received and various outside influences. In this section, each of these types of environmental influences will be described and linked to self-management.

Social supports

The types of social supports that people living with illness receive from their environment can have an effect on self-management skills. Burton et al. (1989) defined social support as “information received by the respondent that he is loved, wanted, respected, valued and a part of a context he can count on should the need arise” (p. 438). Social support for people with renal failure can come from a variety of sources such as family, friends, neighbours, co-workers and health care personnel. However, in order to receive support people must first reveal that they have an illness, which may be a difficult and frightening undertaking. According to Charmaz
(1991), disclosure of an illness may involve fear of reduced social acceptance and a concern that the illness will be the defining characteristic by which one is seen. Thus, the decision to tell or not to tell, as well as whom to tell, must be considered in terms of the possible drawbacks versus the benefits of support. Based on two studies on social support and dialysis outcomes, Burton et al. (1988) concluded that people who have intact marriages and stronger ties to other family members adjust better to dialysis as compared to people with fewer family ties. This finding is similar to the results of the study by Berkman and Syme (1979) reported previously.

Social support is considered important because it has a significant influence on self-efficacy. For example, Bandura (1986) found that self-efficacy and outcome expectancies increased when study participants had the opportunity to observe another person completing a behaviour that resulted in success. Further, in a supportive environment, one has the opportunity to learn and perform new behaviours with a minimal amount of anxiety. Burton et al. (1989) found that a supportive hospital environment has an effect both on people with renal failure and their supporters (such as spouse or other family members). In their study of a hemodialysis education program, Korniewicz and O'Brien (1994) demonstrated that an educational program that included social support from nursing staff led to improved psychological, social and self-management skills. However, there were problems with this study design and sampling bias. The experimental group was the only group to receive extra educational support and this may have affected the results (due to a Hawthorne effect). In addition, the experimental group had a larger percentage of people who had high school diplomas, which, as suggested earlier, may have an effect on self-management skills. Thus, further studies on the relationship among hospital educational programs, social support and people's lives seems warranted.

Beliefs of others were also shown to have a significant effect on the self-management skills of people living with illness. Wright, Watson and Tapp (1995) found that nurses' beliefs
influenced the beliefs of people with heart disease and those of their families. However, the nurses may have been unaware of the effect that their beliefs had on the people they are teaching. Thus, nurses may indirectly influence people’s self-management by influencing their health-related beliefs. More research is necessary to test if the results of this case study apply to other people with heart disease and to people living with renal failure.

Research on self-management has shown that social environment can have an important influence on self-management and on people’s health. Social support can help to reduce stress and promote successful self-management (Burton et al., 1986; Burton et al., 1989; Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Korniewicz & O’Brien, 1994; Kutner, 1987). On the other hand, lack of social support or social stresses can negatively affect self-management skills. The amount and type of influence that social supports/stresses have over the lives of people living with renal failure are still unknown. Further, it is not known if all of the important social influences have been illuminated by the research.

Educational programming.

The type of educational program utilized has an important influence on self-management skill attainment. Educational programming is thought to have a direct effect on self-management by helping people acquire the knowledge and skills necessary to self-manage. Educational programs can also influence personal beliefs and provide cues to action, and, thus, can have an indirect effect on self-management. Educational programming that deals with and helps people overcome their cognitive difficulties may be especially influential in supporting the successful self-management of people living with kidney disease.

Earlier it was suggested that people living with renal failure must cope with cognitive, psychological and social challenges in order to manage their disease. These stressors may have a negative impact on educational programs and people’s abilities to self-manage. Although
research has suggested that psychological and social stressors are at least as important as physical ones to the functioning of people with renal failure (Burton et al., 1989), these areas are often not addressed in hospital educational programming. However, meta-analytic research had demonstrated that the majority of educational programs have resulted in improvements in some aspects of self-management (McCain & Lynn, 1990; Tabac et al., 1991; Wilson-Barnett & Osborne, 1983). Researchers have revealed that educational programming can result in improvements in people’s knowledge about their condition (Bowen et al., 1961; Kozak & Yura, 1989; Ozbolt-Goodwin, 1979; Pommier, 1992), improved health due to higher compliance rates (Haynes, Gibson, Hackett, Johnson, Sackett, Taylor, & Roberts, 1976; Hecht, 1974; Reibel, 1969; Tirrell & Hart, 1980), accelerated recovery rates (Fortin & Kirovac, 1976; Klos et al., 1980; Linderman & Van Aernam, 1971; Midgley & Osterhage, 1973), improved self-care (Bowen et al, 1961; Levine & Britten, 1973; Richmond & Peacock, 1989), increased feelings of competence (Reibel, 1969), improved quality of life (as reflected in reduced hospital stays and greater feelings of well-being) (Boulet, Boutin, Cote, Leblanc, & Laviolette, 1995; Bowen et al., 1961, Levine & Britten, 1973; Tilly, Belton, & McLachlan, 1995), enhanced abilities to carry out normal daily activities (Levine & Britten, 1973), and increased positive self-efficacy beliefs (DiIorio et al., 1996; Zimmerman, Brown, & Bowman, 1996).

All of these outcomes are considered important components of self-management. Many of these hospital education studies focus on only one or two of the important self-management educational components. In his review of diabetes self-management studies, Clement (1995) ascertained that self-management education is most successful when it includes behavioral change strategies, positive reinforcements and medication adjustments. Sciarini and Dungan (1996) believed that an integrative educational approach that includes counselling and social support is warranted so that successful self-management may be promoted. Other researchers
have argued that people’s health-related beliefs interact with their educational programs to affect knowledge and other health outcomes (Rosenstock, 1966; 1974; Wright & Simpson, 1991). Wright and Simpson identified two types of influential beliefs — constraining and facilitative — which stem from social and cultural spheres. “Constraining beliefs perpetuate problems and restrict options for alternate solutions to problems. Facilitative beliefs increase options for alternate solutions to problems” (Wright & Simpson, 1991, p. 240). Thus, like Rosenstock (1974), Wright and Simpson emphasized the importance of educational programs that attend to people’s beliefs about their condition and how these beliefs affect people’s self-management. As noted earlier, an educational program can be considered a cue to action and, thus, can be influential over self-management. Thus, it is believed that to promote successful self-management, educators must provide more than facts about diseases: they must assist people to perceive how their disease will affect them personally in order to persuade people living with disease to take action.

Various outside influences.

Finally, other outside environmental influences (such as weather or cost) are thought to affect self-management by compounding the challenges to self-management and/or by affecting “self-regulatory behaviours” (Hampson et al., 1995). In their study of self-management of chronic illness, Coates and Boore (1995) indicated that poor metabolic control is most likely the result of external influences such as lack of time or cost. Similarly, Tirrell and Hart (1980) found that weather has a detrimental effect on people’s compliance with a heart walk regimen. External influences are often hard to predict, and may be highly variable and hard to control. Since much of what people living with renal failure must “self-manage” takes place outside the hospital setting, these individuals may be exposed to many outside influences. Thus, the model
of self-management includes many environmental influences that may have an effect over people’s abilities to self manage.

In sum, researchers have revealed that both personal and environmental influences have an effect on self-management. Just how self-management is measured and the types of activities that are considered successful are the foci of the next section.

**Determinants of Success for a Model of Self-Management**

The evaluations of the results of people’s attempts to self-manage are important for understanding the model of self-management. Traditionally, evaluation of the success of self-management programs was based almost exclusively on medical outcomes. Specifically, researchers have assessed four different aspects of educational program success: 1) people’s knowledge about their disease/condition (Kozak & Yura, 1989; Ozbolt-Goodwin, 1979; Pommier, 1992), 2) people’s compliance with a medical regimen (Hecht, 1974; Reibel, 1969; Tirrell & Hart, 1980), 3) reduction of stress and faster recovery (Fortin & Kirovac, 1976; Klos, et al., 1980; Linderman & Van Aernam, 1971), and 4) improved self-care (Bowen et al., 1961; Levine & Britten, 1973; Richmond & Peacock, 1989). More recent research has supplemented the traditional success indicators by including measures of daily life functioning (Day, 1995; Tilly et al., 1995; Zimmerman et al., 1996). In the following section, the research findings on the self-management based success of both medical and daily life functioning for people living with renal failure will be reviewed.

**Medical Outcomes**

**Disease-related knowledge improvements.**

One of the common ways of evaluating outcomes associated with self-management is to measure changes in knowledge following education program participation (Kozak & Yura, 1989; Ozbolt-Goodwin, 1979; Pommier, 1992). The assumption underlying much of the research that
assesses people's knowledge about their disease is that increased knowledge will have a positive impact on self-management skills. However, one limitation to some of the studies that focus on knowledge attainment is that they do not analyze how people do or do not use knowledge to enhance their physical well-being and to adjust to their health regimes.

Management of physical symptoms.

Many studies focused on the measurement of physical symptoms to assess success. These researchers use indicators such as "compliance", "stress reduction and recovery", and "self-care" to determine how well people living with illness are able to manage the physical challenges of their disease. Compliance studies evaluated success by determining if people are following their medical regimens. For people living with renal failure, compliance may include adherence to complicated regimens such as controlling diet, regulating fluid intake, or completing dialysis therapies. A number of studies revealed that levels of compliance in hospital settings can be improved by educational programming (Hecht, 1974; King, Martin, Morrell, Arena, & Boland, 1986; Reibel, 1969; Tirrell & Hart, 1980). Although compliance may help to improve people's physical health, there are a number of barriers that affect people's abilities to comply with their medical regimes and, thus, to self-manage. For example, in their literature review on diabetes education, Greene et al. (1991) found that knowledge together with attitude influenced compliance and health control in people with diabetes. Further, it is common knowledge in our society that smoking and excess weight are damaging to health; the large number of smokers and obese people in our society attests to the phenomenon that compliance is not merely a matter of knowledge. Some research indicates that focusing on compliance may actually have a detrimental effect on people's abilities to self-manage. In her study on compliance in the classroom, Corno (1994) found that in classrooms where the focus was on compliance with teacher directives, there was a negative effect on students' level of involvement in their own
learning. Simply put, compliance focuses on passively following the instructions/rules set by others. This passivity is at odds with self-regulation, which focuses on active, independent learning (Zimmerman & Paulsen, 1995).

Some studies focus on directly testing health outcomes to measure success. Intervention studies designed to reduce stress and accelerate recovery often monitor people's well-being by measuring positive physical outcomes such as lowered blood pressure, fewer days spent in the hospital, or fewer somatic complaints. This focus is commonly used in projects designed to alleviate surgical stress and improve recovery (e.g., Fortin & Kirovac, 1976; Klos et al., 1980; Linderman & Van Aernam, 1971). Some of the benefits found were improved ability to breathe deeply and shortened hospital stays (Linderman & Van Aernam, 1971), fewer medical complications (Midgley & Osterhage, 1973), and improvements in physical function and comfort (Fortin & Kirovac, 1976; Klos et al., 1980). However, these types of studies gave indications of people's physical well-being; they did not consider other aspects of people's lives.

Self-care is one outcome measure that may include physical, psychological and social adjustment. It is the most inclusive of the medical-based indicators of success included in the model. Self-care is people's ability to care for themselves and, as such, often includes measures of knowledge, compliance, or stress reduction and recovery. According to Wyness (1987), much of the evaluation of people's well-being is focused on a model of increased self-care in medicine. Improvements in self-care skills are more difficult to achieve than a simple increase in knowledge because of the behavioural component required in self-care. As with compliance, there are many components that can interfere with self-care (Levin, 1978). However, a number of studies have shown that self-care skills can be improved through educational programming (Bowen et al., 1961; Levine & Britten, 1973; Richmond & Peacock, 1989).
Daily Life Functioning

Successful self-management is most often measured by improvements in disease-related knowledge, compliance, issues of stress and recovery, and self-care. However, some researchers, especially in the area of epidemiology, have attempted to broaden their focus to investigate some of the challenges to self-management and include aspects of daily living. For example, in his study on diabetes, Day (1995) focused on the life-long need for knowledge and self-management skills. He cited the importance of attitudes and beliefs, as well as the need for understanding and support. Similarly, in their study on diabetes self-management, Tilly et al. (1995) asserted that a multidimensional approach should be used for evaluation. They held that evaluations based only on health or knowledge outcomes were not sufficient. In their evaluation, they contended that quality of life ratings, along with other measures, allowed for a more complete assessment of outcomes for people living with illness.

Other researchers have also used quality of life scales in an attempt to broaden their concept of success to include improved quality of life (Boulet et al., 1995; Bowen et al., 1961; Levine & Britten, 1973; Tilly et al., 1995). However, many of these quality of life scales focused only on medical indices, such as time spent in hospital and level of health improvement. Some quality of life scales do cover other domains, including indices of social and psychological functioning. These scales can be helpful because they include important outcomes beyond medical indices. At the same time, because the outcomes have been defined and delineated by health care practitioners, they may still fail to include many of the important aspects or influences on the lives of people with renal failure. Measuring improvements in people’s beliefs is another way of assessing the success of self-management. Zimmerman et al. (1996) found that their self-management program for chronic obstructive pulmonary disease resulted in an increase in people’s level of self-efficacy. In models of self-management, it is assumed that there is a
positive relationship between self-efficacy and improved medical outcomes; this, however, has not always been found to be the case (Coates & Boore, 1995; Hampson et al., 1995; Zimmerman et al., 1996).

Understanding the Lives of People with Renal Failure

A review of the research on self-management is important because it leads to many insights into the lives of people with renal failure. However, models of self-management are based on a conception that is cognitive and factorial in nature. Although many important areas of people’s lives are addressed, the research is most often fragmented and investigates only pieces of the lives of people living with illness. The nature of this kind of study does not allow for an intact view of people’s worlds. Therefore, the relative importance of the various influences on people’s lives can not be known and key areas of influence may be missed. Further, self-management is limited by the assumption that the medical model of health and human competence is universal. That is, it is possible that not all people living with illness are rational and predictable, and choose to strive for “optimal” health. The use of terms such as ‘self’ and ‘management’ develop out of the currently popular preoccupation with the individual, efficiency and rationalization. This language may not be relevant to the way people with renal failure operate in their world.

Models of self-management strive to improve past educational models (Bartlett, 1983; Coates & Boore, 1995). The goal is to furnish people with illness more control over their lives and, thus, increase their power or agency. Upon closer inspection of self-management educational programs and their success indicators, it becomes apparent that compliance is still the goal. Self-management gives people a very conflicted message: on the one hand, individuals are told that they should “take charge” while on the other hand they are told to “comply” (Hernandez, 1995). Empirical research has focused on the goal of improving people’s health. It
is assumed that improved knowledge of self-management skills will lead to adherence with medical regimes and, thus, to improved health. These assumptions are faulty (Hernandez, 1995; Lorig & Holman, 1993; Strowig, 1982) in part because they do not take into account the social, cultural and historical worlds in which people exist. The degree to which a model of self-management can be applied to the subculture of renal disease is questionable. The model of self-management is a cognitively based model and as such assumes that cognition is the key to people's behavior. Because one of the common difficulties experienced by people living with renal failure is cognitive impairment, a cognitively-based model may be completely inappropriate for this population. It is possible that other models based on other factors, such as affect, may be a more realistic framework under which people with renal disease really live their lives.

Relationships Between Healthcare Practitioners and People Living with Illness

Earlier it was argued that self-management educational programs were training, rather than educational, and should be labelled as such. Because the content and goals of the program are determined long before the people with illness enter into the program, individuals taking these programs have no input into delivery methods or the type of education offered. Inherent in this dichotomy is the relationship between health care practitioners and people living with illness. An unequal power relationship between people living with illness and health care personnel may leave people with illness feeling as if they have little power over their own lives (Foucault, 1980; Galassi, Schanberg, & Ware, 1992; Mishler, 1981e; Waitzkin, 1989). This loss of power can be detrimental to people's attitudes towards their own care. Further, health care personnel's position of power may have an effect on attitudes towards people with illness, the type of research done, the emphasized research outcomes, and what is taught in educational programs.
The history of medicine is long and well chronicled. During this history a number of significant changes have taken place; this is especially true for treatment practices and biomedical discoveries. Other areas of medicine have been much slower to change. In the earliest days of medical training, prospective doctors were instructed to “capture a patient profile that was as objective as possible” so that it could be placed in a file (Foucault, 1973). This type of training for objectivity is still prevalent in medical schools of today. Hauser (1981) argued that when medical training encourages “detached concern” and “emotional distance” in a quest for objectivity, there is a strain on the relationship between doctors and people living with illness. This strain is further exacerbated because physicians expect people with illness to follow their advice without question, whereas people living with illness want to have some say in their own care.

A proliferation of studies having to do with “patient satisfaction” exist, in apparent contrast to the quest for objectivity. Most of these studies demonstrate that people are more satisfied when the “doctor-patient relationship” is personal and affable (Glasser & Bazuin, 1985). The affective demeanour of a physician was found be strongly linked to the satisfaction of people living with disease (Burgoon, Pfau, Parrott, Birk, Coker, & Burgoon, 1987). When physicians dominated medical interviews, people were more dissatisfied and actually had lower levels of understanding of their physicians’ expectations (Hauser, 1981). Thorne (1990) found that people living with illness actually preferred and sought out those physicians who were able to put aside the typical role of authority. These findings seem at odds with the prevailing physician training practices.

Foucault (1980) argued that there is a connection between knowledge and power, and that people with illness should be given the necessary knowledge to gain power over their own situation. Further, Galassi et al. (1992) found that people living with illness often received better
care when they were trained in questioning and information techniques, so that they were able to gain more power in the medical interview setting. However, when people living with illness were able to gain some control over their own health, trust in their health care practitioners declined (Thorne, 1990). Thus, an increase in control for people living with illness may be quite threatening to those already in power (Mishler, 1981e). There are traditional social roles that physicians and people with illness hold in our society and these roles (which occur in a social and historical context) have an influence over the relationships between physicians and people living with illness (Mishler, 1981c). People living with illness are expected to subscribe to the role of a sick person: that is, someone in need of help and unable to care for herself or himself. Physicians, on the other hand, hold a role of authority and power, and as mentioned earlier expect people living with illness to accept their advice without question (Hauser, 1981; O’Neill, 1985). As Foucault (1994) stated, the physician’s role may be likened to a shepherd guarding the sheep.

Mishler (1981a) contended that within the social institution of medicine, it is physicians who dominate and control those who are considered deviant: that is, those who are labelled as ill. Similarly, Fox (1993) believed that health care practitioner control stems from the giving of care and from the labelling of people as “patients” or “clients”. The power of health care practitioners is most obvious in studies on compliance, where it is assumed that people living with illness should comply with health care practitioners’ advice. In fact, noncompliance with the medical regime is considered irrational by health care practitioners (Thorne, 1990) and often people living with illness who don’t comply are decreed to be “in-denial” (Charmaz, 1991). Many nephrological health care professionals equate non-compliance with suicide (O’Brien, 1983). Healthcare professionals interpret noncompliant behavior as a problem within people living with illness, whereas people living with illness often ascribe noncompliance to the
limitations of medical science and/or to an accountability for their own care (Thorne, 1990). Further, judgements of non-compliance by health care practitioners were not found to be congruent with the judgements of the people living with illness; the latter individuals gave themselves higher compliance ratings than did the health care professionals (O'Brien, 1983). However, most often, the views of compliance by people living with illness are not taken into account.

Health care practitioners may also be limiting the power of people living with illness by their exclusive concern with the medical aspect of people’s lives. Despite only gathering a portion of the available information from people living with illness, physicians often make decisions that can affect the lives of these people (Carpenter, 1994). There is more to people’s lives than their disease and its symptoms (Charmaz, 1991; Foucault, 1973; Mishler, 1981a; Waitzkin, 1989). In the past, health care practitioners used language that identified people with their disease, referring, for example, to “a kidney disease patient” rather than “a patient with kidney disease”. People living with illness were often treated as if they were conditions rather than persons (Glasser & Bazuin, 1985). Much of today’s language has changed to reflect the understanding that a medical condition does not define the complete person. Unfortunately, a vast majority of the studies that purport to be conducted in the interest of people living with illness and to improve satisfaction or treatment practices were actually done from the caregiver’s point of view. The result was that people living with illness, rather than the institutions or health care practitioners, were touted as the objects in need of change. Researchers focused on making “good patients” (Bain, 1985), “modifying patients” (Nash, Connors, & Gemperle, 1977), or assigning attributions to “inferior patients” (such as SES, gender, etc.). In a similar vein, other studies found the answer to this problem by having the doctors “come down” to the level of those living with illness (Bain, 1985) or by having the care-providers “give” dignity to those
living with illness (Nash et al., 1977). Although the model of self-management is an attempt to move away from this type of focus, in reality, it is people with illness who must change and learn to self-manage in the manner that is prescribed by their health care practitioners.

Another study changed the focus from the characteristics or behaviour of the people living with illness to the performance of health care providers (Burgoon et al., 1987). In this investigation, health care practitioners' characteristics and mannerisms were the objects of scrutiny, which suggested that the physicians were the device of change. However, on closer inspection of the study, it became apparent that the underlying purpose was to increase the compliance of those living with illness. So, once again, the object of change was in reality the people living with illness, and not the health care practitioner. There are other examples where changes to the medical system, supposedly to improve the conditions of people living with illness, were in fact beneficial primarily to the health care providers. One such instance is consent forms, which originally were intended to increase the power of people living with illness. They are now are predominately employed to protect physicians from malpractice suits (Wiener, Fagerhaugh, Strauss, & Suczek, 1980). However, some progress has been made for and by people living with illness. Some studies have concluded that it is the health care practitioners who need to change or be the focus of educational programs (Carpenter, 1994). Also, although an unequal power relationship still remains, doctors are no longer considered infallible experts. People living with illness are beginning to question their physicians, seek second opinions, or use alternative health-care methods (Wiener et al., 1980). However, physicians are often the section of society that labels what is normal and/or desirable behavior (Foucault, 1980).

Healthcare practitioners have a strong hand in supporting the ideology of the society of the day. Foucault (1973) argued that there is a link between medicine and political ideology. O’Neill (1985) maintained that the social control of health care practitioners is a consequence of
a society that values health above illness and scientific knowledge above other types of knowledge. By supporting the established order, physicians may maintain their class and positions of power. Healthcare practitioners obtain their position of authority though the uses of technology, and their knowledge about the body and its illnesses (Fox, 1993). Foucault (1973) noted that in their quest for signs and symptoms of a disease, physicians subject people living with illness to a “medical gaze”. The importance of this gaze lies in the power that it affords to the physicians who are considered to be the ones with knowledge and expertise. This power is achieved, however, at the expense of those subjected to the gaze, namely, the people living with illness (Fox, 1993). Through their gaze of power, physicians become the experts over the bodies of those living with illness. As well, during their encounters with people living with illness, physicians direct problems away from society and onto people living with illness, thereby helping to maintain satisfaction with the social order (Mishler, 1981a,d,e). Physicians have defined health as the ability to work (Waitzkin, 1989), and, thus, help to inculcate the current economic system.

Much of health care practitioners’ socially controlling behaviours are exhibited in their communication with people living with illness. During encounters with people with illness, physicians use their knowledge to control the nature and topics of discussions. By interrupting and asking numerous questions, health care practitioners display their dominance and exert control over conversations with people living with illness (Waitzkin, 1989). During medical interviews, people living with illness relate personal problems to their doctors, but many of these problems are caused by social issues (Waitzkin, 1989). The causes of problems in people’s lives are generally treated as not medically relevant and, thus, doctors tend to focus on treatment of symptoms while ignoring the social context in which they were created (Engestrøm, 1993). According to Mishler (1981c), there are two “voices” in the medical interview, the voice of
medicine and the voice of the "life-world" (p. 85). Through their position of power in the interview doctors have discouraged the voice of the life-world and promoted the voice of medicine. According to Foucault (1980), health care practitioners exhibit these socially controlling behaviours but are virtually unaware that they are doing so. Further, this control has gone beyond medicine to permeate everyday life.

The Contexts of Illnesses

As stated previously, medicine is responsive to and reflects sociocultural values and norms, as well as dominant economic and political interests. Mishler (1981c) believed that we need to move away from the traditional scientific medical paradigm. He stated that medical conventions, such as diagnosis, were seen as interpretative work and were one of the ways through which reality was socially constructed. When a person has an illness, that illness is culturally defined until a physician medically defines it. Physicians use a system of rules to translate symptoms into diseases, which then turns people into patients (Mishler, 1981a). This model of medicine is grounded in our culturally specific notion of disease and how disease should be treated. Society is structured for people who are healthy and, thus, the lives of those who are ill may be more restricted than necessary (Charmaz, 1991). According to Kagawa-Singer (1993), in our Western culture, people with illnesses are treated as "non-persons" or are considered "in-valid"; this, however, doesn't have to be the case. Kagawa-Singer cited examples of cultures where the prevalence of certain illnesses is so common that people with these illnesses do not lose their social position or power. Further, there are some cultures where having a certain disease can actually raise a person's value or esteem in that society. On the other hand, there are some diseases or cultures where people's value or esteem is reduced to devastatingly low levels. For example, in her study on leprosy, Waxler (1981) found that despite the fact that leprosy is curable, may leave no deformities (if treated early) and is only mildly infectious, societies'
strong negative reactions have far-reaching effects on people's experiences of this disease. Health and illness then, do not function in isolation of people's lives, and, thus, a redefinition of these terms is needed to ensure they include the physical, social and contextual aspects of people's lives (Kagawa-Singer, 1993). Other authors have argued that there should be a distinction between illness, disease and sickness (Fox, 1993; Mishler, 1981). Disease is grounded in physiology and is treated and diagnosed by a physician, whereas illness is a person's subjective experience of that disease and sickness is a result of the response of a person's social world to their disease and illness.

The responses that people have to disease can vary greatly. According to Fife (1994), the coping strategies that people use to deal with disease depend on the meaning that they give to their disease. Meanings depend on people's perceptions of the significance of their illness on their life at present and their future goals (Fife, 1994). These meanings are influenced by both internal and external forces, and can have a significant impact on a person's identity. There are many threats and challenges to personal identity once a disease has been diagnosed. Some of the areas of influences on identities are past identities, knowledge, past experiences, belief systems, time, culture, social spheres, age, gender, occupation, and severity and intrusiveness of the disease (Charmaz, 1983, 1991; Fife, 1994). People also have to learn to assimilate this new identity of "patient". In her book on living with chronic illness, Charmaz (1991) stated that:

Having a chronic illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life. This struggle is grounded in concrete experiences of managing daily life, grappling with illness, and making sense of it. (p.5).

Her conception of living with illness varies greatly from the traditional medical perspective where living with an illness means coping with physical symptomology. Diseases do not occur
in isolation; people who are located in a particular time, place and social world experience
diseases. According to Mishler (1981a,f), health and illness are social and biological entities.
Much of the medical literature focuses on the biological aspects of disease and often ignores the
social realities of illness. However, the context in which a disease is experienced may have an
effect on the number and severity of the symptoms (Loveys & Klaich, 1991). Stein (1992)
contended that a disease is located in many people; that is, there are many other people who are
involved and contribute to the disease process. In Stein's ethnographic study of a woman with
diabetes mellitus, she found an “intricate drama” that included many voices and issues that
contribute to this woman's so-called “non-compliance” with her diabetes regimen. Thus, health
care practitioners need to expand what they consider important in order to improve diagnosis and
treatment protocols.

It is unfortunate that medical practice can have negative effects on those it intends to serve.
Some problems stem from hospitals or medical institutions that strip people living with illness of
their agency by requiring strict adherence to rules and procedures. People living with illness are
often treated though they were “conditions” rather than “persons” (Glasser & Bazuin, 1985).
This situation was most aptly described by Branch (1969): “Hospitals do not help the situation if
they are ‘emotionally’ cold, impersonal, over expensive, uncomfortable and apparently designed
to permit, and even perpetuate, meaningless and atavistic rituals on the part of the cave-dwellers
within” (p. 403). This type of atmosphere is most often seen in hospitals that are very large and
have high ratios of the numbers of people living with illness to health care practitioners (Mishler,
1981c). Unfortunately, as time goes by, it seems that hospitals are becoming larger and the ratio
of people living with illness to health care practitioners is growing. Historically, hospitals were
places of learning and observation so that physicians could discover and describe illness; they
were places of science and not necessarily places for healing (Foucault, 1994). It may be that the
historical foundation of hospitals has an effect on the activities of today. According to Mishler (1981e), hospitals are most often organized so that they best suit the health care professionals rather than the people living with disease. He reported that within the hospital it is quite common to find that people living with illness are mistrustful, suspicious and perplexed. People living with renal failure may spend substantial amounts of time in the hospital setting. Research has not yet been conducted that reveals the effect of the hospital setting on the lives of people with renal failure.

The medical institution has also invented illnesses as new domains have fallen under its rubric. Some of the new areas now under health care supervision are family life, work dissatisfaction, sexuality, life cycle problems, difficulties in the educational system and environmental pollution (Waitzkin, 1989). Within the field of education alone, there have been a number of medical “diseases” discovered. Some of these include dyslexia, learning disabilities, hyperactivity and attention disorders. A diagnosis of one of these problems is often taken as scientific fact rather than an artifact of our society. The phenomenon is aptly expressed in two articles dealing with learning disabilities in the school system (McDermott, 1993; Mehan, 1993). These authors argue that children are not learning disabled until they enter the school system and are labelled as such. Upon entering a school system which has the resources for special education evaluation and placement, a child “becomes” learning disabled when given the official status of this title (Mehan, 1993). The school system in our society is based on a competition model where the focus is on doing better than others do. Thus, this system has created slots and labels for those who do not do as well as others. In this way, many students will acquire the label of learning disabled once they enter into this system (McDermott, 1993). These studies of learning disabilities differ from most research in that they include the cultural and historical contexts in which a phenomenon takes place, and, thus, give us an understanding of the world in which
students function. Similar studies, which include the cultural and historical contexts, are needed in the medical sphere so that the world of people living with illness can be included as part of the medical knowledge base.

The Sociocultural View

Educational research on kidney disease has been almost exclusively focused on predictions and explanations of educational outcomes that deal with improvements in physical health. It has been argued that self-management, the model most frequently used in the medical context, is limited in a number of ways. For example, self-management is limited in terms of the assumptions on which it is based, the type of hospital educational programs that it produces and the way it dissects different aspects of people's lives. New kinds of information need to be gathered so that the lives of people living with illness can be more fully understood than at present. It is not enough to do yet another empirical study on the factors that have an influence on outcomes or a study on the effectiveness of educational programming. What is needed is an integrated look at the lives of people living with renal failure — a look that includes the historical, social and cultural world in which they must live and function. This type of sociocultural study could inform education and the practice of health care practitioners, and at the same time give value and respect to the lives of people living with renal disease.

The biomedical model, the most common model in medicine, is founded in the science of biology and is assumed to be neutral and value-free (Coates & Boore, 1995; Mishler, 1981a,e,f). However, medicine is not only influenced by, but also has an influence on, the sociocultural, historical and political framework in which it functions (Mishler, 1981e). Medicine has been used to brand certain strata of society less able than other strata. Some examples include the use of medical justifications to deny women's rights to participate in higher education, public life and the electoral process; the greater likelihood of being labelled mentally retarded if one
belongs to an ethnic minority; and the higher rates of illness among those in the lowest socio-economic class of society (Mishler, 1981e). From the biomedical point of view, disease and/or illness are independent objects understood through a compilation of physical signs and symptoms (Coates & Boore, 1995; Foucault, 1973; Mishler, 1981a). Diagnosis, then, is a matter of matching people's physical symptoms with the symptoms characteristic of a disease. This, however, assumes that diseases truly exist and that they manifest themselves in the same way for everyone, everywhere (Mishler, 1981d; O'Neill, 1986). Further, a biomedical focus does not acknowledge that despite standard diagnostic procedures, there are often large inconsistencies in diagnosis (Mishler, 1981a). Treatment focuses on the amelioration of physical symptoms by using a kind of "applied technology." That is, the science of medicine attempts to understand the usual responses of different treatment protocols to determine which treatments work best for which diseases (Brown & Williams, 1995; Mishler, 1981a,c). Thus, biomedicine is concerned with the diagnosis and treatment of disease, and focuses physical symptomology. In terms of renal disease, medical science researchers have developed various treatment protocols (dialysis and transplantation), but have not yet discovered a cure. Although research to find a cure for kidney disease is certainly necessary, since currently there is no cure, research must also focus on life with this disease.

According to Wertsch (1991), a sociocultural approach focuses on combining cultural, historical and institutional settings with the action that is taking place. He argued against studying the individual in isolation and maintained that individuals are inextricable from the world in which they function. This theoretical base focuses on a naturalistic view of person and environment, where both are an integral part of the action taking place. Human action is the unit of analysis used to describe and explain how people live and function in the world around them (Wertsch, 1998). Similarly, Lave (1988) argued that action and settings are a necessary part of
any analysis and cannot be teased apart from the person doing the action. These actions are mediated through the tools and language that shape the action (Wertsch, 1991) and can only be understood by incorporating multiple perspectives (Wertsch, 1998). According to Wertsch (1998), language is just one of the many cultural tools through which action is mediated and these tools have an effect on power and authority. Further, mediated action is culturally and historically situated; thus, power and authority are also culturally situated.

The environment and cultural contexts in which people live can both constrain or enhance the options made available to them, and, thus, are a part of the actions in which they engage. An illustrative example taken from Wertsch's (1998) text focuses on a pole-vaulter. In order to understand the action of pole vaulting one must include both the person (the agent) and the mediated means (the pole); understanding action is difficult if not impossible without the cultural tool and a user of that tool. Both the tool and the agent are culturally and historically based. Thus, for example, the material used to make the pole is influenced by cultural knowledge and materials available. The pole in turn influences skills and method of vaulting as well as the criteria for evaluating the skills of the agent. This simple example helps to illustrate that in order to understand the experiences of people with renal disease we must consider more than just illness trajectories. From the sociocultural perspective, the biomedical focus on physical symptomology would be severely limited. People with illnesses cannot be reduced to elements of analysis separate from the world in which they function.

Similarly, Engeström (1993) maintained that an institution is continually constructed and cannot be broken down into the action or actions that take place within it. Engeström applied this to the medical context and found that the system of the institution, the biomedical focus of the doctor and the life view of people living with illness work together to create an asymmetrical relationship between doctors and people living with illness. In this relationship, the doctor is
dominant and subtly represses the concerns of people living with illness that do not focus on the medical model. The power held by health care practitioners has been discussed earlier. This power can be ascribed to the type of voice given to physicians, which has been called the voice of authority. Further, power comes from the “privileged” status of scientific language (Lave, 1993; Wertsch, 1991, 1998). This power of the physician tends to discourage contact and requires unconditional compliance.

The notion of compliance, as it is more commonly conceived, has been discussed and scrutinized earlier. There is some movement toward changing our understanding of compliance. Taken from the viewpoint of people’s lived experiences, compliance or non-compliance may be seen as deliberate choices that allow people control over their own lives (Rittman, Northsea, Hausauer, Green, & Swanson, 1993). For example, in her study on constructive noncompliance Thorne (1990) found that people living with illness made a “conscious and reasoned decision not to adhere to professional advice” when they labelled themselves as noncompliant (p. 63). Compliance from this frame of reference is not due to misunderstandings, forgetfulness, denial, or lack of knowledge, but rather is seen as a way for people with illness to improve on how they live. In this sense noncompliance can be seen as a normal and rational part of living with a chronic illness.

Thorne (1990) described three types of noncompliance: 1) when people alter their treatment regimen without the advice of a health care practitioner, 2) when people pick and choose which portion of the regimen to comply (and not comply) with and 3) when people with illness agree to comply with the prescribed regimen when in reality they know they will not comply. This kind of noncompliance can have many benefits for people living with illness. One of the most notable of these benefits can be found in a longitudinal study of people undergoing dialysis therapy, which determined that survival rates were lowest among those people who
showed the highest compliance behaviors and highest among people with the lowest compliance behaviors (O'Brien, 1983). O'Brien conjectured that this may be due to the difference between "ritual" and "reasoned" compliance. Reasoned compliance occurs when people living with disease assess what they are willing and able to do, and understand the consequences (costs vs. benefits) of not following medical prescriptions (Charmaz, 1991). Reasoned compliance may allow people living with illness to remain active, and continue with valued pursuits while maintaining an adequate level of health (Charmaz, 1991; Thorne, 1990). For example, Kelleher (1988) found that people living with diabetes who coped well with their disease knew how their treatment worked and were willing to modify their treatment protocols. Thus, those people who coped well with their disease were able to modify their regimens so that they could continue with their social role and function as usual in their social world. These people were able to achieve a sense of control over their lives and take on more responsibility for the decisions regarding their own care and, thus, improve their quality of lives. When people living with illness lead health care practitioners to believe that they are following the prescribed regimen, this allows them to maintain positive relations with the practitioners (on whom their very lives may depend) and at the same time avoid partaking in activities which they believe will not be beneficial for them (Thorne, 1990).

Another alternative approach to compliance comes from Mishler (1981c) who suggested that there is a need to change the way we think about the medical system as a whole. Part of this change involves turning the concept of compliance around and shifting the responsibility onto the physicians. He stated:

The notion of patient compliance, a concept that itself contains the view that the essential task of a patient is to obey doctors' orders, might be inverted; we might instead ask, and study, the extent to which physicians attend to patients' definition of their problems and
design treatment plans accordingly. In other words do physicians “comply” with patients’ requests for help? (p. 100)

This kind of compliance cannot help but change the current system where the “physician’s job” is to be the expert and the “patient’s job” to be the listener and complier (Mishler, 1981c). In the past, many of the proposed changes to the medical system were limited because they were bound by the biomedical model. Mishler (1981c) argued that more radical change is necessary, a change that would result in a shift in emphasis from the science of medicine to the social organization of health and illness.

People living with illness do not function in isolation and, thus, a sociocultural approach is an important basis for research concerned with people living with renal failure. The position of power held by health care practitioners has an effect on how people living with illness are viewed and can function in the hospital setting. Because people living with illness have little power and are not a part of the medical discourse, they have minimal access to legitimate practice in the medical community (Lave & Wenger, 1991). People with renal failure, as a group, have a high risk factor for social and institutional subjugation. Sociocultural studies have often been done on populations “at risk” in order to paint a picture of a phenomenon in a culturally sensitive way. One excellent example of a sociocultural study is Shirley Brice Heath’s (1983) ethnography on racial integration in the Southern United States. In nearly a decade of observations she followed three communities’ lives, both in and out of the classroom. The focus was on different patterns of communication in these communities and how these patterns were culturally and historically based. While some language patterns assured school success and gave greater access to goods, services and power, all language patterns were seen as equally valuable. In Heath’s writing, cultural differences were presented as neutral rather than pathological, and, thus, one form of communication was not seen as better than another. This type of analysis
encourages the use of all forms of communication to break down the power of one language pattern over another and one community over another. This sociocultural study helps us to understand that, while power may reside in one type of language, the solution is not to eliminate other “less powerful” forms of language.

Deyhle (1995) conducted a similarly focused sociocultural study on the lives of Navajo youth. Deyhle found that the cultural context in which Navajo youths are born is at odds with the school and work contexts in which they are expected to function. Success in school often means denying the Navajo cultural heritage, which focuses on the family, group harmony and cooperative responsibility. Adopting the dominant Anglo view of competition and the importance of individual success is costly, especially when considering that most of the avenues of Anglo success are closed to those of Navajo decent. Awareness of the power of the Anglos is essential to understanding the lives of Navajo youth and how these youth attempt to negotiate their world. While popular theory suggested that in order to succeed in school Navajo youth must subscribe to the Anglo view of the world, Deyhle found though the use of ethnography that the opposite is true. Navajo youths are more successful in school when they are secure in their culture and when schools incorporate Navajo culture within their rubric. As in Heath’s (1983) study, when the culture of the groups at risk is valued, power may be shared more equally. These two studies demonstrate the value of a sociocultural investigation, especially when dealing with populations at risk.

Similarly, some studies on specific illnesses or disabilities have employed the sociocultural approach. For example, Stein’s (1992) study on diabetes included multiple voices and cultural issues in order to understand this chronic illness. As well, a sociocultural look at family life with a hearing-impaired child revealed that the social and cultural contexts in which the family functions cannot be separated from the life of the individual; that is, life is not experienced in
isolation (McKellin, 1995). As was noted earlier, most research thus far has focused on the medical model of care on the person in isolation, and has yielded information on how to make "better patients". Recently, researchers have begun to recognize the importance of obtaining peoples' perspectives on their health and illnesses. Some examples are studies which focus specifically on the lived experience of people living with diabetes (Hernandez, 1995), Parkinson's disease (Marr, 1991), spinal cord injury (Carpenter, 1994), arthritis (Brown & Williams, 1995), myocardial infarction (Johnson, & Morse, 1990), and renal disease (O'Brien, 1983; Rittman et al., 1993). These and similar studies add to the traditional biomedical approach by allowing a view of illness in the context in which it is experienced. Not only does this type of research provide new insights into what it is like to live with a disease, but it can also extend power and respect to people and all the important aspects of their lives (Brown & Williams, 1995; Marr, 1991). Research on the perspectives of people living with disease lets them know that they do have important input into the kind of care that they are given, and indicates that they are an important part of medical research. Further, sociocultural research on the lives of people with illness can expand health care practitioners' understanding of what it is like to live with an illness and, thus, enables the practitioners to provide more appropriate supports than at present.

Summary of the Approach

The inextricably connected character of people and the milieus in which they live argues for the utility of a sociocultural approach to research (Wertsch, 1991). This kind of research offers, I argue, a more adequate foundation for implementing research whose aim is to describe the lives of people living with renal failure — people who by the nature of their disease live lives dispersed across multiple institutional locations. From a sociocultural standpoint, both person and environment combine to create the action taking place and the agency by means of which it is accomplished — there is no such thing as person in isolation (Engeström, 1993; Lave, 1993;
Wertsch, 1991). In this way, the focus moves away from any notion of an autonomous self and supports instead a situated account of lived experience. Therefore, for this research study, in order to paint a picture of the lives of people living with renal failure in context, a sociocultural model will be used. A qualitative study that focuses on how people living with renal failure function in their everyday lives will highlight the areas that are important for health care practitioners and educators to understand.

This sociocultural qualitative research study will attempt to provide an understanding of life with renal failure both inside and outside the hospital setting. As well, it is hoped that this study will provide a means for people living with renal failure to determine their own success criteria for adjustment to their disease. Educational and health care practitioners then can focus on providing the supports necessary for attaining this success (even if success sometimes means choosing not to comply with medical regimens). Further, information will be gathered to note if and how people living with illness are excluded from medical discourse, and the effect of relationships between health care practitioners and people living with illness. A sociocultural model can change the focus so that health care practitioners can better serve the needs of people living with illness. In this way, it is possible for the power to be shared both by those who give care and by those who receive care. In the following chapters I will discuss this study’s methodology (chapter 2), results (chapter 3) and will conclude with a discussion on the significance and implication of these results (chapter 4).
CHAPTER TWO

Method of the Inquiry

The purpose of this study was to understand how the disease of renal failure affects people’s lives. People living with renal failure may have to face many life difficulties once they are diagnosed with kidney disease. In the previous chapter, the limitations of research pertaining to the medical model of health were noted. The questions pertinent to this study rise out of the gaps and limitations revealed in the literature review. A sociocultural model was used in this study in an attempt to overcome the limitations of previous research. In this way, it might be possible to give people living with renal failure a voice in how their care will be provided.

Research Questions

The overriding question of this study was: What are the life experiences of people who have to include in their life the chronic illness of renal failure? This general question gives rise to number of specific questions. They include:

I. How do people living with renal failure define their disease?
II. What are the important disease-related components that impact on the lives of people living with renal failure?
III. What are the important cultural and historical components that impact the lives of people with renal failure?
IV. How does the institution of the hospital affect the lives of people with renal failure?
V. How do the worldviews of the institution and people living with renal failure differ?
VI. What is the relative importance of the significant aspects of renal disease on the lives of people with this illness?
VII. How do people with renal failure define successful adjustment to their disease?

VIII. How can health care practitioners and educational programs best support this success?

Logic of Inquiry

The research design utilized comprised multiple qualitative case studies. These case studies are grounded in the sociocultural approach discussed earlier. Multiple qualitative case studies are an appropriate means of providing insight into the lives of people living with renal failure because they allow for holistic descriptions and explanations of real life events (Yin, 1994). Further, a multiple case study approach permits a focus on the needs of individuals living with kidney disease within the relevant context of their world (Merriam, 1998). The institution of the hospital and people living with kidney failure do not stand alone; that is, they have influence on and are influenced by one another. The unit of analysis then is not a person in isolation but rather a person acting in a setting (Lave, 1993; Wertsch, 1998). For this particular study, then, the unit of analysis is the lived experiences of people with kidney disease. This requires an investigation not only of those living with renal disease, but also of people centrally involved in their lives. Further, the investigation must be situated in the cultural and historical settings in which the action in taking place. A multiple case study design, grounded in sociocultural theory, can provide information on the lived experience of people with renal failure. This type of study can provide information on the life both inside and outside of the hospital setting, and can include the important people in those settings. Further, multiple case studies allow for the investigation of both single and multiple cases. By investigating more than one person's view of life with kidney failure and their social supports, as well as investigating the views of health care practitioners involved in the renal program, it is possible to compare different viewpoints and to come to conclusions that are compelling and robust (Yin, 1994).
Thus, a multiple case study design was chosen because it is an excellent means of addressing the complexity of life for people living with renal failure.

Heed was taken on a number of issues that might influence the research and its conclusions. The presence of a researcher in any context will have an influence on that context. The process of observation and interviewing also affects the atmosphere and, therefore, the results. Lincoln and Guba (1985) argued that since the investigator is the “major instrument” of a qualitative case study, there is a need to explain the credentials, predisposition and biases of the investigator. In this study, there was only one investigator. I am a Ph.D. candidate at the University of British Columbia in the final year of my program. I became familiar with people living with renal failure when I worked for three years as a research assistant in the renal division at a large city hospital. As a research assistant, I was involved in a study of the impact of a pre-dialysis educational program on people’s medical outcomes once on dialysis. People on dialysis were followed up to six months after dialysis commencement in order to glean information on their medical health as well as their self-reported quality of life. I was involved in all phases of this research project and took part in the study’s formulation, data collection, entry and analysis. In addition, I helped in the preliminary construction of data collection tools. The experience of working in the renal division of a hospital provided me with some initial insights into the lives of people living with kidney failure, although these insights came from a decidedly medical perspective. This experience solidified my previously held beliefs about the importance of medical outcomes and the need to design educational programs that would improve compliance (and, therefore, medical outcomes). My bias at that time was that of the biomedical/educational perspective; this, however, is no longer the case.

Through my studies at the university, I have also gained some familiarity with people living with renal disease. I conducted an extensive literature review on current practices in
educational techniques and educational program evaluations designed for people living with illnesses in general and for people living with renal failure (Faber, 1996). This literature review was presented at the national symposium of The Canadian Association of Nephrology Nurses and Technologists in 1996. I am also familiar with qualitative methodologies through my studies at the university. As part of my course-work, I conducted two pilot qualitative studies designed to explicate the perspectives of those with kidney disease (both studies took place through the renal division at a city hospital). The first study focused on the examination of the hospital setting from a sociocultural perspective that centred around one person undergoing dialysis (Faber, 1993). This study involved an intensive but informal interview with a person living with renal disease as well as three short interviews with health care practitioners (two doctors and one nurse). The results of the study demonstrated that the viewpoint of a person living with renal failure may be very different from the viewpoints of health care practitioners. In the second study, I designed and implemented a preliminary qualitative multiple case study on people’s perspectives of a renal dialysis education program (Faber & Levitt, 1996). For this study, two people undergoing dialysis were interviewed in order to understand their perceptions of the dialysis education program. Also, researcher observations and documentation collected from hospital files were included as data. During this second study, I was able to practice and refine my interviewing skills, and had an opportunity for data analysis using more than one case and source of data. I also was able to enhance my understanding of the lives of people living with renal failure from their own perspectives. These studies helped me move away from a biomedical focus towards a more situated understanding of people’s lives.

There are problems of bias that must be recognized and acknowledged. First, because I am a researcher, and not a person living with kidney failure, it may be argued that I am unable to truly understand the perspectives of participants in this study. Second, since I do not have
kidney disease I may be viewed as a person with power and, thus, the information gathered may be influenced by this power division. The power relationship and bias of the researcher was addressed by having interviews that were mostly informal. By means of informal interviews, the participants were able to lead the discussions and, therefore, focus on the issues that are most pertinent to them (and not necessarily the ones pertinent to the researcher). Because it is the participants who have the expertise in their lives, it was they who controlled the direction of the interviews. Another means of limiting the effects of researcher bias was to conduct member checks. At various (and numerous) points during and after the data gathering and analysis, the participants were asked to assess the interpretations and findings of the researcher to ensure that these were reflective of their perspectives. Further, the questions asked by the researcher were carefully framed in a way that would not lead participant responses. For example, the question “What psychological problems have you encountered since the onset of your kidney disease?” reflects a bias that assumes participants have experienced psychological problems. A better question would be, “What has your life been like since the onset of your kidney disease?” This and other similar questions were developed beforehand and placed in a question bank that was used by the researcher. This bank helped the researcher ask questions that avoided leading the participants and, at the same time, helped them focus on the topics of interest (so as to gain understanding of the participants’ world and fill in the gaps revealed by the literature). These questions stemmed from the literature and included many of the specific study questions listed earlier (see Appendix A for sample questions).

Another important issue that must be addressed is generalizability. In qualitative research, the goal of generalizability is not to be representative of all, but rather to provide information that is grounded in the real lives of those studied (Sandelowski, 1986). The type of generalizability utilized in this study is analytic (sometimes called interpretative). The purpose
of this study was to provide evidence that builds a theory of life for people living with renal failure, which is one aim of analytic generalizability (Yin, 1994). Further, this type of generalizability is often used when an existing theory is not sufficient and more data are needed to enhance the research (Merriam, 1998). Earlier it was argued that the model of self-management derived from the research left many gaps in our knowledge. One goal of this study was to provide data to fill in some of these gaps so that a fuller understanding of what life is like for people living with kidney failure could be gleaned.

The final issue that is addressed is the credibility (reliability/validity) of this study. Qualitative reliability has been described as problematic because the concept of reliability is based on the notion of a single reality or truth (Merriam, 1998). Reliability in this traditional sense is said to be impossible for this type of research and some researchers have suggested not using reliability measures at all. For example, Merriam (1998) held that:

Because what is being studied in education is assumed to be in flux, multifaceted, and highly contextual, because information gathered is a function of who gives it and how skilled the researcher is at getting it, and because the emergent design of a qualitative case study precludes a priori controls, achieving reliability in the traditional sense is not only fanciful but impossible. (p. 171)

Consistency and dependability of results have been suggested as a way to measure reliability rather than replicability (Lincoln & Guba, 1985; Yin, 1994). It has also been argued that because a study cannot be internally valid without being reliable, it is possible to use internal validity as a measure of reliability (Guba & Lincoln, 1994). In this study, reliability was enhanced by explaining the investigator's position, by using multiple sources of data (for triangulation) and presenting methods in detail so as to leave an audit trail (Merriam, 1998; Yin, 1994). However, as with many qualitative studies, reliability suffers in the pursuit of validity.
Internal (content) validity is the strength of qualitative research that focuses on understanding the perspectives of participants in a holistic and contextually grounded manner. Validity in qualitative research is based on truth-value and because it is accepted that there are multiple realities, these realities must have multiple constructs that are represented adequately. The object is not to find what is the one truth, but rather it is to find what is true for people in the study — that is, how they understand their world (Merriam, 1998). Guba and Lincoln (1989) used the term credibility in place of internal validity to evaluate this type of truth. Credibility in this study was established by collecting multiple sources of evidence (triangulation) and by conducting member checks (Lincoln & Guba, 1985; Merriam, 1998; Yin, 1994). The multiple sources of evidence were gathered from observations, interviews and documentation, and by doing more than one case study. Further, interviews took place with health care practitioners and the social supports involved in participants' lives. The member checks were both formal and informal, and took place throughout the study to provide evidence of the credibility of the results.

Participants

Purposive theoretical sampling was used, so that as much as possible could be learned from a small sample. The sample included three full participants and one partial participant all of whom had chronic renal failure. Of the participants who identified themselves as willing to participate, there was an attempt made to select participants who varied in age, gender, educational background, time on and type of dialysis, and marital status. In this way, it was possible to glean an in-depth understanding the lives of people with kidney disease from many different points of view. Further, according to Firestone (1993), a diverse sample can help improve generalizability — as each case can be thought of as a replication. The intent was to make the cases as similar to the target population as possible. All of the participants selected
were undergoing some form of dialysis therapy and lived in the Lower Mainland. They were at least 18 years old and were able to speak and read English fluently. All selected participants went through the hospital training program and were not slated for kidney transplant for at least six months. It is also important to note that the participants had no other complicating medical illnesses. That is, they had no other serious disease or illness unrelated to renal failure. The main social support person in each participant’s life were also included in this study. In addition, interviews were held with health care practitioners involved in the renal program (renal doctors, nurses, dieticians, and social workers).

The participants were people undergoing dialysis therapy through a large hospital in British Columbia, Canada. Hospital treatment and educational programs can vary substantially, so the use of only one hospital in a study may limit conclusions that can be drawn from the research findings (especially concerning educational programming). However, because I am familiar with this hospital and its program staff, there is an advantage of having open access to this participant group. This study required that participants allow a researcher into their homes and into their lives. Thus, recommendations from program staff may have been influential in encouraging participants to volunteer to participate. Further, the trust and rapport built in this hospital may have allowed me to gather more information on the various aspects of participants’ lives, as they may have been more willing to share information with someone who was familiar with their environment than someone who was not.

Method of Data Collection

The bulk of the data was gathered through one-on-one semi-structured interviews. Semi-structured interviews are often used when attempting to understand the perspectives of those being interviewed (Merriam, 1998). These interviews were conducted so that the participants were able to take the lead in discussions, and would have control over the direction and content
of the interviews. This approach helped to limit the influence of researcher bias as well as to
target the areas and topics of greatest concern to the participants. A few appropriate, non-leading
questions were developed and available to the researcher. These questions arose out of the gaps
found in the literature and focused on having participants tell their life story from the onset of
kidney disease. Other questions were developed that focused on obtaining information from
other sources, such as doctors and nurses. Secondary questions arose out of the interviews
previously conducted. These questions either helped to clarify what participants said or were
used to obtain information from different perspectives (for example, from participants’ social
supports). Developing some questions prior to conducting interviews aided the researcher to ask
non-leading questions, and to hone question-asking skills. This a priori work contributed to
improving the quality of questions that developed spontaneously in the interviews.

Interviews were conducted with the hospital staff involved in the renal program. These
interviews were more formal than participant interviews so it was possible to gain information
that could be compared to the information gathered from the participants. However, there was
an opportunity for health care practitioners to talk freely about the issues that they believed were
important. It was important to get the health care practitioners’ views in order to understand if
and how their view of renal disease differs from the view of participants. Further, these
interviews were used to triangulate the data. Interviews with health care practitioners provided
information from the medical perspective, which was compared to the life-focused perspective of
participants. Doctors provided information on typical medical problems associated with renal
disease, and how participants are viewed in the hospital setting, as well as the theories behind
educational and medical programming. Nurses shed light on the day-to-day lives of participants
in the hospital and the typical difficulties that the participants encounter. Social workers and
dieticians provided information on what is expected of participants once they leave the hospital setting as well as on the typical problems that participants reported encountering.

Similar interviews were conducted with the primary social support person that participants identified as important in their lives. The social supports in participants’ lives shed light on the types of supports that participants required and the availability of those supports. As well, interviews with people who support participants provided another data source that helps in the triangulation of data.

A number of follow-up, one-on-one interviews were conducted with the participants to help verify what was said and to fill in gaps where information was lacking. On many occasions, one participant raised an issue that was not raised by others or conflicting data arose. These conflicts were not seen as negative, but rather useful in understanding each person’s unique experience of renal disease. All interviews were recorded and transcribed. Transcription was done by the researcher and by a paid assistant. All transcripts were verified by listening to the recordings while reading the transcripts to note transcription errors or omissions. Recording and transcribing the interviews allowed the researcher to review and analyze all of the data gathered numerous times. As well, while the interviews were being recorded, the researcher was free to make notes and observations.

Another form of data gathering involved the use of tape-recording devices. On three different occasions, each participant was given a small recording device to use for one full day. During each of these days, participants were asked to speak into the recorder so that information could be gathered on what a typical day is like for someone with renal failure. Data from these recordings were collected both on dialysis and non-dialysis days. These tapes were also recorded and transcribed using the same procedures as the interview data.
Direct observation was another method of data gathering. Observation is important for a number of reasons. First, observations allow the researcher to note activities and objects that may have become routine to the participants but which can give important information about the context. Second, observations can provide information that participants are unwilling or unable to talk about. Third, observations can reveal data about which the participants are unaware. Finally, observations can provide verification of information gathered in participant interviews (Merriam, 1998). There are a number of environments that are important in relation to the lives of people with renal failure. The hospital setting has a number of locales in which disease-related skills are taught and carried out. Hospital personnel and people with kidney disease were observed in the training room, examination rooms, dialysis ward, and dietician's office. Dialysis also takes place outside the hospital, and, thus, a community dialysis centre was also observed. Observations in these settings permitted the gleaning of information on participant/practitioner relationships, social supports/stresses and on educational programming. Observations took place in participants' home environments as well. Information on social supports/stresses, and daily life functioning were gleaned during home observations. This information helped the researcher understand participants' perspectives by learning about and being involved in the contexts in which participants live. Further, observations often resulted in new questions being raised that helped clarify participants' perspectives. Observations most often took place before, during and after interviews with participants, their health care practitioners and social supports. The hospital environment was observed during interviews with health care practitioners as well as during interviews with participants that took place around their dialysis runs. The home environments were observed when the interviews with participants took place in their homes. It was also possible to observe the home environment during interviews with the participants'
social supports (if these people lived with the participant). When necessary, other observations were done outside the interview times.

The final data source is documentation. Documents were a helpful source of information because they were most often produced independent of the study and, thus, may be grounded in the context under study (Merriam, 1998). Further, because some of the data gathered for this study relied on participants' memories, documents helped to verify data gathered from interviews. For this study, participants' hospital files were scanned for pertinent information. Participant files were a valuable source of information on the kinds of medical outcomes emphasized in the hospital setting. As well, participant files often contained comments from social workers that elucidated the types of challenges that participants had to face and provided insight into the participants' psychological functioning as rated by hospital personnel. This information was compared with the viewpoints of participants.

In summary, the data sources that were used to triangulate the findings and improve the credibility of the research included interviews, participant self-recordings, observations and documentation. These data, however, were influenced by researcher perceptions and bias, and are reflected in the researcher's particular approach. According to Merriam (1998), because the researcher is the primary instrument in qualitative research, all the data reflect the researcher's particular "worldview, values and perspective" (p. 22). In this study, interpretation of the data was filtered through an integrative approach that holds, on the one hand, that multiple realities exist and, on the other, that there is a structure or essence to experiences. In both the interpretive and phenomenological approaches, the emphasis centres on shared meanings and lived experiences (Merriam, 1998). The focus of this research was to gain an understanding of the lived experience of renal disease and so I began with the belief that there is an essential experience to be delineated. Further, the data were filtered through the sociological tenet that
experience is situated in and cannot be extracted from the context in which it occurs (Lave & Wenger, 1991; Wertsch, 1991, 1998).

Procedure

Before beginning the study, I approached the hospital administrators to ascertain their willingness to participate in this research. After obtaining hospital consent and ethical approval from both the hospital and the University of British Columbia, I requested that the renal program manager determine participant eligibility (see Appendix B). Those people with kidney disease who were deemed eligible to participate in the study were sent request for participation letters from the hospital's renal program manager (see Appendix C). I spoke to all participants who volunteered to participate to explain what this study would involve for them. I reviewed study procedures and asked the participants to sign a consent form before they began the study. Further, social supports and health care practitioners involved in this study also were asked to sign consent forms (see Appendix D for sample consent form).

Data gathering.

After participation letters were sent, some initial data gathering was done at the hospital. The type of educational program that people undergoing dialysis treatment experience was examined. As well, observation of the health care personnel involved in the educational process helped to shed some light on participant/practitioner relationships. Other preliminary observations in the hospital setting were done at this time to gain insight into this part of the participants' world and to provide some background for participants' perspectives. They included observations of the dialysis ward, as well as of the training and examination rooms.

Once all possible participant volunteers were identified and the consent forms signed, some initial data gathering was done to select participants. This data gathering focused on each participant's age, gender, educational background, time on and type of dialysis, and marital
status. It was hoped that participants who differed on these variables would be able to offer a variety of viewpoints on the world of participants with renal failure. Three participants who differed on these variables were chosen to participate in the study. In order to provide age and gender balance a fourth partial participant was added to the study. The initial interviews were arranged with consenting participants. Where possible, the initial interview took place in participants' homes. Interviews in participant's homes are important because they provided an opportunity to raise questions about and observe the cultural context in which participants spend their daily lives. Observations of the participants' home environment also took place at this time. The initial interviews ranged from one to two hours, depending upon the needs and wants of each participant. These initial interviews were an important start in getting to know the participants, learning about their lives and determining their primary social support/s.

In the second phase of data gathering, second interviews took place. The purpose of the second (and subsequent) interviews was to augment and clarify information gathered at the previous interview, as well as to verify the researcher's emergent categories. The second interview most often took place before, during and/or after a dialysis run so that direct observation of the requirements of the process of dialysis was possible. Some participants dialyze in a hospital while others dialyze in a clinical setting. It was important to note the contextual information of these settings as a way to monitor one of the natural environments in which participants live. For this same reason, observations were also done at the site where the participant's medical education took place and the site where their initial dialysis sessions occurred (these were done before the participants were identified because these areas are common to all people undergoing dialysis therapy through this particular hospital).

In the third phase of data collection, I conducted interviews with the primary social supports identified by the participants. In these interviews, the people identified as social
supports were asked to describe their opinion of the impact of kidney disease. They were also asked to provide information on the type of support that they provide and how this impacts on their life. The people providing social supports were given the opportunity to discuss freely any topic they felt pertinent to their or the participants' lives. The health care practitioners were also interviewed during this phase of data collection. In these interviews information was gleaned on what practitioners perceive to be important in the lives of people living with renal failure. In these interviews, it was also possible to gather information on health care practitioners' perceptions of participant/practitioner relationships and on the atmosphere of the hospital in general.

During the first three phases of data collection, documents on each participant were reviewed for pertinent information. Participants' files were scanned for relevant information — such as social workers' and nurses' notes, and the ratings of success of dialysis from the medical perspective. Any notes that the participants took during their educational session and their educational program evaluation forms were also copied and reviewed at this time. This document review at times verified information gathered from observation and interviews, and at others raised new issues that were addressed in member checks. Also, during the different phases of data collection, each participant was given a tape recorder on three different occasions to use for one day. The tape recorders allowed participants to record all that occurred during a day in their lives. These recordings provided additional insight into what it is like to live with kidney disease both on and off dialysis therapy.

In the fourth phase of data gathering, final interviews were conducted. The primary purpose of these interviews was to verify the information gathered and to check the conclusions of the researcher. In these interviews, the researcher revealed the constructed picture of life with renal failure for evaluation by the participants. As well, final questions were asked about their
conceptions of how health care practitioners could best help them adjust to their disease. The participants were asked if they had any new information to add. It is important to note that this was not the first and only opportunity for the researcher to verify the emerging theories and conclusions. A number of member checks were conducted throughout the research as the data were compiled and new questions arose. These member checks varied from very informal (telephone calls) to very formal checks as more data were collected and compiled.

**Data analysis.**

After each phase of data collection, time was spent on data analysis. Each of the interviews were transcribed verbatim (by either the researcher or a professional transcriber) from the interview tapes. The transcripts were then read several times in order to begin to get a "picture of the whole" (Agar, 1980). As well, each of the transcripts was read while listening to the tape so that notes could be made on the transcripts about any "meaning-filled pauses" or emotional displays (Swanson-Kauffman, 1986). Further, listening to the tapes while reading the transcripts provided an opportunity to check the accuracy of the transcripts. Each interview and participant self-recording was analyzed for key points and important issues, and this was augmented by the data collected from observations and documentation. The transcripts were hand-coded by breaking down segments of talk into different topics. Codes were as simple as possible, so that they related directly to what the participant, their social support, or the health care practitioners had said. Each case was coded separately; however, as new codes arose, a re-evaluation of data was done to standardize the coding throughout. After the initial coding, a cross-case analysis was done to note similarities and differences between the perspectives of the participants, as well as between the participants, their social supports and health care practitioners. This analysis gave rise to some of the questions that were discussed in later interviews.
The above coding procedure was followed after each phase of data collection and with each of the interviews. Following the analytic techniques laid out by Miles and Huberman (1994), there was a search for common threads that led to the recognition of the salient issues that pertain to the lives of the participants. This was done using the cut-and-paste method. Once all the transcripts, observations and documentation data were coded, each section of text labelled with the same code was cut out and pasted together. Categories evolved out of the newly organized coded sections of text. Then, a categorization of ideas and topics was completed in order to facilitate the organization of data. It is important to note that data gathered from interviews with health care personnel and social supports were coded differently than participant-derived data so that they were kept separate. The participant data were then compared to the data gathered from other sources — including researcher observations and documentation from hospital sources. In order to improve reliability, a number of checks were done throughout the analyses. These checks include re-coding and categorizing random portions of data to compare them to the original codes/categorizations to check for consistency. The researcher at numerous points throughout the research completed the re-coding of random passages. This process of re-coding was executed until very few (if any) changes were required. At this point, random portions of the data were re-coded by other graduate students until there was little debate over the coding and categorization. Finally, members of the dissertation committee also re-coded random passages to verify consistency of coding.

The categories were revised and the preliminary theories based on the participants' view of their lives emerged. Using the categories derived from the data sources, there was an attempt to formulate a description of the "worldview" of the participants. This was then compared to the view of participants' social supports and health care practitioners. At this point, the study participants were re-approached so that member checks could be conducted. A number of
questions were asked during these more formal member checks. Participants were asked
questions in order to clarify what was said in their initial interviews. They were also asked about
issues they had not previously addressed which had been raised by other participants, or resulted
from researcher observations or from gathered documentation. Further, participants were asked
to verify or refute the interpretations made by the researcher. Questions were broached about the
suitability of the categories, plausibility of the researcher's representations and relevance of
theories proposed.

A final compilation of all the gathered data was then done. Categories and theories were
revised as required by the new information. A final member check was done to verify the
credibility of the data as well as to verify research interpretations. This process was repeated
until the participants were satisfied that the researcher's interpretations were a fair description of
their lives. The results were then presented in terms of descriptions of the participants' views,
the categories and themes that emerged, and the relation to the medical model. See Appendix E
for general codes and a sample of coded text, as well as an overview of data collection and
analysis procedures.
CHAPTER THREE  
From Person to Patient to Participant  

Overview  

The case studies of four people living with kidney disease are presented in this research. According to Wertsch (1991), it is necessary to understand the social and cultural contexts in which a person lives; that is, a person does not function in isolation. As Lave (1988) argued, a "person" as unit of analysis is different from a "person acting in a setting", and action and setting are a vital part of any analysis. To this end, people living with kidney disease were interviewed, as were their families and their health care practitioners. Further, these interviews took place in two of the primary environments where people living with this illness spend their time: at home and in the hospital or dialysis setting. Also included in this research are observations of these primary environments, as well as reviews of hospital documentation and medical textbooks.

This chapter begins by introducing the study participants to the reader by way of a brief description of the participants and by sketching out their personal illness histories. Following this introductory section, the themes that emerged from the data will be discussed. The central theme that emerged from the data relates to the work involved in living with kidney disease. The work of living with renal disease takes place in a particular context, culture and history; thus, the work of participants is situated activity rather than isolated encounters. This work falls into three sub-themes: 1) the work in the biomedical community, 2) the work outside the hospital or dialysis setting and 3) the work of living with the consequences of kidney disease. In the biomedical community there is much for people living with renal failure to learn and to which they must adjust. People diagnosed with renal failure must learn about dialysis and, with the help of their health care practitioners, choose a dialysis modality. Their work then entails adjusting to the hospital or dialysis environment and submitting to continuing dialysis therapy. The medical
system has clearly defined procedures and roles, and the work performed by health care practitioners is clearly delineated and recognized. Although the participants in this study felt that, on the whole, the medical system was serving their needs, they nevertheless had some critiques and suggestions for that system.

The work of living with renal disease also takes place outside of the medical setting. This work entails people monitoring their diet, fluid intake, medications and exercise. The findings of the present study revealed that this work is often much more difficult than it first appears. Finally, people living with renal failure also work to live with and adjust to the losses associated with their disease. These losses fall under three categories, namely losses in physical health, losses in cognitive function and psychosocial losses. While most of the work of living with renal failure falls in the hands of the people living with this disease, there are others who are also involved in the work. The significant people in the lives of those with renal failure also do a notable amount of work once renal disease has been diagnosed. Most of the work of others falls into the hands of family members; however, friends also work at living with kidney disease. This study revealed that the diagnosis of renal failure has a profound impact not only on the life of the person living with this disease, but also on the important people in the lives of these individuals.

Introduction to Research Participants

Four people participated in this study. These four people represent a diverse sample, and yet they share a commonality—living with kidney disease. All have chosen hemodialysis as their primary therapy. Each person will be discussed in turn.

"Bassan."

I first met Bassan during one of his dialysis sessions at the hospital. At that time he had been on dialysis only two months and he was very open to talking about himself and his experiences with kidney disease. Bassan, who described himself as a 74-year-old East Indian
male, was born and raised in Africa. He married in Africa and later (approximately 19 years ago) moved to Canada with his family. Bassan and his wife Anshu have been married for 50 years. They have two grown children — a son who lives in British Columbia and a daughter who lives in another province. Although he is now retired, Bassan has had many occupations and prides himself on being very organized and doing well at all that he has tried. He is an army veteran, and held high positions in both the police force and in a national investigation department. Once Bassan moved to Canada, he worked his way up from a parking lot attendant to becoming a property manager in the same company in British Columbia. After his retirement, Bassan led a very active life. He was involved in his Mosque, did volunteer work in a number of capacities, participated in leisure activities with friends and was “enjoying” his retired life.

According to Bassan, all this came to an abrupt halt with the onset of his kidney failure.

Bassan began his story in 1983, when he was diagnosed with diabetes. Since this diagnosis, Bassan, who believes strongly in the importance of following the advice of his physicians, has punctiliously taken his medications and monitored his blood sugar levels daily. He believed that compliance with his prescribed regimen would help him to avoid subsequent damage to his health. However, in 1996 Bassan suffered a diabetic coma, which ushered in the decline of his kidneys. After his diabetic coma his doctors monitored his creatinine level and he was referred to the predialysis kidney ward at the hospital. Over time Bassan’s creatinine level increased, and he began having some trouble with low hemoglobin. For these reasons it was suggested that he have a fistula placed in his arm, in preparation for dialysis therapy. Bassan expected that this would help him get the medication (EPO) he needed without charge. Generally, medications without charge are provided only for people undergoing dialysis therapy. Further, it was Bassan’s understanding that this was only a preparatory measure and that he had plenty of time
before dialysis started. Unfortunately, this surgery was the catalyst for the start of Bassan’s dialysis.

I wasn’t in need of the dialysis then, maybe for the future. But the surgery he did, such a mess of my arm, all the way right up to my chest here. That it gave me a couple of heart attacks... My creatinine went from 400 to 600 and all that and I was pushed into this dialysis.

"George."

George, a Caucasian, 62-year old retired police officer, had been on dialysis for five years when I met him at his home in British Columbia. He is married, has two grown children (both of whom also live in British Columbia) and two dogs. When relating the story of his renal failure, George described how “shocking this whole thing” was for him. Ending up on dialysis was a complete surprise to him because he had “no signs of illness prior to this incident with my kidneys.” George’s kidney troubles began about three years after he retired when he became “rather suddenly ill with continuous nausea.” After some diagnostic tests at the hospital, it was discovered that George had tumours on both of his kidneys and it was at this point that he began emergency dialysis therapy. Because there was no prior warning, he was not yet fixed with a fistula and so George’s initial dialysis sessions took place through a neckline⁶—which added even more stress to an already stressful time in his life. Soon after dialysis commencement, he had two surgeries to have both of his kidneys removed and then had a third to have a fistula placed in his arm. George, to this day, is uncertain if the tumours were cancerous, as he was never referred to the Cancer Clinic—but it was thought on diagnosis that the tumours were malignant. For the first two years of dialysis therapy, George went to the hospital for dialysis; however, after some training he was able to transfer to a community dialysis centre to begin self-care hemodialysis (approximately three years ago).
Pearl is an upbeat and positive 32-year-old, single, Caucasian woman with a history of kidney disease that spans most of her lifetime. She was born and raised in Manitoba, and there she completed a degree in science and a degree in the health care field. She moved to British Columbia approximately four years ago to begin work on a master’s degree in Health care Education and Research. Her great love is travel and she collects art from all over the world, which she proudly displays all around her apartment.

Pearl was first diagnosed with kidney disease when she was 12 years old and began dialysis at that time. It wasn’t long before she received a kidney transplant with a donated kidney from her mother. This kidney allowed Pearl to live without dialysis therapy for 10 years; however, it began to fail when she was 22 years old. When this kidney began to fail Pearl “decided to go to Australia for a year” against the advice of her doctors. After 10 months she was “ordered home” because her creatinine level had skyrocketed to over 1000. Once back in Canada, Pearl began emergency dialysis and after being weaned from her transplant medications for two months she was placed on the transplant list. Pearl was fortunate enough to receive a kidney after being on the transplant list for only one day—this is something so unheard of that Pearl had a hard time believing her mother when she was told the news. Thus, at age 23, Pearl had an operation to receive her second donated kidney. This new kidney lasted seven years before it too began to fail, and she was then back on dialysis again. When I met Pearl, she had been on dialysis since May of 1995 and was undergoing self-care hemodialysis at a community dialysis centre. She was again on the transplant list.

Olive is the oldest of the participant group, at 86 years of age. She is Caucasian, a highly independent and personable woman. Olive has both children and grandchildren living in British
Columbia and has many long-time friends with whom she enjoys social activities. She was widowed a few years ago and now lives on her own in a condo with a “lovely view of the water.” When I met Olive, she was undergoing dialysis therapy at the hospital and had been doing so for nearly a year. Although she was diagnosed with kidney disease almost 10 years ago, she was able to go without dialysis for nine years. However, after experiencing a number of congestive heart failures, she believed she had no other choice but to submit to dialysis therapy in the Spring of 1997. Olive was not interested in being a full participant in this study; thus, her social supports were not interviewed and she only participated in interviews that took place during her dialysis runs at the hospital. This way, she felt that she could be a part of the research study without having to give up any of the precious few hours she has away from dialysis.

The Work of Living with Kidney Disease

Throughout the interview process the participants, their families and the health care practitioners all made it clear that living with kidney disease is a burden that is difficult and time consuming. While not all those interviewed agree on which part of the disease is the most difficult or burdensome, there were some themes that emerged that reflected the various difficulties associated with this disease. It is clear that kidney disease results in many physical ailments which often place limitations on participants’ lives. Further, people with renal failure are confronted with life-and-death decisions on a daily basis. People with kidney disease must not only decide whether they will submit to dialysis as a life-saving therapy, they must also make daily decisions regarding diet, fluid intake, medications and more. These decisions have a profound effect on the people’s feelings of well-being and overall health. In contrast to models of self-management and self-regulation, we will see that the person does not make these decisions in isolation. Cultural, historical, psychological and social factors have an influence on the decisions that people living with illness make, as well as, on the options that are made
available for them to choose from in the first place. Thus, some of the limitations on the lives of
people living with illness stems not from their kidney disease per se but, rather, from the worlds
in which they function. Further, the decisions people with renal disease make have an influence
not only upon their own lives, but can also affect the lives of the people around them.

This section begins with a discussion of life for the participants in the biomedical setting.
In this setting people living with renal disease must work to learn about and deal with their
disease. However, life for people with kidney failure also takes place outside of the medical
setting and the work that is done outside the hospital/dialysis setting is also discussed. Finally,
living with renal failure requires that people work to deal with the losses associated with their
disease. These losses typically occur in the areas of physical health, cognitive function and
psychosocial domains.

The Biomedical Community

Living with kidney disease is work, though it is not always considered such. According to
Strauss and Corbin (1988) any long-term illness requires work of the people who are ill, their
families and their health care practitioners. The work of living with renal disease encompasses
many spheres of life; this work, however, is not done in isolation. People living with renal
disease belong to and participate in many different communities. One community is the medical
community. It is in the medical community that people living with renal disease are taught about
dialysis and the dialysis modality choices. Further, it is in this community that people with renal
failure begin to adjust to life with dialysis and to learn their role in the medical system. The
participants in this study all felt that they had learned to adjust to life in the hospital/dialysis
centre but they had some critiques and suggestions for the medical community. It is in this
community that people are not thought of as people but, rather, are thought of as "patients."
In recent years researchers and health care practitioners have recognized that a disease or ailment does not define a person's being and, thus, there has been a change in discourse such that people are no longer referred to as their disease. People are now identified as patients with a specific condition or ailment (for example, "patients with kidney disease" rather than "kidney failure patients"). However, the use of the word "patient" itself can be problematic in that it intimates that people are merely recipients of care rather than legitimate participants in their own care. Further, being labelled as a patient suggests that all other areas of a person's life be subsumed under this title. Pearl, for example, did not "see" herself as a patient; she was a person who happened to have this disease. In fact, she didn't even consider herself to be unhealthy. This flies in the face of all her nursing education, where health is defined as "absence of disease." In her words, "I can function, I do whatever I want, I go to school, I do volunteer [work], I'm busy...." Pearl, as well as the other study participants, have not accepted the medical definition of "health"—despite acknowledging that they have a chronic disease, all consider themselves to be "healthy."

In this study, people living with renal failure are referred to as "participants" rather than "patients." All language has a cultural and historical base (Wertsch, 1998) and "patient" is no exception. Few would argue that in our society the word 'patient' denotes notions of ill-health, passivity, pain, sadness and someone in need of care—this is especially true when related to the
hospital setting. According to Wertsch (1991), language mediates action, and therefore, being labelled as a patient affects both how people act and how others react to them. Thus, being in the position of “patient” is often negative and disempowering. There is a need for a change in discourse, such that people do not “become” patients once they enter the medical arena. I believe that more than being participants in this study, people living with renal failure are participants in their lives and in their daily well-being (though currently this participatory role is limited in the medical setting). They are not under someone’s care as the word patient might suggest — participants play a large role in their own care outside of the medical setting. Further, I would argue that the word “participant” suggests that people share in the work of their care and, thus, gives a new value and importance to this work.

In the biomedical community, the symptoms and suffering of people are made legitimate with the “scientific” diagnosis of a disease or illness. Aronowitz (1998) argued that because our society accepts the biological model of disease, pressure is put on individuals to understand their suffering in these terms. Frieda (George’s spouse) observed that George was doing a lot more physical work around the house before he was diagnosed with kidney disease. For example, “…he was shaking the roof of our house when he had a hemoglobin of 69. He would shake for a while and then come [in] and lie down…and he did more then, more not knowing that he was sick, than he does now.” Thus, despite being “healthier” because of dialysis therapy, the diagnosis of a disease changed how George functioned in his daily life. Our cultural understanding of disease has an impact on how those living with disease make sense of their lives and their illnesses.

Since diagnosis of disease is in the hands of health care practitioners, specifically doctors, it is the health care practitioners who hold the power over the legitimacy of people suffering (Aronowitz, 1998). Without a diagnosis, a name for their suffering, people may not receive the
support they need from health care practitioners, family and society in general. However, diagnosis of a disease is not as “scientific” as it appears (Aronowitz, 1998). Payner (1996) argued that “while medicine benefits from a certain amount of scientific input, culture intervenes at every step of the way” (p. 26). Her multinational study demonstrated that the same “clinical signs” might not result in the same diagnosis. Further, a person’s disease and treatment protocol may change just by virtue of changing the country of residence. Even within the same country, diagnoses and treatment protocols may vary in different medical settings, with different health care practitioners and over time. For example, in Manitoba, people with kidney disease are not allowed to eat while on dialysis because health care practitioners believe that eating results in dialysis complications (such as cramping), while in British Columbia this is not the case. In fact, it is common for people undergoing dialysis therapy at one of the dialysis centres to order in food for dinner and the nurses at the centre distribute this food. It is clear, then, that some of what is accepted as good medical practice in one place may not be in another.

In Pearl’s long history with kidney disease, she had noticed that there were trends and policy changes in acceptable medical protocol. These changes can sometimes make life difficult for people with renal disease because what was acceptable protocol one week is not the next. For example, Pearl talked about the renal dietician with regards to changes in protocol:

Pearl: I mean if you look at my blood work, everything is normal.
Shawna: Yeah.
Pearl: Is in the normal limits but that seems not to be good enough for her, the minute something is out of whack slightly, she jumps all over it. Or that, because they’ve just changed the policy that you’re albumin has to be more like 40 and mine is only like 36 or 37, all of a sudden, you know, she’s telling me to eat more protein. It’s like well, yeah, but you just changed the policies and you know I eat protein but I go through stages. And you know, sometimes I can’t afford it.
Shawna: Eat beans.
Pearl: You know… but anyway, I mean, it also you know, it has to do with trends.
Shawna: Right.
Pearl: You know but if my albumin has been like 37, 38 for like 20 years
Shawna: Yeah
Pearl: If it is going down yeah, or if my potassium is all of a sudden on an upward, yeah, I can see. But trend wise, I mean, everything is normal. So I mean, I think I’m doing a pretty good job of it.

Pearl obviously believed that she is doing “fine” and although she appreciated the amount of respect that the health care practitioners do give her, she still would have liked to more say in her own care. Similarly, Payner (1996) argued that given the subjective nature of medicine, people living with disease should be given more say in their own care. However, it is Payner’s contention that “scientific medicine” dominates over “unscientific patient desires.” This dominance can be seen in all areas, not the least of which is in the institution of the hospital.

One of the major arenas of the biomedical community is the hospital. The hospital is a very familiar place for those living with renal disease. Participants are introduced to the hospital setting through dialysis therapy and the numerous other procedures related to their disease. It is in the medical arena that people with renal disease learn to speak using medical discourse and, thus, become members of a dialysis community. Membership in this and other communities is facilitated by knowledge of the distinctive discourse in that community. However, community membership also requires activity (Lave & Wenger, 1991). In the medical community, people living with illness are limited by the restricted role allotted to them and by their limited access to the discourse.

**Learning about dialysis.**

From the health care practitioner's standpoint, an ideal situation is when kidney disease is diagnosed early. This way, before any medical procedures are required, people with renal disease have the option of familiarizing themselves with their kidney disease and the hospital setting by participating in a pre-dialysis clinic. Both Bassan and Olive were given this opportunity and both chose to attend the pre-dialysis clinic. George, on the other hand, was not able to attend pre-dialysis because he was diagnosed with kidney disease at a point when his
kidneys were no longer functioning. Therefore, he had to start dialysis therapy on an emergency basis. Pearl, too, began this round of dialysis in an emergency situation and, thus, did not attend a pre-dialysis clinic. However, given her long history with kidney disease and her health care background, a pre-dialysis clinic would probably not have been as helpful to her as it might have been for others with this disease.

Whether or not the participants were willing and/or able to attend a pre-dialysis clinic, all in some way had to work to obtain new knowledge about kidney disease. While much of what people living with renal disease learn comes from their own lives and experiences, more formal training takes place in the hospital setting. Formal training is considered the province of health care personnel: doctors, nurses, dieticians and social workers. The dialysis educational program is designed by health care practitioners and focuses on: instruction about kidney function, different dialysis therapies, reducing fluid intake, the make-up of most foods, the dialysis diet, necessary adjustments to accommodate the dialysis schedule, transplantation issues, and more. The participants’ educational programming took place at the hospital; it began in pre-dialysis (where possible) and continued as participants began dialysis therapy.

Patient education is defined as “the process of influencing behavior and producing changes in the knowledge, attitudes, and skills required to maintain and improve health” (Ranking & Stallings, 1990) and, as such, involves teaching and learning. Teaching is defined as “the intentional structuring of content and environment to enhance human interactions in order to facilitate learning,” while learning is defined as “a change in behavior” (Baer, 1995).

(Wick & Robbins, p. 839)

There are many things that people with kidney failure must learn and one of the most difficult of these may be learning that they have a disease for which there is no cure. Although
people living with renal disease may hear this fact from their health care practitioners during the formal educational program, adjusting to this happens in the activity of their lives, both inside and outside the community of the hospital. It often takes a great deal of effort to adjust to the fact that life has changed dramatically. Most of the study participants had little knowledge of kidney disease and dialysis therapy before the onset of their disease. Except for Olive, no one had any close friends or family with this disease before they themselves found out about their illness. The reaction to life with kidney disease was often surprise and angst, especially when the reality of dialysis therapy set in. During his pre-dialysis training Bassan didn’t really believe that he would end-up on dialysis:

...Dr. ___ referred me to the clinic here at ___[hospital name]. And here I was shown on TV by a nurse, she showed me how the hemoglobin at that time I was, I guess I never thought I’d be one of them. I just took it, blah, blah, blah and got out of it, that’s the time they were actually wanted to show me. They brought me in here and I saw the same gentlemen sitting in the chair enjoying his tea and on dialysis so I thought it was like fun until I realized that you had to sit for four hours like that, like a statue there.

So, while Bassan was exposed to and taught about kidney disease and dialysis, it wasn’t until he was part of the activity that he really understood the implications of his disease. It is work to learn about and depend on a dialysis machine for your survival, although this is not work that is legitimized by the hospital institution. In Olive’s words, “...it is the dialysis that keeps you alive,” though once you have decided to submit to dialysis therapy you have “no other choice.” It appears, for these participants at least, that the real learning is in the doing, the living with dialysis, not in the hospital training programs.

Learning about and choosing a therapy

At some point after renal disease had been diagnosed, participants had to learn about different types of dialysis and, with the help of their doctor, family and/or friends, select a form of dialysis that best suited their life and health. This decision was not a simple one. Through educational programs designed by health care practitioners, participants were taught that there
are two basic kinds of dialysis, hemodialysis\(^7\) (HD) and peritoneal dialysis\(^8\) (PD). PD is a form of self-care dialysis and requires that people with renal failure be trained to administer their own therapy. There are two types of PD, one requires that people with renal failure dialyze during the night and the other requires dialysis numerous times during the day. People with kidney disease undergoing PD must have a tube placed in their abdomens so that they have a permanent dialysis access site and they must undergo dialysis daily. HD, on the other hand, occurs three times per week for four hours and is done in a hospital or special self-care dialysis centre. Participants who choose HD must have a permanent access site placed in their arm where needles can be inserted at each dialysis session. Although this very basic information may be more than people with renal disease can comprehend (especially if they are still dealing with the fact that they have kidney disease) this does not give them a real understanding of life with each of these therapy choices. Nor does it give them access to dialysis technologies from a perspective other than that of the health care practitioners. This lack of transparency of the meaning of the technologies from which they must choose makes it a very difficult decision indeed.

All the participants in this study chose to undergo hemodialysis therapy. The reasons behind their choices were quite diverse and sometimes contrary to "expert" medical opinion. While one form of dialysis may be better from a strictly medical standpoint, the reasons for choosing one form over another may have nothing to do with physical well-being. For example, Pearl said that she chose hemodialysis over peritoneal dialysis because:

...it [a fistula] is better than having this tube out your stomach as far as I'm concerned...I'm young, I'm single, I still like to wear a bikini, I like to swim, you know, it just wasn't for me.

Similarly, despite a recommendation to do so by his doctor, Bassan did not want to undertake peritoneal dialysis.

Bassan: ...there is a suggestion to get dialysis done at home, but it appears that at the moment, as it is, my wife has to do only limited for me because of cooking and all
other house work and all that. And she mentally cannot cope with it. She’s scared that if I start doing at home we have not enough room in the house and everybody will go haywire. So my son and everybody suggesting you stay if possible in hospital for your dialysis rather than at home, because I’ll mess up everybody. Myself, my wife, my house, everything. So I’m trying to explain that to Dr. next time when I see if I can, see if there is a way we can delay the whole question of my surgery in the tummy.

Shawna: Right.
Bassan: Because also my arm isn’t getting enough blood circulation in this part, it always cold.
Shawna: Yeah and you have to wear a glove for that.
Bassan: Yeah, and this was after the surgery, all the blood is pumping up and not pumping enough down. And Dr. he was to cut artery from my leg and put it here (points to arm). Now that would be another surgery. Now I already had two heart attacks from the last surgery and I hardly survived and I don’t know whether any more surgery, particularly under this condition of my hand, whether I’ll survive.
Shawna: Yeah.
Bassan: So I was requesting everybody to delay it and let’s see for the future.

Further, Bassan’s family believed that doing home dialysis would be a “disaster” for both Bassan and Anshu, yet they felt pressured by his doctor to do so. According to Bassan’s daughter

Salima:

Salima: ...you’ll end up having two patients and I really mean it, you will end up having two patients, if he starts having dialysis at home, it’s going to be a disaster.
Shawna: ...Are they trying to make him have it at home?
Salima: ...they are trying to convince him to have dialysis at home, but little do they know what’s going to happen. The dialysis at home is ...three times a day, four times, four times, so what will that do to him?
Shawna: Yeah, that’s interesting and has he stated that he doesn’t want it?
Salima: No, he doesn’t want it.
Shawna: And so why are they trying to?
Salima: I don’t know, because they need the dialysis machine in the hospital, I don’t know. ...So you know, when you look at it from all, that way he gets out of the house, he meets some other people. Socially, mentally, it’s better for him. Okay, but if he’s in the house then he has to do four times a day. Just going for dialysis the next day he’s collecting his clothes and this and that. Then you can imagine what will happen if it’s four times a day.
Shawna: Right and then more work falls on your mother, yeah?
Salima: But you know, for that [home dialysis], two patients, that’s all I can do, that’s all I can say. If the government is rich, they can do that.
Shawna: It’s not worth it.
Salima: No, it’s not worth it, you know, so I don’t know.
Shawna: Yeah, that’s a good, actually a very good point that they need to listen to that instead of trying to push him into something.
Salima: Yeah, well they've been... I haven't talked to them personally but from what I hear from my father and even my brother. I think they wanted him to do home-dialysis because it's better for you and this. I agree it's better because you're doing it four times a day.
Shawna: Right.
Salima: So you're cleaning out, you know, more. But what will it do to the other side of the life?
Shawna: Because they're thinking medical and not anything else.
Salima: Yes and medical is inter-related with your other life too. If you're mentally, socially, every each way, if you are happy you will be able to accept your illness and you will work it out okay, because it's a positive attitude.
Shawna: Right.
Salima: But he doesn't want to have a positive attitude at all... he's an outgoing man, he can't stay in. She'll [Anshu] end up in a loony bin. I tell Mom, you end up in a loony bin.

It seems clear that there is much more to choosing a form of dialysis than merely medical considerations.

Like Bassan, Olive had no interest in home dialysis, or any other form of self-care dialysis for that matter. “I don’t want to be bothered, and looking after myself, because it’s too nerve racking, at least I would find it so.” It is interesting to note, however, that most self-care hemodialysis patients are notably younger than Olive. It is possible that her choice of dialysis mode was constrained by our cultural understanding of age. That is, older people are thought to be not as adept at learning as younger people are and they are expected to be more ill and more in need of care. Thus, when dialysis options are being discussed, it may be that the self-care option is not presented as a real option for older people living with renal disease. According to Wertsch (1998), our actions are both constrained and facilitated by the choices that are made available. In Bassan’s case, despite his age, PD was suggested because it was thought to be better for him medically. However, when he and his family dismissed this option, there was no suggestion from health care practitioners that he undertake self-care HD. This is particularly interesting because the reasons for rejecting PD would not interfere with self-care HD, yet self-
care was not suggested. It is possible that Bassan did not fit the typical profile of a self-care HD participant and, thus, this option was not suggested for him.

Both George and Pearl were given the option of, and chose to undergo, self-care hemodialysis. They underwent the extra training at the hospital that enabled them learn how to carry out the necessary steps of dialysis. This training and the experiences of running their own dialysis allow increased knowledge of medical “dialysis speak” so that George talked about blood pressure and pulse rate like a health care practitioner and Pearl uttered sentences like the following:

...and plus 3.3 per rinse back and then whatever you’re going to drink they add, so the bottom line seems to be, you know, higher. I’m sometimes up in the five’s but it’s usually because I’m having a coke, some ice maybe, maybe something to eat, soup or something. So it gets all very technical, figuring how much you can drink, how much to weigh...

Whether or not people with renal failure undertake some form of self-care dialysis, there is much to learn about kidney disease. All participants have taken on some of the medically focused “dialysis speak” that is used in the hospital or dialysis centre. Understanding how kidneys function and what they do for your body is a complicated matter, yet those living with kidney failure become “lay experts” in the area through their own activities and experiences of living with this disease. Lay expertise is evident in George’s explanation of kidney failure:

...you have been deprived of a vital body function you know, because the kidneys not only clean your blood and so on, but they also have a lot of other functions that you don’t really think about. They produce certain kinds of enzymes for your body which you are now without. And certain things that you can make up for like, you get your, every time you come for dialysis you get your EPO hemoglobin injections and certain things that can make up for it... I’m not sure that they know all the functions of the kidney.

Renal Failure (1995)

The kidney is the main emunctory of waste products as well as the regulator of volume and electrolyte composition of body fluids. To perform this function, the kidney produces (exocrine function) and subsequently excretes urine.
In addition, the kidney plays a critical role in the modulation of arterial pressure, red blood cell production, and skeletal growth/structure by secreting humoral factors (endocrine function). (Adrogue & Wesson, p. 3)

While people living with kidney disease do have some access to medical discourse though their use of “dialysis speak”, this access is limited. Lave (1993) argued that the use of scientific or technical language is one means used to legitimize the power of some at the expense of others. In this way it is possible for health care practitioners to have a stronger voice in the discourse and, thus, to have their opinions prevail. The limited access of people with renal failure into the medical community through the use of scientific discourse is further exacerbated by the set-up of the dialysis environment.

The hospital and dialysis centre environments.

Both George and Pearl dialyze at a community dialysis centre while Olive and Bassan dialyze at the dialysis ward at the hospital. The differences between these two dialysis settings are quite substantial, though the actual process and the machinery of dialysis are identical. From my observations I noted:

The dialysis ward at the hospital looks remarkably similar to any typical large hospital ward. There is a large nurse’s station, and patients lying in beds all around a large room, as well as a few smaller rooms. Most patients are either sleeping or using earphones to watch the little individual televisions that hang over their heads. Some people look really ill; others look more “normal.” However, there appears to be a look of fatigue for those on dialysis, maybe it is the fatigue of having to sit in the same spot for so many hours. Some patients have friends or family members to keep them company, but most are on their own.

It is most common for people with renal failure to have plenty of visitors when they first commence dialysis but as time wears on, most people on dialysis are left on their own. For example, when George first began dialysis, Frieda came with him to every dialysis session. She felt this was necessary as he had a neckline and was unable to move around. Frieda helped George eat, get as comfortable as possible and generally adjust to his new situation. This
experience with dialysis spurred Frieda (already a health care practitioner), to take more training
to specialize and work with people on dialysis. As time passed, and George was better able to do
things for himself, Frieda no longer sat with George during his dialysis session. Now he, like
most others, sits and watches TV to help pass the time.

On my numerous visits to the dialysis ward at the hospital, I became familiar with the
routine and the feel of the ward. Like that of the participants,

my first stop is the daily dialysis board, where the hospital staff maintains a list of all the
dialysis patients, the times and bed numbers in which they will be dialyzing that day (these
change at each dialysis session). The beds are organized numerically and labelled so that
they are easy for patients, staff and visitors to find. I search the list for Olive and Bassan’s
names and bed numbers and then set out to find one of them. I again get confused about
where the numbers start and need to wander around a bit to get my bearings (this is
especially true for the extra rooms they’ve [the hospital] added at the back to accommodate
more patients).

Most times the participants in this study, like other people on dialysis, were quietly watching
television, and welcomed my tape recorder, all my questions and me. At other times, interviews
were delayed (e.g., when a nurse was lecturing Bassan on the dangers of his high fluid gain) or
put off altogether (e.g., when Olive was sleeping or feeling unwell).

I find it so interesting that the participants look different in the hospital beds than they do at
home; they look sicker somehow.

The only thing that separated the appearance of this ward from others in the hospital was
that each person is hooked up to a dialysis machine. That is, this ward did not appear any
different than other wards where the people were constantly changing. From an observational
standpoint, there was nothing to indicate that the people on dialysis may have been dialyzing in
this same ward, with many of the same people and health care practitioners, for many months
and/or years. Very little (if any) social interaction occurred between the people on dialysis or
between the people on dialysis and the health care practitioners. Conversation between people
on dialysis is difficult because of the placement of the dialysis machines and because people on
dialysis do not have freedom of movement. Olive, for example, had her arm “tied” down to her bed so that she would “remember not to move.” This would make it very difficult for her to talk to the person in the bed next to her for any length of time. As well, some people on dialysis utilize neckline accesses and, thus, lie facing the ceiling and must try to be as still as possible. This makes conversations with the other people on dialysis all but impossible.

In my observations, I found that health care practitioners rarely spoke to the people on dialysis on matters other than medical. Further, practitioners often performed their work without speaking to, or even looking at, the person who was receiving care. On one visit to the hospital, I wrote the following in my notebook:

How hard it must be to be tied down to a bed and to look around you and see others [practitioners] moving about freely. The lack of interaction between practitioners and participants seems astounding. Again and again I see people going up to the machines to do work and yet not even acknowledging that there is a person tied to that machine. It beeps, they come, they fix, they leave. No interaction (or no human interaction).

There was a clear division between health care practitioners and the people on dialysis. No division was so clear as the large nurses’ station that separated those who gave and those who received care. As well, the health care practitioners all wore some type of uniform and were easily identifiable on the ward as they went about their work and/or socialized amongst themselves. Participants, it appeared, were seen as the recipients of care and not as members of the hospital community. This may stem from our cultural history where institutions place a high value on the “scientific attitude,” which lauds objectivity and professional conduct (Smith, 1987). It seems astonishing that people can spend so much of their time together and yet have very little social contact. However, it is important to note that health care practitioners are limited in the time they can spend with each person on dialysis. An increase in the number of people on dialysis coupled with a decrease in medical funding has left health care practitioners
with fewer and fewer resources. Healthcare practitioners, too, are constrained by the medical system in which they must function.

All the health care practitioners whom I interviewed (doctors, nurses, social workers and dieticians) found a large amount of support and camaraderie among the staff at the hospital. They liked the environment of the hospital and described the dialysis ward as “a warm and caring place.” At the same time, these health care practitioners recognized that people who come to the hospital for treatment may have a very different perception of the hospital environment. That is, they recognized that as health care practitioners, they had chosen to spend their time in a hospital environment whereas the people on dialysis had not chosen to have kidney disease. Further, all people undergoing dialysis therapy have endured a number of unpleasant procedures in the hospital and cannot help but be reminded of these every time they enter the hospital setting. Most of the practitioners do not have to deal with these kinds of unpleasant memories.

All of the study participants had undergone surgery related to their disease. Most of these surgeries took place before dialysis onset (and, thus, before this study began). Both George and Pearl had their kidneys removed. For George this meant two separate surgeries, one for each kidney. Pearl had four surgeries on her kidneys, “I’ve had two kidney transplants and I’ve had them both taken out....” Further, everyone who undergoes dialysis therapy requires an operation to insert a permanent site in order to access the blood stream. For those undergoing hemodialysis this is commonly a fistula, which is most often placed in the middle to upper arm. As George explained it, “...they actually join an artery and a vein with the fistula so that they can use it, they can keep tapping it in this fashion.” Like any operation, the surgery for having an access inserted is painful and has many risks. In Bassan’s case, problems arising from this access surgery were the reasons he believed that he began dialysis prematurely.
It all started, my kidney was functioning around 400 and it was suggested that I should take fistula fix, so that in future, if I need it I'll be able. So it was arranged with Dr. _____ to go for a surgery. Somehow when I woke up in the morning, next day he had made a mess of my arm. You can see, right up to there, all the way up to there [pointing to shoulder area]. And then I was told that he couldn't fix the fistula so he has put a graft in here, in my upper arm and also here and I went home. The next day the nurse came for dressing and she saw my bleeding and all that and she told me stop dressing everything, go immediately to hospital, you are under heart attack....That it gave me a couple of heart attacks....and I was pushed into this dialysis.

Also unfortunate was the fact that this graft didn't last long for Bassan. After only four months, a clot developed in his graft and he was forced to undergo another access operation. Fortunately, this time, the operation was more successful and Bassan received a fistula in his other arm. However, during the fistula healing time (approximately 6 weeks), Bassan had to use a temporary neckline access, which is painful and uncomfortable.

Bassan is not the only one who has had problems with his access; it seems that access problems are a regular part of life for those undergoing dialysis therapy. Olive has had a number of problems with the lines of her fistula.

Olive: But, uh, and sure it's fine right now but I've had, the line in four places before I had this and that makes it rather rough.
Shawna: Does that mean four different surgeries? Is it a line or is it, are they?
Olive: Yes, this is a fistula.
Shawna: Yeah.
Olive: But the lines come, they started here and they couldn't find anything, a vein and two hours later after poking around they started on this side and found one. And it stopped working and they put it under my collarbone. That stopped working, then they put it in my groin and that stopped working. So you just put up with it.
Shawna: Yeah.
Olive: Period.
Shawna: And these ones are doing okay? Knock on wood.
Olive: Please God. Yeah, and like I have a friend in here who is having her dialysis on a fistula and I just saw her when I was coming in, and she was going down the elevator as I was coming up. And she's had one awful time so I pray to God that my fistula doesn't blow, as they say, because it's just one thing after another. And I'm sure that I'm not the only one who's gone through this.

Similarly, George has had some problems related to his fistula. His fistula has swollen quite significantly and there are obvious mounds on his upper arm, "You always find that with long-time, long-term fistulas, they get swollen...they become pretty large with prolonged use." As well, George had one site that he had to abandon because of clots. Another related fistula problem occurs when clots develop and move up the arm and into the chest. This occurred for both Olive and George, and, as a result, each had two angioplasties, which as George explains is "where they expand your vessels." Consequently, it is easy to see why people with renal disease may have many unpleasant memories associated with the hospital.

The atmosphere at the community dialysis centre is quite different from that of the hospital. Unlike the hospital, the self-care centre is not linked to memories of difficult, painful and/or frightening health care procedures. The dialysis centre is located in the community, in a regular office building and not in the hospital setting. According to Pearl, an advantage of the dialysis centre is that one does not have to deal with the "illness mentality" of the hospital. For all those undergoing therapy at a community dialysis centre, dialysis is not new; these people have already spent some time adjusting to their disease and dialysis therapy during training and dialysis therapy in the hospital.

The patients at this centre sit in reclining chairs rather than beds and tend to be a lot younger and appear healthier than the hospital population. Most often the patients have an assigned chair and, thus, they always dialyze in the same spot (though it seemed to me that every time I come to interview Pearl she was in a new spot). Like the hospital, there is a list of all the patients and the chair in which they are dialyzing; however, I find that the set-up of this centre made looking at this chart unnecessary—both George and Pearl can easily
be spotted from the entranceway. George is the easiest to find—I just scan for the most restless person in the room. Somehow both of them look different here (different from how they look at home).

Though the atmosphere of community dialysis seems more congenial than the hospital, there still seemed to be very little socializing going on between the people on dialysis and between health care practitioners and people on dialysis. Like the hospital, there was a nurses’ station that separated the people on dialysis from the health care practitioners. Unlike the hospital however, this separation was exacerbated by a glass partition that spans from the top of the desk to the ceiling. Thus, health care practitioners could be seen, but communication required that they step out from behind the nurses’ station. This obvious physical barrier could be one reason that the practitioners tended to socialize amongst themselves rather than with the people on dialysis therapy. However, the barrier between participants and people on dialysis was more than merely physical. Although people on self-care dialysis have more input into their care than they did when they were in the hospital, they are still not in the same privileged position as the health care practitioners. It was the practitioners who had the power over the tools used by the people with renal failure. That is, practitioners had full access to the medical discourse, they decided when people with renal failure would dialyze, how much fluid they should take off, how much they should weigh, etc. This inequality in access to the tools of the dialysis community could also have had an effect on the relations between the practitioners and the people living with renal disease.

Dialysis Therapy (1993)

Writing orders to achieve prescription dialysis therapy commences with a careful assessment and review of the patient’s physiologic condition. Prior to writing dialysis orders, the nephrologist consults with the interdisciplinary team members (i.e., surgeons, nurses, technicians, dieticians, and social workers) to ensure that all potential patient
parameters have been evaluated. Using this holistic approach, the data collected can be assessed by the physician and assimilated into the orders so that the best possible treatment plan of care can be prescribed.

...After orders have been written for an individual patient and followed for a variable amount of time (usually 3 months), the written prescription is reviewed. Usually the review process includes assessment and input from the entire interdisciplinary team. The status of the patient, including the laboratory data, old orders, and previous treatments, are evaluated. The prescription changes are dictated by correlating the collected assessment data with the accepted standards of care for the chronic hemodialysis patients in the particular facility. (Corea, pp. 91-92)

In terms of people on dialysis socializing with each other, the large number of dialysis machines in a relatively small space makes it difficult to socialize. Both Pearl and George made mention numerous times of difficulties due to the overcrowding in the self-care unit. Because of the need for more dialysis spots, they (the health care practitioners) have increased the number of chairs at the self-care unit. This decreased the amount of space allotted for each person on dialysis and necessitated having the machine placed in a way that obstructs people from socializing. Despite the amount of time that people on dialysis spend together, Pearl and George agreed that people on dialysis do not really get to know each other, or socialize in any significant manner.

Shawna: Do you get to know any of the other patients or...?
George: Hardly ever, no.
Shawna: They’re always changing?
George: It’s not conducive to, although I knew a couple of guys, they were both doctors. Actually, one was an MD, the other was a psychiatrist. They used to sit side by side and they used to get together and play chess. They used to move the machines around so they could play chess...
Shawna: Right, do you know any of the other patients here? Or...
George: Well, not really, just know them from seeing them around all the time. And you just, you get to meet them in the halls and hello and that’s just about it.
Shawna: Yeah, you’re right it isn’t...
George: Well actually there’s no reason why you can’t hang around and talk to them, I guess after. But most people, when you’re finished, they’re just anxious to get the
hell out of here and then of course if they’re hanging around, it just adds to their congestion and confusion around here, with the new patients coming in and the other shift patients coming in.

Shawn: I can see, yeah, you’re right [looking around at the dialysis space]. Especially maybe with more machines, how would you move the machines even, the machines to get talking?

George: Yeah, you see these machines are far too close, you know....

Most people on dialysis spend their dialysis sessions either sleeping or watching their individual televisions using headphones. Through my many observations of the dialysis centre, I came to believe that people on dialysis interact more with the overhead televisions than they do with other people sitting only a few feet away.

**Undergoing dialysis therapy.**

The whole process of dialysis is a lesson in boredom, frustration and pain and this lesson is repeated three times per week for months (or years) on end.

Participants sit in a chair (or lie in a bed) for four hours or more, with needles in their arm, tubes full of blood coming out of these needles and machines hooked up to these tubes. The machine cycles the blood and makes the tubes move, as though they are pulsing along with the participants’ heartbeat. There is little happening in the ward during dialysis sessions. Participants are quietly watching their televisions or are attempting to get some sleep, and the practitioners are going about their work or talking amongst themselves.

George was the most restless of this study’s participants and was always moving about in his chair, though, of course, no one sits completely still. For example, after one interview I noted, “He was continually moving around during our interview. He can’t seem to sit still; he was rubbing his legs, arms, and chest. He took his shoes off, put them on, took them off again, etc.” He, like many others in self-care dialysis, used a long stick (meant to help him adjust values on the dialysis machine) as a scratching stick and had become very adept at getting things done while still sitting in his chair. Even more impressive was the fact that despite having the use of only one hand during dialysis, he had learned how to do most of what he needed — including being able both to take off and put on his socks. In both the community dialysis centre
and the hospital the main source of noise was the hum of the dialysis machines. Also common was the intermittent beeping of the different dialysis machines, which indicated things such as blood pressure-taking time, a need for more fluid of some sort, or the presence of a problem with the equipment. This beeping was so common that most people on dialysis didn't even seem to notice it, even, it seemed, when it was their own machine that was beeping.

People with renal failure spend much of their time around dialysis. While a typical dialysis session is 4 hours, what is not included in these hours is the time it takes to get to and from the dialysis centre/hospital and the preparation time before and after dialysis. Thus, a 4 hour dialysis run may actually take 5-7 hours out of the day. For example, a typical day on dialysis for Bassan started at 11:45 a.m. when he began his wait for the Handy-dart to take him to the hospital. By 12:40 p.m. he had arrived at the hospital, his dialysis machine had been prepared and he was ready to start dialysis. His dialysis run lasted four "long and boring" hours, then he held his "sites" until the bleeding stops, and then did some final procedures (weigh-in, blood pressure check, etc). Bassan then waited for the Handy-dart to take him home at around 5:30 p.m. and did not arrive home until after 6:00 p.m. Thus, for Bassan, dialysis took more than six hours out of his day, which meant that his "whole day [is] gone." In Bassan's words, "...then you get worn out by the time you reach home...." Olive’s account was very much the same; "...the Handy-dart picks me up at 12:00 and I don't get home until 5:45." This left her very few "free days" and, for her, the worst part of having kidney failure was having to be in the hospital.
Key Topics In Renal Medicine (1997)

HD is delivered thrice weekly for the majority of patients. The number of hours of therapy depends upon the intensity of the available technology. With high blood-flow rates, high dialysate flow rates and large, very permeable dialysers the unit can deliver a high-efficiency HD treatment in as little as 2 h. With less efficient technology, treatments of 4-5 h may be needed. All treatments should aim to deliver minimum targets of urea clearance. This is expressed as the normalized urea clearance parameter, Kt/V. For individual treatments a Kt/V of 1.2-1.4 should be sought. (Tomson & Plant, p. 91)

George’s day was a little longer than the others are because his dialysis runs were 4 ½ hours. As mentioned earlier, both he and Pearl were on self-care hemodialysis, which meant that they also had to spend time setting up before, and cleaning up after, dialysis. With all the hours taken up by dialysis, George said, “it is like having a part time job.” Pearl found the “amount of time that you have to give out of your life to get your treatments every week is very limiting.” For her, this was the worst part of having renal disease. Further, not only do people on dialysis have to give up so much time for their treatments, but also they must do this on the schedule of the hospital or dialysis centre. Dialysis shifts run three times a day — morning, afternoon and evening — at both the hospital and dialysis centres. Schedules are set so that each person with kidney failure is assigned a particular shift times on particular days. For example, Pearl dialyzed on Tuesday and Thursday evenings and Sunday mornings. This type of scheduling necessitated that the people on dialysis work their lives around their dialysis schedules. George, for example, would not choose to get up at five o’clock in the morning, yet he must in order to be on time for his morning dialysis session. He was given the morning shift despite preferring the evening shift because the priority for shifts was given to those who work — George was retired and, thus, he was low on the priority list.
Of course, there is more to the difficulties of dialysis than scheduling problems. There are numerous discomforts that may be experienced during a dialysis run. At the beginning of a dialysis session each person must have two needles inserted into his or her arm. No matter how many times this “needling” is done, it is still painful—something that is difficult to get used to. It is even more painful for people on dialysis when the nurses “put the needle in the wrong place” or when several attempts are needed to get the needle in the correct spot. When I went to a community dialysis centre to “experience” dialysis (and what it was like to sit in a chair for four hours) a number of the people on dialysis (George included) yelled out from their chairs that if I were to really experience a dialysis run that I needed to “be needled”. The consensus seemed to be that needling is the worst part and, thus, I was missing a large part of the experience of dialysis therapy if I didn’t experience this. Luckily for me, it would not have been ethical for the nurses to insert needles into me just so that I could experience the pain. I noticed the large size of the needles and knew that it would have been quite painful (not just a typical blood test).

Contemporary Nephrology Nursing (1998)

After the AVF (arteriovenous fistula) matures, the veins proximal to the anastomosis are used for placement of both needles required for hemodialysis. The arterial needle is placed most distally, but at least 3-5 centimeters from the anastomosis. The venous needle is placed proximal to the arterial needle and at least 5 centimeters away. This lessens the possibility of recirculation of dialyzed blood during hemodialysis. The arterial needle can be inserted, pointing away from or toward the heart, and the venous needle is inserted pointing toward the heart. The manner in which the needles are inserted can affect the longevity of the AVF. (Salai, p. 543)

The needle may also cause pain later on in the dialysis session. Olive has had difficulty with pain around her needle site and, thus, generally had freezing done to alleviate the pain.
Olive: ...because for instance I’m having pain in my arm right now, don’t ask me why because it’s supposed to be frozen for about six hours. But it’s just a niggling pain. It’s not much but that’s why Dr. __, who is an associate of Dr. __, gave me this freezing. And maybe it’s, I don’t know that everybody gets it by any manner of means, the nurses seem to be quite surprised when they, I tell them that it is put away for me.

Shawna: Oh.

Olive: And, but whether it’s my age or what, I don’t know why they, but it certainly helped me because I was climbing the walls in here the last hour every time I was dialyzed. And it hurts today too, which it’s not supposed to, however.

Having freezing done on a regular basis is frowned upon by many of the health care practitioners. Both George and Bassan were unclear as to why freezing was frowned upon, but both thought it had something to do with the toughening of the skin. Some participants have felt “pressure” to just “grin and bear” the needle pain. Yet these same participants are not given full access into the community in such a way that their pain is legitimized, and so that they have an understanding of why freezing is harmful.

Bassan had also experienced pain in his arm during dialysis, especially when he had to endure the treatment of nurses who were unfamiliar with a graft access. He continually asked for the particular nurses whom he found to be “good at grafts” but the system of the dialysis ward did not allow participants to select their preferred nurses. Thus, for Bassan, each dialysis session was preceded by worry over which nurse would be assigned to him.

Shawna: I know you were having some problems before with your, because you have a graft and not a fistula, are you still having some problems with the nurses being able to...?

Bassan: That’s right, somehow nearly a week it went when they couldn’t find the right spot and they had to pull out and put elsewhere. And three, four times in the one session for inserting, it was happening around that. Somehow I think the recent staff...coming to see me for one week. I think, what is graft? Because now I’m told that down here they mostly handle fistula and not graft. And [hospital name] they mostly deal with grafts, with grafts and not with fistula. And here some of the nurses are not used to grafts. So anyhow I hope they have inserted enough instructions how to handle the graft.

Shawna: So it hasn’t been a problem the last week?

Bassan: Well, one week at least, experienced people have come. I pray they continue and not another nurse or somebody who is not acquainted with this stuff.
It was just another way that Bassan felt he has “lost control” over his own life. Approximately one month into the study Bassan’s graft access failed and he was forced to endure dialysis through a neckline (while waiting for a new fistula to heal). During the six weeks he waited for his fistula to heal, he experienced pain in the neck area. Undergoing dialysis through a neckline leads to extra discomforts.

Shawna: Yeah and, yeah I can see you’ve got your legs raised, is that because of the neck line or because just circulation?
Bassan: What did you say?
Shawna: You have, um, your legs are higher that, the bed is leaning.
Bassan: Yeah, because of the neck line. If I, if I’m higher it starts buzzing there so I keep...
Shawna: So they keep your head lower.
Bassan: Lower, yeah.
Shawna: Is it more uncomfortable?
Bassan: It is obviously very uncomfortable, that’s why I’ve forgotten last. This is the fourth surgeon with neck line and I forgot I can’t watch TV now.
Shawna: Right.
Bassan: Because it is difficult for me to watch it.
Shawna: Yeah, so you just have to lie here.
Bassan: Yeah.

Thus, Bassan had to remain as still as possible and lie supine with his legs raised higher than his head. Sometimes even talking caused enough movement to shut off Bassan’s dialysis machine. Although it is not as extreme as a neckline, dialysis through a regular fistula also requires that movement be restricted, as George notes:

George: ...I set off the alarm because I’ve been moving.
Shawna: So it stops if you move around?
George: Yeah, it causes, I don’t know what it causes, a rush or something on the machine but it cuts off and you have to reset it. So really you have to kind of keep, keep this arm still, you know, you can’t be moving around a lot or you’re going to set off alarms right away, actually.

It can be quite arduous to be unable to move around freely for long periods of time. As Pearl put it, “...sitting in the same spot for four hours, your arm gets sore, your neck gets sore, your back gets sore....” Although dialysis is four hours or more, many of the participants find that the longest part of dialysis is the last 20-30 minutes. It is at this point, when there is some
end in sight, that participants are just “itching” to get off the machine and to get on with their day. I, too, found the last 30 minutes the hardest to bear and could not imagine having to do this as a part of my weekly routine — especially when this procedure might be something I would have to do for the rest of my life.

The medical system.

The medical system is a hierarchical institution. At the top of this hierarchy is the government (Federal and Provincial) and at the bottom is the “patient.” In between these two extremes lie hospital administration and health care practitioners. Culture has a large influence on how people function in their positions, no matter what level in the hierarchy they occupy. The people with the most direct influence on the lives of people with renal failure (in the hospital setting) are the health care practitioners. These health care practitioners are both constrained and enabled by the system in which they function and by the kind of knowledge they possess. For example, what health care practitioners learn is socially constructed — their textbooks are a part of a sociocultural history of medicine. Both what is included and what is left out of these textbooks tell practitioners which aspects of medicine are important. In a review of several current kidney disease textbooks for doctors (Brenner, 1996 (vol. 1); Brenner, 1996 (vol. 2); Greenberg, Cheung, Coffmann, Falk, & Jennette, 1998; National Kidney Foundation, 1998; Whitworth & Lawrence, 1994), the focus on the science of disease, symptomology and medical treatment demonstrate what information is considered important. Not one of these textbooks had a chapter on people with kidney disease that went beyond “medical science” to include the sociocultural contexts of living with this disease. According to Aronowitz (1998), “Both inside and outside the biomedical mainstream, people have been aware, if often implicitly, of the limitations of a strict ontological model of sickness” (p. 167). Despite these acknowledged
limitations, he argued that there has been little success in bringing new more inclusive models into practice.

Many health care practitioners are involved in the lives of people undergoing dialysis therapy and within the medical system each practitioner has been assigned an area of responsibility. These areas are clearly delineated and were transparent to both health care practitioners and people on dialysis. Doctors are in charge of diagnosing and monitoring people’s kidney disease. They also oversee dialysis and prescribe the necessary medication and treatments. Nurses work with the people with renal failure on a day-to-day basis in the dialysis ward. They, too, oversee the dialysis, are responsible for needle insertion, monitoring and record-keeping for each dialysis run. Special nurses are in charge of training people who are about to go on dialysis or about to begin self-care dialysis. Dieticians are in charge of educating people with renal failure on their nutritional needs and monitoring their eating patterns and blood-work. Most dieticians make rounds on the ward just after the monthly blood-work has been done, so that they can assess with the people living with renal failure how they are doing nutritionally. Finally, social workers take care of the emotional needs of the people with renal failure, as well as helping with life skills and problem-solving treatment issues. The preceding provides only a general description of the areas of responsibility assigned to each type of health care practitioner. In reality, this may not describe the actual work that is done in the hospital setting and the kinds of pressures under which health care practitioners function. As well, it neglects the work of the people living with this disease, although, as mentioned earlier, the responsibilities of people with renal failure are not often considered work.

When asked, the health care practitioners stated that they are doing the best that they can under the current circumstances and that they are proud of their work. They believed that they had a good relationship with people with renal disease, although most admitted that there are
some people with renal failure with whom they do not get along. Communication problems do exist, especially with those people on dialysis for whom English is not the first language; however, there are second language services available (although this is not a problem for the participants in this study). The health care practitioners whom I interviewed appeared to genuinely care for the people with kidney disease with whom they worked. For example, one doctor found it painful when people who have been under his care for a long time died. To him, it felt as though he had lost a friend. This same doctor often found himself worrying about what might happen to people undergoing dialysis therapy should there be a large natural disaster. He was “very aware that a disaster like the ice storms in Quebec or a large earthquake would be devastating” to the dialysis population — without electricity there is no dialysis and without dialysis, the lives of people with renal failure are in jeopardy. This practitioner in particular often wondered if the people with renal failure worried about these kinds of issues.

From the participants’ perspective there were many ways that the medical system was meeting their needs. George, for example, when asked about the health care practitioners, said, “Everybody was more than helpful.” He also had great respect for his doctors and believed that both his nephrologists have taken a “personal interest” in his case. When George’s original nephrologist retired, he was quite upset and believed that the hospital had lost a great resource. Bassan, too, respected his nephrologist and most of the nursing staff. As he put it,

...98% of nurses here on the whole they are good. They are doing their job; they understand the noble profession they are in. There are maybe one or two who are bad eggs but that can be anywhere. On the whole it’s a good teamwork.

Bassan was also very grateful to the social workers at the hospital.

Bassan: ...I must thank the Ann Most [pseudonym] and her assistant, they gave me very good book...to raise my morale and help me out in my problems to get my shifts to suit me, the timing for my Handy-dart and all that. They help me a lot.

Shawna: And who did that?

Bassan: Social...
Shawna: Oh, the social worker.
Bassan: The social worker.
Shawna: Oh good.
Bassan: Ann Most, I think.
Shawna: Okay, Ann Most.
Bassan: And her assistant too.
Shawna: Okay.
Bassan: So that was one that I’m really grateful. I don’t know whether I would have survived without them and their help, commit suicide even.
Shawna: Wow.
Bassan: I was so fed up with all this, couldn’t tolerate it.

Overall, he was satisfied with the hospital environment.

Olive and Pearl also agreed that, on the whole, their health care practitioners were caring and conscientious. Pearl often compared the medical system in Manitoba to the one here in British Columbia. In her experience, the health care practitioners and the system here were far superior to that of Manitoba. In British Columbia, she said, the health care practitioners were accommodating and flexible. They were helpful when she wanted to change dialysis shift times and would often make the change for her.

Shawna: How flexible is it? Is it hard to get a time change?
Pearl: No, they’re really good here. [City Name], no, you don’t change at all, they don’t even consider it. Here if there’s not an open spot they’ll ask other patients if they’d mind switching. And I’ve switched with a lot of people so, you know, they’re usually, they don’t put up a fuss. They don’t say, “oh again” or you know, “what do you want to change for?” You don’t get any of that here, they’re just like “oh sure, well let’s see what we can do.” You know, and if you know, even it’s like I was going out on my brother’s boat for a few days and I remember saying, you know, “Can I switch this day?” and she said, “yeah.” And the nurse came back later and she said, “well you know, how about if I ask this patient, then you can come back, you know, even later that day. And I said, “oh no, I don’t want to cause any trouble.” She goes “oh no, no, like you’re going out you know, you should have as much time as you can out there” They were making suggestions about changing and...

Shawna: Right.
Pearl: …and you know, so they’re really good that way.

They also tried to make the dialysis centre less like a “sick-space.” For example, during a shift people would often order food and eat while on dialysis (something that is prohibited in Manitoba). There was also a video machine available so that while on dialysis people could pass
the time by watching a movie. Overall, Pearl trusted the doctors and nurses and liked the fact that they treated her with respect.

It is important to note, however, that the high cultural status and power of health care practitioners (particularly doctors) may make it difficult for people with renal failure to complain about or seriously question the care that they have been given. Engestrom (1993) argued that the asymmetrical relationship between people with illness and practitioners leads to the stifling of the concerns of the people with illness through professional dominance. Even Pearl, who had a strong voice in her own care, sometimes deferred to the authority of her doctors. For example, when she asked her doctor about the possibility of having children, Pearl’s doctor told her that “it will be a bit of a challenge. She [the doctor] said it’s not for you to worry about, that’s for me to worry about.” Through her voice of authority, the doctor had taken away Pearl’s right to decide what she should and should not “worry about” and had effectively shut down this discussion. By accepting this response from her doctor, Pearl had deferred to the power of her physician. Further, people with renal disease have a vested interested in believing their health care practitioners are competent. People with kidney failure have to rely on these health care practitioners, and the system in which they functioned, for their very survival.

Participants’ critiques of the medical system.

As a whole, it is important to recognize that although these participants did not enjoy the time that they spend on dialysis, all were able to “get used to” the hospital or dialysis centre environment. Coming to dialysis just became part of participants’ routine of everyday life. However, there is no denying that sometimes the atmosphere could be very unpleasant. There were times when the participants’ dialysis was going well, but that of others on the ward was not. Participants had to witness others on dialysis getting physically ill, listen to others moaning and groaning, and put up with unpleasant odours. On one of my visits to the dialysis ward at the
hospital, the smell of faeces was so strong and unpleasant that I felt that I had to leave — the participants, however, did not have that option. As well, while on dialysis, participants were forced to deal with, and were at the mercy of, the moods of hospital staff and/or with staff members with whom they did not get along. They were forced to participate in a system that allowed them very little control in their own care.

As mentioned earlier, one of the difficulties in the hospital and dialysis centre arises from an increase in the number of participants requiring dialysis therapy. In the dialysis centre, overcrowding has resulted in having more chairs but not more televisions, so that some people are left without anything to do for four hours. I noted that in the hospital,

...sometimes there is only one television for a number of participants (in the smaller back rooms.) This necessitates long discussions on what to watch and how loud the sound should be. It often seems that the most forceful person rules, rather than the majority (or maybe some people really just don't care).

The importance of having a television to help pass the time was expressed many times and in numerous ways by each of the participants. And while one doctor lamented that placing televisions in the ward has reduced the amount of socialization between people on dialysis, most practitioners, family members and participants agreed that television helps to make life on dialysis more bearable. George is very concerned with issues of overcrowding in the ward:

George: It's a good facility as it could be, I guess. Except it's far, far too over, it's overcrowded and it's overcrowded to the point that it's unhealthy, in my opinion.
Shawna: In terms?
George: Being the patients are too close together and they don't, you know, they don't have any, you know, patients are coughing and anything that's going around there you pick it up whether it's a cold or...
Shawna: Yeah.
George: ...and it too damn crowded, the nurses can't in my opinion give enough attention to, to each patient. It's just, it's just, the space, they're too crowded for space.
Shawna: Right.
George: They recently added two chairs down there and it makes it increasingly crowded. They had to take away the night tables or side tables to create space and things like that.
Shawna: Right.
George: It's just...
Shawna: I guess it's a dilemma if they've got more people.
George: And you've got, where you had about six feet between you, now you only have four. And you've got people that are that close to you that are coughing and wheezing and... it's just, it's very uncomfortable, really I think.

George also felt that the nurses were unable to monitor all of the people on dialysis, which resulted in clean-up not always being done properly. It was very disturbing for participants to come to their dialysis machine and see blood left over from the last treatment. This is especially problematic considering the existence of ailments like hepatitis and AIDS.

Some problems in the hospital or dialysis centre have to do with the equipment. For example, Olive experienced great pain and anguish when a wheel chair broke while she was in it. Bassan has sometimes had to sit in a chair despite it being much more comfortable (because of his graft) for him to be in a bed. Because participants in the hospital setting did not always get the same dialysis spot, each time Bassan came in for dialysis he would worry about having to dialyze in a chair. He complained several times and was finally able to get his doctor to "write an order" so that he would always get a bed. It wasn't until Bassan's doctor legitimized his complaints with an order in his medical file that other health care practitioners recognized Bassan's concerns. Pearl also found that some of the chairs are very uncomfortable. On one particular interview, Pearl was unable to sit properly in her assigned chair due to the stiffness of the chair and her light body weight. The chair kept returning to an upright position despite Pearl's attempts to recline in a more comfortable position. She tried various measures to keep the chair from retracting, but to no avail. Despite her outlandish suggestions of ways to "make the chair behave" which set the two of us laughing as she slid down the chair, it was obvious that this problem was not one to be taken lightly. An uncomfortable chair can become a large problem when a person must spend a substantial portion of their day sitting in it.
One of the major problems with the system for Bassan was with the Handy-dart. He must travel from the city where he lives to another city to get his dialysis, and this travel can take over two hours. While he appreciated having a system like the Handy-dart, he took great issue with some of the scheduling. Often he had to rush to the pick-up spot only to find out that the Handy-dart was 30 to 45 minutes late. When the van was late, there were many people waiting, often “too afraid to go to the washroom even” for fear that they would miss their ride. Bassan believed that if people were informed in advance, many of these stresses could be alleviated. He was asking for more transparency and input into the workings of the Handy-dart, but his voice was not being heard. Another contentious issue has to do with scheduled lunches for the van drivers.

Bassan: On the time, the rough time was I find was that the Handy-dart bus. We are released from here because eight o’clock to twelve is four hours dialysis, then another ten, fifteen minutes for dressing. So about twelve thirty you are free. You go down, but Handy-dart driver goes for lunch at twelve thirty and he doesn’t come back till quarter past one. So for forty-five minutes you have to sit down there and wait for him. So by the time we reach home, having been picked early in the morning, before seven o’clock, even before six o’clock because I’m the last they pick me up because of the route.

Shawna: Em, that’s nice to be last.

Bassan: But then you can imagine from 6:00 to 2:30 or 3:00 to reach home. And one man keeps all the people starving down there. And he goes, they have scheduled him to go for his lunch. So a fit man goes for lunch and the sick people, you have to wait until they reach home for their lunch.

Shawna: That’s ridiculous.

Bassan: Yeah, so I don’t know what to do about this. But I said if I complain its not good also.

Shawna: Yeah, that’s ridiculous, wow.

These kinds of scheduling and equipment issues introduce more stress into the lives of those already living with the stress of kidney disease.

Besides some of the system issues, the participants also had difficulties with some of the health care practitioners themselves. For example, both George and Bassan blamed the onset of their dialysis on the failings of doctors. George believed his kidney tumours were a result of an experimental blood pressure medication given to him by his family doctor. Bassan believed that
he had a diabetic coma because his doctor neglected to tell him about the side effects of a sinus medication that would require him to alter his diabetic medication. Further, Bassan also believed that a botched fistula surgery led him to dialysis therapy a couple of years earlier than should have been necessary. Olive also had problems because of her fistula surgery; she had very poor circulation in the arm with the fistula.

Olive: ... and they gummed up my circulation and then they put the fistula in and my hand goes blue.
Shawna: Yeah, I see that today, all the time it goes blue or just occasionally?
Olive: Just occasionally.
Shawna: I noticed that you’re kind of blue today.
Olive: Yeah, oh it, you don’t, that’s nothing.
Shawna: Oh really.
Olive: It gets navy blue.
Shawna: Really.
Olive: It gets ink blue, dark ink.
Shawna: That must have been scary the first time you saw that?
Olive: No, I realized what it was but it’s, it’s a profound nuisance, because it bothers me in bed. I can’t sometimes get my arm comfortable, where it’s not, um, you know, it’s not numb.
Shawna: Right, does it get cold as well?
Olive: Yes, freezing cold.
Shawna: That’s annoying.
Olive: Yes, indeed.

Pearl, too, had some difficulties with doctors; however, these had mostly been doctors in emergency wards who had been unaware of the intricacies of renal disease.

Sometimes it is the nurses who seem to present a problem. Participants felt that some of the nurses were not sympathetic and/or had a very “poor attitude.” This poor attitude is illustrated in the following quote from Pearl:

I one time had a nurse say to me, when she found out that I was doing my, I think that was when I was in my master’s, master’s degree. Anyway, yeah, she said, “What are you doing that for?” I said, “Well, because it’s something I want to do and I think it’s important.” “But you’re on dialysis.” It’s like, “Yeah.” Oh yeah, it was when I was doing stats in the hospital once. I had surgery that summer and she’s like, “Just go on welfare, just let them pay, like just, like why would you want to, you know, do anything, you’re sick.” And I just looked at her and I said, “Oh man, do you ever have the wrong attitude, I hope you’re not telling all the patients this.” I just couldn’t
believe it. I was like floored, then I proceeded to tell her exactly what I thought of her views (laughs) in a nice way, I mean.

Pearl, like most of the participants, did not consider herself “sick” and was insulted at the suggestion that she was unable to be a “productive person in society.” Pearl believed that this type of attitude on the part of health care practitioners is very detrimental to the attitude and well-being of people undergoing dialysis therapy.

On one particular visit to the hospital, I witnessed firsthand the result of unprofessional nursing practice. I went to the dialysis ward to interview Bassan, and when I arrived at his bed I heard a nurse reprimand him for not monitoring his fluid intake properly. My notes from this incident read:

I walk towards Bassan’s dialysis area and see he is talking to a nurse and I am concerned that this might not be a good time for an interview. As I get closer I notice that he is being talked TO by this nurse and in fact, is doing almost no talking. She is talking to him like a child with a stern voice saying, “...if you don’t watch your liquid you won’t make it two years. It will affect your heart.” She then goes on to berate his (and his culture’s eating habits) when she says, “you guys eat rice and yoghurt...” and then she tells Bassan how these all contain large amounts of water. The nurse turned to me after her lecture and offered an explanation of the reprimand, not to Bassan, but to me! She told me, “I’m very forthright, I tell them cause no one else does and they need to know. Because high fluids cause cardiac arrest.”

Bassan was visibly upset after this incident and said:

Well, all of a sudden, for three months nobody told me this. I don’t think she spoke to me about this. It’s the first time that they tell me I have too much fluid in my body and all that.

During our next interview he brought this up again:

Bassan: From the nurses, I don’t think she, she was right that day. Because my pressure was getting low.
Shawna: Yeah.
Bassan: They disconnected me.
Shawna: Oh really.
Bassan: As soon as they disconnected me, there was left some water in me.
Shawna: Oh, so you had left over fluid from the day, the time before?
Bassan: Yeah.
Shawna: And so she thought you were having too much fluid. Well she certainly wasn't very nice about it. I wish I had my tape recorder running when she was talking. Oh, well.

This type of incident highlights the type of authoritative discourse that often occurs between practitioners and participants. Similarly, Frieda, George's spouse, herself a dialysis health care practitioner, noted:

Sometimes I think they're a little callous because they don't understand what the patient, what their life is like. They [nurses] only see them there [hospital] and I think that they feel; well everyone [people on dialysis] that comes here they just want to be waited on. Well, maybe they [people on dialysis] need to be taught, you know, that they can look after themselves.

One of the most intense and often cited complaints relating to any of the health care practitioners has to do with a particular dietician at the self-care unit. George said, "I just dread seeing her." Pearl felt very much the same, yet they were given no other choice. Frieda, talking from her experience as a dialysis health care practitioner and as a family member, said:

Frieda: You can't do a thing about it, as soon as you tell somebody they can't have anything, then they want it.
Shawna: Oh yeah.
Frieda: You know.
Shawna: Yeah, anybody on a diet, and as soon as you say you can't have it, they want it ten times as much.
Frieda: I know they can't, yes. I know they eat it. So, and I know when I've worked at KDS they all laugh down there, whenever they know it's blood work time they're really careful that they eat for a week. They all joke, oh it's blood work, we've got to watch what we're eating now. Next week, and it's like, so they know.
Shawna: Yeah.

Both Pearl and George admitted to telling the dietician things that were "not exactly true" so that they wouldn't be "reprimanded."

George: I just had a session with, on Tuesday, a session with the dietician. And I'm not doing so good there, my potassium and phosphorous are too high.
Shawna: Yeah, is that the dietician from here or a different dietician?
George: No, she's from [hospital name].
Shawna: The one you don't like or a different one?
George: (laughing) It's not a case of not liking, it's just. I find those sessions just completely repetitive, you know. She just tries to find out what I had to eat. How the hell do I remember what I had to eat from day to day? I don't keep a record of it.
Shawna: Right.

George: So, I’m just guessing at it or, or lying about it or something. I don’t know. I guess, I’m just guessing at it, you know. I don’t know what they want, it’s obvious I’m eating and I know where I’m having problems. I’m having problems with dairy products because I really like dairy products and I really have a problem controlling my dairy product intake.

Frieda also was familiar with the problems of this particular dietician:

Frieda: I used to read his report from the dietician down at KDS and she once wrote that he had trouble cooking for one. (Laughs) Because he never does cook, so, but he must have told her that eh. (Laughs). I used to read some of the things that he would say to her and it would just crack me up. Because I can’t stand the dietician down there.

Shawna: Yeah, I’ve heard that from somebody else too.

Frieda: It’s too, you know, there’s no point in going down there and lecturing someone over and over because they don’t, they’re not going to listen. They just blank. They should have some kind of slides or, I don’t know, just something different that makes it fun. But they just go nuts when she comes. In fact, he phoned me, he was all in a panic because she was coming in and he wanted to know what was in these foods eh. Oh he was just beside himself, but I don’t know. I think if, I don’t think it helps them any. They just dread her coming every month.

Contemporary Nephrology Nursing (1998)

The registered dietitian (RD) serves as an integral part of the renal health care team by assessing the patient’s requirements and recommending the appropriate nutritional intervention. In addition, dietitians counsel patients and their families in the diet, follow patients for compliance, and help determine additional or changing nutritional needs (Roberts, p. 287)

Pearl believed that she should be treated more like an adult. She said:

Pearl: Well, the way that they have it is that they do blood work every month and then after the blood work comes back, the dietician visits everyone. And I don’t know if it’s just the dietician because I’ve only had one or if it’s the way it is but it’s, how do I put this? It’s like she’s not talking to you, she’s talking at you. Every single person, every single week, the first thing she says is, “And how was your appetite this month?” It’s like, I’m a person, like she doesn’t try to get to know you. I had a wonderful dietician back in Manitoba, I wish I could combine the two. Who, you know, took time to get to know me, took the time to get to know what I’m having troubles with. This one just picks the bad and dwells on that. Not, “Oh, you’ve done really good in these areas” you know, “What did you do differently?” or anything.
And it’s just the minute she starts walking to me, my hackles go up and I’m rude to her. And that’s not me, I don’t like who I become. And I think it also has a lot to do with my experience in [city name] with the dietician there is just wonderful. The fact that I’m a [health care practitioner], I’ve got education in diet.

Shawna: Yeah.
Pearl: My mom’s a home economics teacher, diet and food groups and everything has been drilled into me since I was like this big. Not to mention I’ve had kidney disease since I was twelve.
Shawna: Yeah.
Pearl: I know what I should eat, I know what I shouldn’t eat. If I choose to eat something I shouldn’t eat it’s because I choose to. It’s not because I don’t have the knowledge and she should know that by now. And I don’t think, ... and I know a lot of the patients feel the same way, they don’t like it, they don’t like her, they don’t like the whole set-up. And what I, and the nurses they’ve got the information as well, they know about diet.

Pearl also had arguments with the dietician about her weight. It got to the point where Pearl “couldn’t help” but be rude to the dietician and so the dietician often skipped Pearl when she did her rounds. Pearl thought her poor relationship with this dietician was unfortunate because she did have a great relationship with her dietician in Manitoba. Further, Pearl resented having to be rude in order to be heard (or to be left alone). It is unfortunate that sometimes health care practitioners can be more of a hindrance than a help to the lives of those with renal failure.

Participants’ suggestions for the system.

Although overall, the participants stated that they were satisfied with the care they received in the system, a number of suggestions arose out of their interviews. The first was to have dialysis centres in additional communities to help reduce crowding and travel time. Bassan was hoping for a centre in the city that he lived in so that he could eliminate almost two hours of travel time from his dialysis days. George too, (before receiving a transplant) was hoping for a dialysis centre closer to his home. Even with no other dialysis centres, the participants believed that something had to be done about the overcrowding. They stated that a lower ratio between nurses and the people on dialysis would reduce stress and improve care. Bassan would like to
see a small history sheet placed in all the charts of people on dialysis so nurses could easily see what is required for each person.

Bassan: ...because they don’t know, so I don’t know how far it is recorded in my file. I think they should record in my file, I think they should record it on top that I am on a ticlid, so every nurse when they open the file, they should see it, that I’m on a blood thinner. Number two, I have gone through two bypass surgeries, I had two heart attacks, I had a stroke, I had a coma. I have gone through all that. And maybe, maybe with the strong willpower I am fighting, but I don’t know how long. So it looks, someday I want to, I think now is enough; I want to give in now. But it is so, it, I never know how far I can go. The nurse comes, they don’t know how much I under suffered.

Shawna: It’s very true.

Bassan: If there were a small history sheet so they would prepare and put it in the file, on the top. And also the medication, if I am on a blood thinner, it should be marked on the top. Because every, every station they have to hold it for 10 minutes and it is such an awkward position that she told me, “Hold, hold” and I was holding wrong because I could not see. The blood was there; the whole blanket was full of blood.

Bassan got very tired of having to explain all that he had gone through to each new nurse. Of course, Bassan would also have liked to see an improvement in the Handy-dart system and, along with that, some support in terms of better planning and scheduling for those people who were going to meet the van.

George would have liked to see more attention paid to physical education and physical programs. He and Pearl also hoped for changes in the activities of the renal dietician. As Pearl put it:

So what I think would work is having that person as a resource, that, you know, maybe you can have an initial consultation with them. If you have questions you can go to her with them, either on the phone or she can be there certain evenings and you can ask to speak to her. Or you could speak to the nurse and the nurse could relate anything that they couldn’t understand. But I think it’s a waste of money. I think it’s a waste of time and I think that it’s making a lot of patients, including myself, resentful. Like, excuse me, we know this.

With all the money saved from eliminating a full time dietician, Pearl believed that people on dialysis would be better served by having a massage therapist coming in once a month to work on muscle soreness. She and other participants found that sitting in a chair for four hours caused muscle aches and pains.
One of the more important supports for normalizing life is the occasional ability to switch a dialysis treatment time. Pearl felt it was important to note that having flexibility in shift times is vital:

I will try to switch the dialysis around and that, being able to do that makes it so much easier to have a normal life. And I think that’s very, very important and I want to see that in the results and then the recommendations [referring to the results section and implications section of my dissertation]. Being able to have flexibility in the unit, to be able to do stuff like that you know.

Thus, the support of health care practitioners is imperative for having flexibility in a person’s life. With the support of the dialysis staff, Bassan was able to switch his dialysis shift and rearrange his Handy-dart so that he was able to attend his niece’s engagement ceremony. Pearl, too, had changed her dialysis treatment times so that she was able to travel or attend important events. On one occasion, she arranged to have an extra dialysis session just before her cousin got married.

...my cousin got married and I was in the wedding party. She was getting married on a Saturday and I dialyzed Thursday and then Sunday. So I asked, you know, the doctor if I could go Saturday and Sunday. Saturday before the wedding so that I would look good for the wedding. And then not, you know, instead of then just going Tuesday again, going Sunday so that I could suck it all off and feel good for the rest of the weekend. I had full intentions of just drinking everything and anything I wanted to.

All the participants in this study opined that flexibility in a dialysis schedule is very important. Bassan attempted to have his dialysis schedule changed so that he could attend evening services at his Mosque more often. Services on Friday nights are the most important and he would like to be able to attend, but his dialysis schedule interfered. During the course of this study, he was unable to change schedules. Unfortunately, the increase in need for dialysis along with a decrease in medical services renders this flexibility more and more difficult to achieve. Thus, a person on dialysis who wishes to change a shift is at the mercy of the schedule set by the health care practitioners, the availability of space and/or the willingness of other
people on dialysis to switch shifts. This is an example of where the goals of those with renal failure and practitioners may clash, but unnecessarily so.

At some point, all of the participants in this study had stood up for themselves by asking (or demanding) something from the system and their health care practitioners. As noted above, it may occasionally be the case that difficulties arise between practitioners and people on dialysis because they are working towards different goals. Practitioners are “experts” in medical technology and work toward the goal of improving the health of people with renal failure. People with renal failure, on the other hand, are “experts” on their own lives and work towards the goal of living as “normal” a life as possible. Although these goals sometimes may be complimentary, there are times when they contradict. It is at these times that people with renal failure and practitioners most often clash. For people living with renal failure, taking care of themselves sometimes means going against the advice of health care practitioners. For example, missing a dialysis session is one way that participants did not “comply” with the recommendations of their health-care workers because they chose “normality” over health on that particular day. As well, there were times when participants chose to disregard diet and fluid regulation recommendations. Pearl often had higher fluid gains than she was “supposed to.”

She said,

I don’t restrict myself to the point where I’m really wanting or needing or feeling like I’m gypped, and so that’s why my fluid gains are sometimes higher. And I don’t know if that’s good or bad, I mean is it better to have the lower fluid gains and feel sick, or you know,
feel like you’re being controlled by your illness rather than controlling it? Or is it better to have slightly high and feel more in control? …Let’s put it this way, I know what I should be doing, if I don’t then I chose not to.

George, too, often made choices that went against the advice of his health care practitioners, especially concerning his diet.

George: And I do eat them [dairy products] way more than I should.
Shawna: Yeah, it’s very difficult, I can’t imagine, I cannot imagine.
George: So that’s the, the worst thing you have to deal with is diet.

Contemporary Nephrology Nursing (1998)

What is compliance? The answer to that question is not as straightforward as might be expected. Nurses in dialysis units typically describe noncompliant patients as those people who gain more than 2kg between dialyses, have serum potassium levels above 6mmol/L, serum phosphate levels above 5.5mg/dl., or those people who miss dialysis treatments or other medical appointments. However, various researchers have used different definitions of compliance behavior, and there are no agreed upon definitions of the concept.

…Many believe that good teaching is key to compliance. As a result, they become frustrated, when despite excellent educational programs their patients do not follow their instructions. There have been numerous studies describing strategies to increase compliance. Some of these strategies have involved educational programs, while others have involved individualized programs. In some cases, behavioral strategies such as contracting have been employed, and yet others have involved nursing care modalities such as primary nursing (Molzahn, 1989).

However, there have been mixed results. Sometimes the interventions work, and other times (more often than not), they do not. (Molzahn, p. 273)

Although it is often assumed that “doctor knows best,” it is clear that in many cases this is not true. People are the experts in their own lives and care, and sometimes need to fight for the right to their own self-determinism within the confines of the medical system. Olive, for
example, was adamant about not using another wheelchair after one broke and left her injured; she was afraid that she would be hurt again:

...and I said no bloody way... ...that's why I bring my walker and to hell with them. I'm not gonna go in their wheelchairs unless I'm, they can take me out in a bed so I'll be flat on my back. But no way would I go near a wheelchair.

Olive also was able to delay dialysis for a number of years because she (along with her doctor) chose to ignore the clinic's initial recommendation to start dialysis.

Shawna: Um, let's see, did you ever think about choosing to not go on dialysis?
Olive: I did for quite a number of years. I chose not to and I, I looked upon Dr. ____ as my anchor because they, they used to suggest it in the clinic that I should...
Shawna: Right.
Olive: ...and I said no bloody way and that's...
Shawna: That's okay.
Olive: ...until such time as I have to.
Shawna: Yeah.
Olive: So I had, uh, nine years that I wasn't on it.
Shawna: And then one Dr. ____ told you to go on that was
Olive: Em, em.

Olive always had her arm tied down to the bed while she was on dialysis as a reminder not to move. This way she alleviated the worry of: "...suddenly moving my arm and having the needle, you know, something might happen. I don't know what it would be but I'm not keen on having it happen anyway." She also reminded the dialysis staff to not "take too much [fluid] off" her as she felt very ill when this happened. Bassan, too, had stood up and asked for the things he believed were beneficial to his life and his health. He had asked to have some surgery delayed, he requested to stay in hospital a few extra days in order to give himself time to recover and he had refused to undertake home-dialysis despite this being recommended by his doctor.

Pearl had the advantage of being a health care practitioner and so she believed that she was often treated with more leeway than some of the other people on dialysis. Her nursing education gave her greater access into the discourse of health care practitioners as well as making the technologies more transparent. Her knowledge of medicine had also helped her get what she
needed for her health, and she believed that on at least two occasions this knowledge may have saved her life. Once, when in hospital for dehydration, she had great difficulty convincing health care personnel that they were giving her too much fluid:

I'm like, "You're crazy, you know, to a point yeah, you need to rehydrate but this is ridiculous." They kept turning them [IVs] up, I kept turning them down...I said, "look what they're doing to me!" My fingers were swollen, I couldn't get my rings on, my face was puffy. I was fluid overloaded... And the doctor was obviously the doctor on the ward and not a kidney specialist. And they discontinued them and I peed like a race horse for two days. They put fourteen pounds of fluid on me when I only really needed like maybe about five, if that. So if I'd been left all night the way he had wanted to, I would have gone into cardiac arrest and I wouldn't be here probably... I mean I know a lot about myself, I know what I need and I know the health care profession too because I'm a [health care practitioner], I'm lucky that way.

As mentioned earlier, she also has had trouble with the dietician at the dialysis clinic and often had to fight to be heard. For example, Pearl has taken issue with the goal weight that had been set by the dietician:

I said to her, "You've got your book and you've got your numbers but that's not me. I've weighed that and I'm not comfortable at that weight." And she'd say it every single time so I finally just told her once, "If you're going to tell me to gain more weight or something, don't bother. You know you can keep telling me, I'm not going to do anything unless I decide it's something I want to do.

People on dialysis can also 'challenge the system' by not following the recommended protocol. Each participant is scheduled to submit to dialysis therapy three times a week, and although it is rare for the participants in this study, sometimes people on dialysis choose to skip a dialysis treatment. Olive and Bassan have not yet missed a dialysis session. George, on the other hand has missed a few dialysis treatment sessions.

Well, on a couple of occasions I've missed a session for one reason or another. For being sick or having, there was one time I actually slept in and I just said to hell with it, I'm not coming in till the following day or the following, my next turn around. They wanted me to come in the next day and catch up but I said to hell with it, I can last till the next turn around and it's pretty tough to do.

Pearl said that she would "never even consider" purposely missing a dialysis run. She once did miss a treatment,
There was once that I phoned and said I would be late and it just kept getting later and later and later and I finally said I'm not going to make it and I ran the next day. But I've never skipped. ... and that was that one time and I felt so guilty but it's just the way it turned out.

Review of Hemodialysis for Nurses and Dialysis Personnel (1993)

Noncompliant behavior can be manifested in a number of ways:

1. Some individuals eat outside the diet even though they are intellectually aware of the need for limitations. This seems to be a manifestation of the denial mechanism gone astray. Often there is a relationship between noncompliant behavior and psychological treatment and physical condition.

2. Some patients consistently ingests excess fluid. This behavior also represents denial that has become potentially lethal.

3. Inadequate care of vascular or peritoneal access is sometimes a problem. Episodes of clotting may not be discovered until it is time for dialysis. With peritoneal dialysis, use of an improper technique may lead to infection.

Such behaviors can contribute to malnutrition, neuropathy, bone disease, cardiac failure, and the like. The end result is physical deterioration and, in extreme cases, death—a form of passive suicide. (Hersh-Rifkin & Stoner, p. 244)

The medical system is a large part of the participants’ lives. There is a lot of work that falls into the hands of the health care practitioners. Overall, most participants agreed that the medical system in which they participate was more than adequate. Previously I have noted some problems with the system and some changes that participants would like to see. From the health care practitioners’ perspectives, the main problems in the hospital were due to limited resources and limited funding. As one doctor put it,

So I realize that we have to do whatever we can to make the environment as accommodating but the realities are that in a hospital we have the sick along with the relatively more stable. We have tremendous turnover at the moment, we have
overcrowding in all of the units in the lower mainland. We have staff shortages, we don't have the time to spend with each patient asking them how they are and getting to know them and comforting them and doing all that stuff. We’re there to do the job, which means turning the patients over and I think patients are probably feeling very stressed and very alone without support.

Other practitioners also recognized that a decline in care has resulted from limited resources.

Shawna: Great, and what about the hospital environment, what’s that like for you, for them?

Nurse: Personally, I think the hospital environment today isn’t as, well, I can’t say it’s great, that’s not true. I feel the patients, we’re trying our best but I think they’re being pushed through a mill because it’s so busy.

Shawna: Uh huh.

Nurse: And a lot of times, I think they’re, in that respect I think they’re neglected because you don’t get to answer all their needs, or what they need done. And I think, I just think it’s hard all the way around. They’re not getting the care, I don’t really like saying that because I think we give good care, but I think it could be a little better. They’re not getting the personalized attention that they used to get, where you had time to sit down and talk, but now it’s more of an assembly line. You’ve got too many patients in too small of an area and you’re trying to get new ones in and get the old ones out. And we’re running on time constraints.

Shawna: Right.

Nurse: Where before we had a little bit more leisure time that we could take our time but now we can’t. And the caliber of the patient is getting sicker too. So that people we would like to spend time with are well or relatively well, we can’t because we’re looking, we’re spending all our time with people who are very sick. And I think that just has to do with, because we’re dialyzing people with renal failure that are much, much older and have many more problems because they are older. So we’re having to meet their immediate needs. Where someone else that may be a little bit weller [sic], we’re not meeting their needs with some of them because they’re put aside so we can deal with someone else.

Shawna: Right, yeah, you must have seen a lot of changes.

Nurse: There’s a lot of changes.

Overall, in terms of understanding the people with renal failure and their lives, health care practitioners were proficient at relating the symptoms and medical aspects of the disease. Because of their training and time spent with people on dialysis, health care practitioners were knowledgeable about all of the possible problems that arise from kidney disease and dialysis therapy. When asked questions about what it is like to live with renal disease, the answers were often similar to those of the participants. Where the practitioners fell short, however, was in knowing which symptoms/problems were the most difficult for participants. These
misunderstandings can lead to difficulty in the relations between doctors and people with renal failure. One doctor felt that kidney disease was “so awful” that she said that she would choose to die if she had it. One can only assume that the message this doctor was sending out was not a positive one. Participants’ families were much better at gleaning a real understanding of life with kidney disease. Although families often have no formal medical training, they have the advantage of seeing participants in their everyday lives. Aronowitz (1998) contended that social and psychological influences most often have been considered sources of bias rather than sources of legitimate information. I argue that knowledge of the person by participants’ significant others is a very relevant source of information that needs to be bridged with the knowledge of the health care practitioners.

**Life Outside The Hospital/Dialysis Setting**

There is much more to having kidney disease than the time spent on dialysis. Most of the living and adjusting to kidney disease occurs outside the dialysis or hospital setting and away from the health care practitioners. The work of living with kidney disease means having to make daily decisions about what you eat, how much you drink, taking medications and getting adequate exercise, all of which can have a profound effect on the health of a person living with renal failure. The social and cultural worlds in which people with renal disease function affect the decisions that are made in their daily lives.

**Diet.**

For most people, following a strict diet is an enormously difficult task. In our society food is all around us; we socialize, celebrate and sympathize over food and drink. For those on dialysis, eating becomes part of the work of living with kidney disease. In order to maintain their health, people undergoing dialysis therapy are told to monitor and limit their sodium, potassium and phosphorous intake every day. This requires understanding and remembering the
make-up of most foods. To this end, many participants kept a list of foods high in phosphorus and potassium on their refrigerator. Frieda once threw out the list on her refrigerator, not realizing that George still referred to it. The result was some very bad feelings and a mad panic to get a new list sent up from the United States.

Textbook of Renal Disease (1994)

Good nutrition remains a cornerstone in the conservative management of chronic renal failure and the emphasis should be on the positive aspects of nutrition rather than an unnecessarily restricted diet. A reduced protein intake can relieve symptoms such as anorexia, nausea and vomiting, and reduce the load of hydrogen ion, sulphate, phosphate and potassium which the kidney has to excrete. Many patients have extremely poor dietary habits and badly need education as to the nutritional value of various foods. Moreover, dietary intake may be decreased by anorexia and leave the patient at risk of chronic malnutrition. There is some evidence that continued high solute loads contribute to loss of renal function in patients with established renal failure. (Dawborn, p. 358)

Living under a strict dialysis diet makes it necessary to limit or eliminate foods like dairy products (e.g., cheese, yogurt), some fruits (oranges, bananas, melons, kiwis), highly salted foods, chocolate, nuts, etc. According to Bassan, “You can’t eat that, this fruit, you can’t eat that thing, you can’t do this, you can’t do that, you know.” George found the dialysis diet extremely difficult.

George: Oh yeah, the biggest problem of all is diet, dietary. What you can and can’t eat. You have to, you have to like, I keep my list on the refrigerator on the phosphorus and potassium and you have to watch your potassium and phosphorus intake everyday.

Shawna: So you really know the value, what’s in every food now.

George: Well, you know the things that are high and low. And you can, you can have certain amounts but you always seem to manage to exceed what you need, you know. And you get the consequential problems like itching and so on. And I guess another problem that I find the hardest, the hardest thing of all maybe to control is food intake.
George found that restricting dairy products is next to impossible:

George: How do you get away from dairy products? I mean everything is, it includes so many things, milk and cheese and ice cream, yogurt and all those kinds of things, you know, it’s hard, puddings and, you know, how the hell do you get away from all those things?
Shawna: That must be so hard.
George: You’re really, you’re really up against it, you know, in a dietary sense.
Shawna: Right, what do you do for things like going out for dinner or going to somebody’s house, is that a problem?
George: It’s always a problem.
Shawna: Oh, is it?
George: You know, it continuously a problem, it’s the hardest, it’s the most difficult thing in your life, is in your life now, that’s dietary.

Others were less troubled by the dialysis diet. Olive, for example, didn’t “have a problem with diet at all.” She had been on a salt restricted diet for a number of years and said that she didn’t find it difficult to eliminate some of the other foods from her diet. Similarly, Pearl did not find the diet to be a large problem. She had lived with kidney disease for the greater part of her life and had learned to cope with the diet restrictions:

I’m so used to it that, you know, if I want a bag of potato chips, you know, I’ll have it but it will usually be before dialysis, like the day before or something, or like now [on dialysis] or something...

Other participants used similar strategies to get around the dietary restrictions — for example, drinking Coke while on dialysis is a common practice despite the fact that Coke is high in phosphates and is thus, considered “forbidden.” Not only are people with kidney failure concerned about the contents of food, they must also be concerned about the amounts of food that they eat. Because of medication and other issues, it is important to eat three regular meals a day. As George explained:

...if you are careful about what you eat and eat properly it makes a huge difference, you know. If you’re eating properly and you take your medications...it makes a difference about your feeling good. [If] you’re not eating properly and it really makes you feel, you know, if you miss a meal and only eat one meal a day it makes you feel really awful. So nourishment is, is a very critical thing for you.
While health care practitioners pushed the participants to follow a proper renal diet, it was the participants themselves who had to deal with the consequences of their food choices. The consequences of not following a proper renal diet range from moderate to severe. As George noted above, an improper diet may lead to feeling itchy. Besides itchiness, improper diet can result in fatigue, grogginess, restlessness, feelings of ill health, bone disease and extra strain on the heart. It was the participants' choice whether eating certain foods were worth these risks.

Lave (1988) argued that “a psychology drawn from an ideology of rationality cannot adequately account for practice” (p. 176). What health care practitioners consider rational may not be considered so by the people living with kidney disease. For example, although it may not seem “rational,” sometimes people with renal failure prefer to ignore risks so that they can feel “normal” and eat what they please without having to worry about every morsel. The consequences of following the renal diet may include feeling cheated, missing out on enjoyment, feeling like an outsider, and/or missing socialization opportunities. Thus, sometimes, it may be “rational” to not follow such a restrictive diet.

**Dialysis Therapy** (1993)

The goal of nutritional management of patients receiving hemodialysis is to promote and maintain good nutritional status without exacerbating fluid and electrolyte disturbances or aggravating symptoms or uremia.

Recently, the relationship between poor nutritional status and patient mortality rates has received much attention. Evidence from surveys of large groups of hemodialysis patients shows that mortality rates are higher in patients with low concentrations of serum albumin, phosphate, creatinine, cholesterol, and serum urea nitrogen. With the increased used of urea kinetic modelling techniques to assess adequacy of dialysis, it is clear that serum urea nitrogen is not a reliable guide to the dialysis prescription. Furthermore, estimation of protein catabolic rates from the kinetic model is a better indicator of how well the patient is meeting dietary protein requirements. It is clear that
patients with inadequate protein intake are at risk for developing malnutrition and require increased counselling and assistance from the dialysis physician, nurse and dietician. (Feinstein, p. 197)

Monitoring fluid intake.

Living within the framework of a renal diet includes more than just food restrictions. An equally difficult part of this diet is the severe limitations placed on liquid intake. Most renal diets allow only four cups of fluid per day. At first glance this may not sound difficult; however, when one considers that any food “that converts to fluid, like ice-cream, or puddings and jello”, or is made with large amounts of liquid (like soup, oatmeal, pasta and rice) counts as a part of these four cups, it becomes quite difficult indeed. As with the dialysis diet, it is the people living with renal failure who suffer the consequences of not following fluid restrictions. However, it appears that it may sometimes not feel like a choice:

Pearl: If I drink too much it can be, sometimes it’s like I just, incredible thirst, it’s like I just don’t care (laughs) you know, I’m drinking this, like between Tuesdays and Thursday, I’m a little more careless because it’s a shorter time period.
Shawna: Right.
Pearl: But sometimes it’s just, you know, sometimes it’s like you’re sure you got it through osmosis in the bath or something, because you can’t believe you drank that much, you know. (Laughs) And I say that, I say this is from osmosis but I mean if you eat a lot of fruit or a lot of vegetables or you have noodles or rice, that’s all fluid. It’s all got fluid in there so, so yeah, of course, it’s conscious because obviously you don’t get it by osmosis.
Shawna: Right.
Pearl: So, but it’s not like it’s, okay, I’m going to like drink 5 kilos and go in and, and do they yell at you. No, at the beginning they’re kind of like, sometimes they’ll say, “this isn’t good for you” and you know, “how can we change this” and what you should do different. But for the most part they just maybe roll their eyes, every now and then they’ll say something.
Shawna: Right, but then you feel it yourself, right?
Pearl: Yeah, I suffer the consequences. You have good days and good stretches and bad stretches. Like today I only had 2.5 and I intend on having, I’ve had one coke and I’m having another one, so I’m taking off more than I actually put on, type of thing.
Limiting fluid intake was found to be difficult by all of the participants and all professed to be large fluid drinkers before dialysis. Alcohol, too, of course, is considered a liquid and, thus, must be monitored. It is interesting to note that those people who were alcohol drinkers before dialysis seemed to have lost their taste for it and, thus, didn’t find this to be a large adjustment. Pearl found one benefit of dialysis and drinking: “One thing about dialysis is if you’re hung over, after dialysis you won’t be so.” She shared with me the story of the time she came to dialysis after an all-night party. When she was done dialyzing she felt fine, sober and raring to go; this was not the case for her drinking buddy who was feeling quite ill and hung-over.

It is very common to see people on dialysis chewing on ice-cubes or using other means to reduce their thirst.

Shawna: Right, yeah, I noticed that you were having ice.
George: Yeah, (laughing) ice is meant to discourage you drinking a lot of water, but I eat as much ice as I can drink water. I think that’s the case, you know. It defeats the purpose, you know. It’s designed to, so that you suck on an ice cube until it’s gone, but everybody I’ve ever seen, they chew ice like it’s popcorn.
Shawna: Yeah, I can’t do it, it gives me the shivers.
George: Really.
Shawna: Biting anything cold.
George: Oh really.
Shawna: Yeah, even thinking about it.
George: God, I’d be (laughing) becoming like an ice addict now.

Review of Hemodialysis for Nurses and Dialysis Personnel (1993)

Ice has two advantages: (1) its coldness and (2) the time required for it to melt in the mouth. These factors makes it more effective in alleviating the sensation of thirst. A 200 ml glass filled with ice chips yields about 150 ml of water. Therefore the patient will consume less fluid by eating ice chips than by drinking water. Today because dialysis is more efficient and removal of fluid is better achieved, ESRD [end stage renal disease] patients have less restrictions with respect to oral intake. (Corea, Christensen & Vogel, p. 144)
Pearl has tried sucking on lemons, and Olive has tried taking water into her mouth and then spitting it out. These are only a second-best measure and most participants admitted to really missing drinking water and other liquids. Olive said that she “craves a lot of fluid” and that she was “always a heavy water drinker, I don’t care about coffee or tea, but water, cold water, oh heaven.” George found restricting his fluid particularly difficult.

Shawna: Right, yeah, and you also said you had trouble with fluids, but you don’t seem to have any of the effects of drinking too much fluid so, or do you?
George: I don’t, it doesn’t cause me any discomfort in that I don’t feel bloated or anything like that. Because they will continuously tell you, if you continuously have an excess of fluid on it’s, uh, it’s a over burden on your heart, because it has to pump all these extra fluids through your system. And they all, they continually stress the importance of not taking on excess fluids.
Shawna: Right.
George: But I don’t, I seem to have a hell of a time controlling, losing, God, I always seem to have excess fluid. Like I should be coming in around 2½ to 3, 2½ to 3 kilos of fluid to take off, instead I come in at 4 or 5.
Shawna: Do you think that’s maybe because you don’t get bloated, maybe if you got bloated you wouldn’t, you wouldn’t do it.
George: Well, it could be. I mean, you know, Jesus, I used, I used to consume enormous amounts of food, you know, water and other fluids. Then all of a sudden, now you can’t do that and I’ve had really a hell of a time with it, even though it’s been five years. I should, I really should make more of an effort to control it actually, but I mean when you, when you eat certain foods or you drink certain fluids, it’s a compelling urge of thirst to drink something you know. And it’s...
Shawna: I think that would be the hardest part for me.
George: It’s like being in a desert and there’s all kinds of water in front of you and it’s pretty hard to resist drinking it (laughs) although that may not be a fair analogy, but it’s sort of like that.

Taking on too much fluid can be both uncomfortable and dangerous. When a person’s kidneys are not functioning (or functioning poorly), any liquid that is taken on by the body is retained until the next dialysis session. As many of the participants have learned through experience, poor fluid control can lead to blood pressure problems, swollen joints, difficulty breathing, heart palpitations and other heart problems.

Shawna: What, and what happens when you have more fluid gains?
Pearl: Well, then there’s more to take off and it can affect your heart and your blood pressure can go up, you know, when you drink too much fluid and that kind of thing. And in the beginning I really noticed it, now I don’t know, maybe my body is a little
more used to the fluctuations. But I, I notice if I drink a lot, like I mean a lot, which rarely like, you know, six kilos or something. I’ve done that a couple of times, but it’s usually been a good party the night before, then yeah, you feel just bloated. Like today is good for me, because I was just done Tuesday and then I go today, so I hardly restrict my fluid at all between then. But like on the longer runs, if I don’t watch it somewhat then, then you really notice and you just feel kind of a, kind of bloated or, I kind of, what I get sometimes it’s like, I feel like I’ve got a real chill. It just goes right through me and I think that’s related to fluid overload. But other than that, I used to, my ankles used to swell and stuff, but they don’t anymore. It’s probably because my albumin is better so it keeps the fluid in your blood system as opposed to tissues. But some people, I mean, and it’s happened to me maybe twice, where you have difficulty breathing just because it, you know, it’s in your chest.

Shawna: Scary.
Pearl: Yeah, yeah. You get, you know, pulmonary edema, but very rarely, I mean there has to be a good excuse for me to do that. Like an all night party or something (laughs) but now I drink martini’s so... (laughs)
Shawna: You don’t have to drink lots.
Pearl: Exactly.

**Clinical Dialysis (1995)**

Assuming a standard program of thrice-weekly hemodialysis, weight gain between dialysis treatments should ideally be kept to approximately 0.5 to 0.75 kg/day. This may be achieved by restriction of total fluid intake to approximately 1L/day in the anephric patient, or 1L plus the average daily volume of urine output. (Rostand & Rutsky, p. 667)

**Medications.**

Another form of work to maintain health that people with kidney failure perform outside the hospital setting is taking medications. Taking medications involves remembering to take them at the correct time and at the correct dosage, having the necessary medications on hand at all times and dealing with any side-effects. The most common medications are potassium and phosphorous blockers that are taken every time before eating. Iron is also uniformly taken in either pill or IV form and EPO is generally given during dialysis. Other pills taken that are kidney disease-related include various vitamins, calcium and blood pressure medications.
Beyond these, most of the participants take medications for other medical ailments. These include medications for thyroid problems, arthritis, diabetes, and to avoid blood clots and excessive bleeding. While everyone takes medication daily, the amount of medication and how consistently this medication is taken varies with each participant.

Bassan was prescribed the most medication of the four participants in this study, and took eight pills before eight o’clock in the morning. He was very consistent in taking his medications as prescribed, “…everyday, night, I take and set the ABC, this is for every morning breakfast, this is for the lunch, this is for the evening.” He took pride in his organization and his ability to follow his “doctor’s orders.” Similarly, Olive took all her medications as prescribed:

Shawna: And are you taking any medications?
Olive: Yeah.
Shawna: A lot, a few? What are you taking, EPO you said.
Olive: Uh, uh (nods).
Shawna: And what else are you taking?
Olive: Well, I take, it should say in there [hospital chart], pills for itchy and vitamin and I take, oh what do you call them, for arthritis…?
Shawna: Em.
Olive: Not, I don’t take aspirin, it’s the, whatever, the other thing is and…
Shawna: Are you good at remembering to take your pills, or is it a problem?
Olive: Oh no, I take them regularly, oh, and I have one other pill, it’s a vitamin D that I take three times a week, Monday, Wednesday and Friday. No, I’ve never forgotten.
Shawna: Really.
Olive: And I stick to whatever they say, I do, so.
Shawna: Oh, I’d have a hard time I think with the three times a week one.
Olive: Oh no, its on…
Shawna: I would have a hard time with that.
Olive: You get used to it.

On the other hand, Pearl and George were less consistent and, interestingly enough, were actually prescribed the least amount of medications.

Pearl: Yeah, there’s iron, which they do IV now because I was non-compliant in taking it. I just forget. And then there’s one alpha, which is for, I think it’s thyroid hormone level. I think something to do with the thyroid. That’s one part of me that I’ve never really looked into, like, what’s this all about.
Shawna: And that’s a pill that you take or is it…?
Pearl: No, I take, I'm really bad at taking that, really bad. Like I find it in my cupboard and go, oh yeah, I'm supposed to take this, you know, and it's been like a month. Don't put that on tape (laughter).

Shawna: Don't worry, your doctors won't hear this.
Pearl: Okay, good, Dr. __ going to hear?
Shawna: No.
Pearl: Okay, and then, oh, there's the birth control for the bleeding, which I take continuous, so that's the only other one.
Shawna: So do you remember to take that one?
Pearl: Yes, oh yeah, because if I don't I bleed to death.

George, too, did not always take his medications as prescribed:

George: It's critical that you take those things.
Shawna: Yeah.
George: I didn't take mine this morning (laughter) but I just had some pastries and a coffee anyway so, so there's not much in that.

A couple of months later the issue of medications came up again:

Shawna: I think, I can't remember if I asked you but what kind of drugs are you taking, medications?
George: I'm not taking anything now except I take, I take iron pills and I take blockers for potassium and phosphorous and that's about all.
Shawna: And you take those everyday?
George: Oh yeah.
Shawna: Yeah, are you good about taking your medication?
George: Well, I try to be, I haven't had that good of a record in the past. And I, it's been impressed on me the real importance of doing it and it is, it is important otherwise you suffer the consequences with the itching.
Shawna: Right, so it that, are these pills like a once a day thing or three times a day or...
George: It's three times a day, but supposing that you eat three times a day because every time you eat something you should be taking...
Shawna: And you weren't taking them before?
George: Well, I was missing them sometimes because I didn't have them with me.
Shawna: Oh.

It could be that a larger amount of medications necessitates more organization and, thus, makes it "easier" to take medications as prescribed. However, it is interesting that the older two participants were more concerned with following doctors' orders and, thus, took their medications more faithfully. Perhaps this is because both Olive and Bassan come from an era when doctors' authority was especially great and their advice was not questioned.
Several potential problems with medications are seen in patients on dialysis. The kidneys are a major route of excretion for drugs and drug metabolites. Loss of renal function that necessitates dialysis also reduces elimination of many medications with potential for accumulation to toxic levels.

Metabolic effects of uremia alter drug disposition. Increased magnitude and duration of drug effect may necessitate adjustment in dosage or frequency of administration. Dialysis may affect drug disposition, requiring supplemental doses of drugs removed during dialysis. Medication to facilitate dialysis or to treat concomitant signs and symptoms of renal dysfunction may be used. Conversely, drugs can exacerbate dialysis problems or symptoms of uremia. (Pepper, p. 153)

For the most part, the medications taken help to allay symptoms such as itchiness and restlessness; however, some medications have negative side effects that people living with renal failure have to deal with. For example, both Bassan and George reported a disconcerting amount of growth in their breast size. Further, on one medication, George had an inordinate amount of hair growth on his body.

George: I don’t know what after effects, there’s certain after effects. I was on something called Minoxidil and then I don’t know. I guess they all have some kind of after effects.
Shawna: Yeah.
George: And the Minoxidil was one that caused me to grow, your body hair grows thicker and even your hair grows better.
Shawna: Yeah, I was thinking that sounds like one of those hair growth...
George: It is.
Shawna: ...things, yeah.
George: Oh yeah.
Shawna: So did you get a full head of hair? (Laughs)
George: Well I got my hair a lot thicker, not to a real marked degree, but my body hair grew, grew fast, thicker and I was growing more hair on my legs and my chest and...
Shawna: Not a good thing if you’re a female then (laughs)
George: ...I don’t know, I don’t know what other after effects the medication had but I, um, also, I don’t know if it’s a combination of that, Minoxidil caused me to develop, develop breasts (laughs)
Shawna: Oh really.
George: Yeah it does, it's just like, you know not normal for...
Shawna: For a guy.
George: ...for a male.
Shawna: Yeah, but once you stop taking it...
George: So then my first question to my, my family doctor, am I now susceptible to breast cancer (laughs) and he didn't think so, but you are anyway I think.
Shawna: Yeah?
George: To a lesser degree, I guess.
Shawna: Yeah, it's sort of rare in men.
George: Yeah.
Shawna: So once you stopped taking those drugs, did all the symptoms, other side effects go away? Like, did you lose all the thickness in your hair and chest, or did it stay?
George: No, yeah, I did gradually, yeah.

Also common is an increase in the frequency of bowel movements and diarrhea — which is especially problematic when one is hooked up to a dialysis machine for a number of hours.

According to one participant, diarrhea, "...happens quite often; you’ve got to keep your Immodium handy.” Thus, some medication can lead to the need for even more medications.

Sometimes the side effects of medications subside after a length of time on the medication, or when the medication is stopped altogether; other side effects just become facts of life for those living with kidney failure. There are more difficulties related to medications than possible side effects. Sometimes the medications themselves can be very frustrating. They can be difficult to take (because of timing or the size of pills), they can be expensive and/or they can be ineffective.

For example, Pearl has had trouble with blood pressure medications:

I was on four different kinds of blood pressure medicine, three or four at once and we still couldn’t control it and then, then it bottomed out and it would stay there. And so they started taking ones away to the point where they had to take them all, take me off all of them. So explain that one. It’s frustrating.

Review of Hemodialysis For Nurses and Dialysis Personnel (1993)

For the person with chronic renal failure and on maintenance dialysis, use of any medication requires the utmost caution. Side effects or untoward reactions occur two and a half times more frequently in dialysis patients than in the general population. Comprehensive care of the dialysis patients must include: (1) assessment of new drug
orders with respect to unique characteristics of the individual patient and pharmacologic properties of the drug; (2)
periodic review of medications, especially if there is a change in the patient's [sic] condition; (3) careful monitoring
for therapeutic response and untoward reactions; and (4) thorough patient education. (Pepper, p. 153)

Exercise.

Exercise is another way that people living with kidney failure can work to improve their health. All of the participants in this group report doing some form of exercise (typically walking and bicycling) but believe that they should be doing more.

George: So that's what I do, but I don't, I don't think I'm getting enough exercise. I lined myself up to go to the gym over here but I just don't find myself going there very much.
Shawna: Yeah. Do you get a lot of fatigue and stuff that comes with the disease, or not really?
George: Continuously.
Shawna: Continuously, so it must be hard to motivate yourself.
George: Well I try, I used to have a, I used to have a very, you know, continuous or large capacity to just get, work all the time. And now I just, I haven't even got a third of the strength to do what I used to do.
Shawna: Oh.
George: I just get tired and have to sit down and relax. Not, not, I don't know what it is. It's not, it's not a heart condition, it's just. I don't know, just goes along with your whole being or your whole system I think. I think kidneys do a hell of a lot more than people think they do.

Like most people who do not get sufficient exercise, the excuse is lack of motivation and lack of time. However, considering the amount of time that is lost to dialysis, a lack of time for other activities may be a reality that people undergoing dialysis cannot avoid. This is especially true for Pearl who is both studying for her Masters degree and working, while carrying out dialysis therapy. Whether working or not, dialysis schedules may make it difficult to go skiing or hiking, or to do any other activities that are away from the city. Further, when one is feeling unwell, it is more difficult to get up the motivation to exercise. Those living with kidney disease may never feel 100%, according to George:
...you don’t have the stamina like you used to, or the energy, you know, you just, I mean you just don’t have it and you tire easily and you have to rest frequently and, you know, it’s just, I mean it’s just not fair, you know. I used to be, like if I go cycling or go skiing I just, especially skiing you tire easily, you know and you know I used to be able to just ski non-stop all day. Now I have to, you know, you have to ski about half a mile and you have to stop and rest. You know, it really taxes your energy and stamina.

**Dialysis Therapy (1993)**

Having renal failure and being on dialysis induces a sedentary lifestyle and causes premature aging. It follows that the benefits of endurance training will help dialysis patients, provided these patients are able to exercise. Of the few studies done on aerobic conditioning in dialysis patents, blood pressure has been shown to fall. This lowering of blood pressure could be due to reduced peripheral vascular resistance or better control of fluids by greater loss through sweating.

Although total cholesterol levels tend not to be high in most hemodialysis patients, HDL-C levels are often low. An exercise-induced rise in HDL-C or fall in triglyceride levels would be beneficial by impacting on cardiovascular and cerebrovascular disease. Glucose intolerance, which is present in some dialysis patients not only as a complication of uremia but also as an accompaniment of hypertension, may be improved by exercise and weight loss as well.

(Lundin, pp. 333-334)

**Living with the Losses of Kidney Disease**

No matter what choices each person with renal failure makes concerning dialysis therapy, diet, fluid intake, etc., having kidney disease means having to deal with negative changes in one’s life. The work of living with kidney disease means learning to live with its many physical, cognitive, social and psychological consequences. According to Lave (1993), learning is not a matter of just acquiring knowledge; it is a matter of activity with the world. Thus, people with renal failure learn about life *with*, and the consequences *of*, renal failure through the activities of their everyday lives. Life as it was known before kidney disease is lost and those living with this
disease must work to endure the new and difficult changes in their lives. The most obvious of these losses is physical health.

**Losses in physical health.**

The physical consequences of renal failure are numerous and significant. According to one nephrologist at the hospital:

I’m aware of the fact that [kidney disease has] a devastating effect on their lives. I often tell them that what I can offer them is second best to a normal life. That all I can offer them is an opportunity to feel better than they feel before they start dialysis treatment, but that I cannot often guarantee that they’ll be back to normal.

As George put it, “you can’t say that you’re feeling a hundred percent, because you’re not.”

Before a dialysis run, a large amount of fluid will have collected in the body. A person may feel “bloated” and “like they are ready to just get in there” so they can get this extra fluid taken off. Pearl noticed that she seemed to have more cellulite before a dialysis run, and would not wear certain clothing (e.g., a bikini) until after a dialysis run. If all goes well during a dialysis run, participants report coming off a run feeling generally well, although they might feel slightly fatigued. This fatigue, however, can make doing regular daily activities more difficult than usual. As well, even after a “good” run, occasional problems may occur. For example, one interview with Olive had to be postponed because she began to feel unwell.

Shawna: So how are you doing?
Olive: Not too bad, I don’t feel very good at the moment though.
Shawna: Oh really, how come?
Olive: Well, I guess it is the blood getting back into me or something.
Shawna: Is that normal or just today?
Olive: Um, it sometimes happens.
Shawna: Is that...
Olive: My blood pressure goes down.
Shawna: Oh, that’s not good.
Olive: Uhhhh (soft moan) I get all hot and sweaty.
Shawna: Does that mean that they took too much of you or that…?
Olive: I don’t know, I hope not. Uhhhhhh.
Shawna: You are sounding a little tired, do you want me to get a nurse or are you okay?
Olive: Here she comes now.
Nurse: Hi.
Shawna: Hi, she’s not feeling very good.
Olive: Uhhhh.

A drop in blood pressure led Olive to feel dizzy and generally ill and, thus, ended our interview.

Sometimes after dialysis is complete, there may be problems with getting the dialysis site to stop bleeding. This can add time and stress to a run. Bassan for example often had a difficult time holding his graft site and on one occasion it continued to bleed without his being aware of it. This, in turn, caused other health problems. A “bad” dialysis run can have even more detrimental physical consequences. One of the major problems is when, for some reason or another, too much fluid is “taken off.” Olive found that “...after dialysis, if they took too much off me, I’m a basket case for the whole day, night and then part of the following day.” She described it as “a horrible feeling” and said that “there are days when I get off this machine that I can’t navigate at all...after they’ve taken too much off me, I can’t even stand up.” George found that:

Well, a bad day is if, is if you come in with too much fluid in your system where you can’t, where you can’t take it all off. Or if you take a large amount of fluid off, you know, you feel ill, you don’t feel good after. And sometimes I, you know, in those kind of situations and it happens to me a lot. I frequently have too much fluid to take off and afterwards I have to go home and have a sleep to recover. You know, but otherwise you just feel ill or you feel, you know, you feel real crappy, you know, for maybe five to ten hours or something. You know, so that is, that’s the difference between a good and a bad day, I guess.

Both George and Pearl described having taken too much off as a feeling of being “sucked dry by the machine.” The very fine line between “taking off too much” and not taking off enough fluid makes it difficult for both practitioners and the people on dialysis, though it is the people with renal failure who must suffer the consequences.

Shawna: Em, so when you, when you leave here do you feel better because everything is cleaned out or do you feel worse, or what do you feel like?
George: Well, it depends, if I, if I’ve been gaining weight and then I try to and you don’t take that into account and then you take off too much fluid, it’s like the machine is sucking you dry. Because you’re trying to take off that food when you shouldn’t be
taking off that much fluid. You actually taking off more fluid than you should because you’ve been gaining some weight, so you have to...

Shawna: Right.
George: ... you have to know that if you do that then you feel, you feel just totally zapped out and it takes you quite a while to recover. Like sometimes I have to go home and go to bed; otherwise I’m just useless. I’m just weak and dopey and sometimes you can, you can speed up the recovery by having chicken soup or something like that. But it’s still, you still, you still suffer with it until, you know, rest and sleep and that helps you to recover.

Although people with renal failure (especially those on self-care) have some input into how much will be taken off, it is the practitioners who have the final say. Sometimes, the only way for people with renal failure to have a say in how much fluid is taken off is for them to lie about their starting weight. It is unfortunate that the people living with renal disease must lie in order to achieve their goals. If they had a legitimate voice in the discourse of their care—one that was heeded rather than ignored—this need would not arise.

Clinical Dialysis (1995)

For nearly three decades, long-term patient care decisions for chronic dialysis patients, have been made using an interdisciplinary team approach. The members of the interdisciplinary team, the physician, dietician, social worker, technician, nurse and financial counsellor evaluate each patient. The physician considers the team’s input, then assimilates the information into a written plan for the care of the patient, including the specific dialysis prescription.

(Corea, p. 121)

Sometimes too much fluid is taken off because of human error. For example, on one occasion, George “put the wrong figures on my chart and instead of taking off about 4½ to 5 kilos I took off over six.” This resulted in his having to “take on some extra fluid right away” and then having to “go home and have a sleep and God, I felt awful.” An incident like this can be “very hard on your heart and your heart could even, could even stop on you if you’re not careful.” Another common and potentially serious problem that can occur while on dialysis is
fluctuating blood pressure. Pear often had difficulties stabilizing her blood pressure. She said that when blood pressure “gets too low too fast, then you can get cramps, but if it’s too high then you come off dialysis being thirsty.” Either way, it can be “kind of discomforting when you feel kind of blecky.”

Beyond dialysis-related difficulties, there are many physical effects of kidney disease that people must face every day. Although renal disease itself is “not painful,” living with renal failure often means having to endure painful or uncomfortable procedures. For example:

Shawna: Would you say that renal failure is painful?
Olive: No.
Shawna: No. Was there any discomfort, or is there any discomfort having kidney disease?
Olive: Uh, only when they put the needle in the wrong place or something like that. But other than that I don’t find any discomfort.

Pearl’s response was similar:

Shawna: Alright, I need to know, would you say that renal failure is painful?
Pearl: No.
Shawna: No. Was there discomfort?
Pearl: Yeah, some.
Shawna: Okay, like what?
Pearl: Cramps, ooh, I had bad cramps last time.
Shawna: Yeah.
Pearl: But, um, I don’t know, I think it’s kind of discomforting when you feel kind of blecky.
Shawna: Yeah.
Pearl: Like blecky, can you spell that, blllecky, no, that kind of, but just (makes a face).
Shawna: I know, I do that some days, yucky.
Pearl: Yucky, yeah. Some of the procedures are painful or discomforting yeah, but in general, no.

Some of the more common consequences of renal failure include weight loss, being itchy, restless, having little energy, insomnia and an inability to urinate. This list, however, cannot clearly express how these physical symptoms manifest themselves in the lives of people with renal failure. On first glance these symptoms do not appear to be all that serious, as most people have experienced them at one time or another. However, living with these symptoms on a daily basis can have serious repercussions on people’s well-being. For example, both Bassan and
Olive were concerned about the substantial amount of weight they had lost since the onset of their kidney disease. Bassan had gone from 170 to 125 pounds in a short time, and Olive lost over 30 pounds.

One of the most common and bothersome complaints for everyone in this study is itchiness. As Pearl put it, "...you're just really itchy or something and you just feel like jumping out of your skin... that kind of stuff gets to you." George found that eating well and taking his medications could alleviate some of his symptoms:

...but I think if you, uh, are careful about what you eat and eat properly it makes a huge difference, you know. If you're eating properly and you take your medication in the sense of your blockers and that, uh, it makes a difference about your feeling good. Like you're not eating properly and it really makes you feel, you know, if you miss a meal and only have one meal a day it makes you feel really awful. So nourishment is, is a very critical thing for you. On the other hand, improper nourishment can be just as, cause you just as much discomfort or suffering because you've got, you're itchy and restless and Jesus, sometimes you know, you have an over dose of potassium, it's really miserable. I mean you're just itchy all over you know, and there's nothing you can do to alleviate it at that time, it just has to run its course.

However, George also believed that even if you watched your diet and took your medications you would still suffer a certain amount of itchiness. Another of the day-to-day physical difficulties that those on dialysis often face is fatigue. Pearl occasionally found that she was tired, and Olive said, "...I'm always tired."

Olive: Even now, I get up about eight o'clock and have my breakfast and by nine thirty or ten o'clock I may be back in bed just for an hour's rest again. I just sort of, well, I need it.
Shawna: Yeah.
Olive: And then again in the afternoon and I lie on the chesterfield and watch television. I don't just sit up at all, so that's the kind of days you have.
Shawna: Right.
Olive: I'm sure other people who have days that they can, like, I haven't been in a store to buy anything for myself other than just groceries or the bank since a year ago this past August, 1996.
Shawna: Wow.
Olive: Seven, the last time I was in a store was August 1996. I don't have the energy to go into a store.
Shawna: So would you say that's one of the hardest things for you, is that you don't have any energy anymore?
Olive: Oh, none at all.
Shawna: Yeah.
Olive: No.
Shawna: That must be very frustrating.
Olive: It is.
Shawna: Yeah.
Olive: It really is.
Shawna: Especially if you were active beforehand.
Olive: Yes, I was.

This lack of energy led to concern over Olive’s abilities to shower on her own: “...I still don’t have the energy to do it [shower] by myself.” Further, her daily activities were severely limited by her lack of energy: “Oh my God, I never go anywhere, had my hair done yesterday and went to the bank and came right home and that’s it folks.” George, too, found himself with diminished energy, and at the same time suffered from a “remarkable amount” of restlessness and, thus, had great difficulty sitting still for long periods of time. He found that he was restless in his sleep and couldn’t “stand to have anything on his feet” for any length of time. This caused problems in his social life; he found it difficult to sit for the length of a movie, live play, or even a dinner out. For example, recalling an evening out to see Show Boat, George stated,

I had to get up and move around and finally went to the back and found some empty seats in there. And I sat by myself so I could get up and walk around. I can, I can alleviate the situation if I can get up and walk around...

Further, Frieda noted the stresses and successes that he has had with this problem: “He was so proud, once he went out with all the guys he had trained with and he was so happy because he was able to sit the whole night without taking his shoes off.” Also problematic was George’s restlessness during the night, which led to other problems in their relationship:

George: Yeah, and I don’t know, I don’t know, you know, I don’t know, I think, you know, we, we haven’t had any kind of intimate relations for three years or so years now.
Shawna: Yeah.
George: I don’t know if she thinks I’m impotent or what, which is not the case actually.
Shawna: Right.
George: But, you know, we just seem to have lost the ability to communicate in that sense.
Shawna: Yeah, I think it’s pretty common among dialysis patients.
George: Oh yeah.
Shawna: Yeah.
George: And, you know, it's not, I guess, you know, she found, you know, you know, we have separate bedrooms now because she found it impossible to, because she was working and had to sleep because of my peculiar habits, peculiar sleeping habits. I don't sleep well at night, I'm up and down and...
Shawna: Right.
George: ...in bed
Shawna: Is that because of dialysis, has that always?
George: Oh sure, I've been like that. I don't sleep well and I'm restless at night. And I'm lucky if I get four or five hours of sleep a day, so...
Shawna: Wow.
George: And, uh, you know, its, even in your sleep you don't realize it but you're restless in your sleep, and I was keeping her awake.

Physical symptomology, then, affects not only the comfort of the people with renal failure; it also has an effect on the people in their lives.

Primer on Kidney Disease (1998)

...the quality of life experienced by ESRD patients, as among patients with many other chronic illnesses, such as arthritis and chronic obstructive lung disease, is often significantly compromised. The renal failure itself, the underlying disease responsible for the renal failure and the high degree of associated comorbidity, are likely contributing factors. Patients on dialysis often complain of fatigue, lack of energy, anorexia, depression, decreased libido, musculoskeletal symptoms, and pruritus. HD is usually required three times a week for 3 to 4 hours, and can be accompanied by various physical discomforts, nausea, dizziness, headaches, and lack of energy during or after dialysis. (Bloembergen, p. 426)

Other symptoms reported by the participants in this study include headaches, enlarged and painful breasts, general aches and pains, muscular stiffness and pain, hair loss, hair growth, rapid weight loss and poor circulation (especially in the arm with the fistula access). Further, one doctor, a nephrologist at the hospital, noted other possible physical problems related to renal failure:
...the man may become impotent, the woman may lose her normal hormonal cycle, these patients often have bad breath which they themselves don't notice as a result of the uremia. Young women on dialysis, unless they have good luck with a transplant, they may not be able to have children.

Some of the health problems that may occur, which are directly related to renal disease, have been mentioned earlier. These include blood pressure problems, heart problems, etc. Other health problems that arise may or may not be related to kidney disease. For example, Pearl had problems with excessive bleeding during her menstrual cycle. Therefore, she needed to take birth-control pills continually so that she did not menstruate at all. If she did menstruate, "...I just don't stop bleeding and it's literally hemorrhaging...." She has ended up in the hospital numerous times because of this problem. It was unclear if this excessive bleeding had any relation to her kidney disease.

Sometimes just being in the hospital can be a detriment to one's health. Olive's "major setback" was due not to her kidney disease but rather to two separate accidents in the hospital. First, she fell out of a broken wheelchair: "One of the flaps fell over and I ended up in the emergency with a hematoma like you wouldn't believe." Then, just two days later in the hospital, she was hit in the arm by a helmet belonging to someone in the elevator. This led to another hematoma on her arm. Consequently, she was "flummoxed with my leg, which is still feeling very peculiar, and then my arm was so swollen I couldn't even do up a button." Because of these incidents, she was unable to care for herself at home, had to hire some home-help and was unable to drive. These incidences caused Olive to lose some of her independence, which was very "unnerving" to her as she was normally a very "independent and self-sufficient" individual.

As we have seen, the physical symptoms that people with renal failure must face and work to alleviate are difficult and pervasive. These physical symptoms also have an effect on the ability of people with renal failure to socialize, work and partake in leisure activities. As well,
because people with kidney disease do not live their lives in isolation, the symptoms that they experience may have an effect on their family, friends and their health care practitioners. Unfortunately, these losses in physical well-being are not the only difficulties that must be confronted; people living with renal failure may also have to deal with a loss in cognitive function.

**Losses in cognitive function.**

Although research has shown that people with renal failure experience losses in cognitive function, in this study’s participant group the findings were not so clear. According to one doctor:

...most people, they never quite feel absolutely right, they complain of the inability to concentrate, that there’s always the sensation of a fog in their brain. I’m very aware of the fact that if you walk around a dialysis unit, patients are watching the most inane garbage on TV and I know why they do that. Because they actually get some physical vibration during dialysis, they have some brain swelling, they lose concentrating ability, they lose memory. Very few people try to continue doing work on dialysis, all the professionals try to bring work in with them and I notice within about three months or so they just lie there and rather go to sleep or watch garbage on TV. Most of them don’t try to read a book because they can’t retain what’s, what they’ve read.

In this participant group, some individuals had difficulties with cognition and others did not. Although people with renal failure may not be the best judge of their own cognitive difficulties, it still is important to hear their perspectives. George said that he had no trouble learning self-care dialysis and did not recall having any cognitive difficulties. He did find that he didn’t read as “extensively as he used to” but he attributed that to an inability to “sit still,” rather than to cognitive impairments.

Well I used to do quite a lot of reading. I find it very difficult to sit down with a book and read it, you know, like some people can sit down and read a book and they’ll read it right through without, without moving. Well I can’t do that, I just can’t do that. I have to move around and massage my feet, you know, because you sit down and your legs start, you know, the more you think about it, it seems the worse it gets.
Frieda also did not notice any significant decline in George’s cognitive functioning. She said that although he seemed to “move slower” he didn’t seem to “think” any slower. Frieda did note, however, that George watched “an awful lot more TV than he used to.” Moreover, this could have been due to a lack of energy and ability to sit still (he could move around while watching TV), rather than a decline in cognitive abilities.

Pearl, too, did not notice any cognitive difficulties. This was illustrated by her point that she was “working full time and taking stats three times in the evening and starting dialysis, and I got an A. So, I mean I was functioning okay by that point.” She did find that concentration was sometimes a problem but attributed this to a “lack of energy” and not to a lack of cognitive ability. If she did homework on dialysis it would usually be

...in the early part and then I quit because I get bored, I mean it would be the same at home. I’ve never tried to concentrate on anything later. I did use to do stats and I would do it for like the four hours, I don’t know, I’ve never timed it.

She said that she hasn’t done “any great amount of work here in a long time, it’s just because well, you don’t, you just don’t feel like it.” I, too, had the same reaction when I tried to get some work done during the time I sat in as a participant for one dialysis session. While I certainly don’t have any renal-related cognitive impairments, I still had a great deal of difficulty concentrating at the community dialysis centre; it just didn’t seem like conducive atmosphere for getting work done. Further, Miriam (Pearl’s mother) noted that Pearl has been “doing much better all around” since she began this round of dialysis. Miriam believed that Pearl was thinking “much clearer” and was happier since being taken off all her transplant medications.

On the other hand, both Bassan and Olive have found that their memories weren’t as good as they “used to be”. Bassan remarked that “…recently even my memory is getting little haywire.” He used to have a great memory, “Oh, memory was good, 10, 20, 30 years, I would remember everything, all the names, everything; now I forget everybody’s name in no time.”
Bassan’s family, too, has noted this decline in his memory abilities but is uncertain if this decline coincided with his renal failure. Olive found that she often forgot things that she used to remember; however, she was unclear if renal disease is the cause of this memory decline. Because forgetfulness is a common problem among her friends, she surmised that her memory decline might be a “normal part” of aging. One thing Olive noticed was that she more often watched TV than read while on dialysis. As she put it, “I watch this box, which I don’t usually do at home. I read at home. But with one hand it’s hard to read here and in fact I’ve never bothered and this [TV] isn’t very enlightening I can tell you.” Thus, it seems that, to these participants, their TV watching had more to do with convenience than cognitive impairment. It remains unclear if these participants experienced any cognitive declines related to their kidney disease.

**Dialysis Therapy (1993)**

Chronic renal failure affects central nervous system function, resulting in the appearance of the neurobehavioral syndrome of uremia. Prominent in this syndrome are diminished concentration, slowed and inefficient cognitive functioning, restlessness, and lowered arousal level or drowsiness. The more mild the renal disorder, the more likely it is that the effects will be manifest in higher cognitive processes, and the less likely they will appear in measures of general arousal level or sensory transmission. Because the symptoms of the neurobehavioral syndrome are responsive to dialysis treatment or renal transplantation, sensitive ongoing monitoring or neurobehavioral status, particularly of the integrity of higher cognitive functions, is important for successful management of renal disorders. (Brown, p. 279)
Psychosocial losses.

Socialization limitations.

While undergoing dialysis therapy, people’s ability to socialize with friends and family is limited. It may be limited by the dialysis schedule, feelings of ill health, feelings of fatigue and, as noted earlier, by the inability to sit still. For example, George was disappointed because his dialysis schedule did not allow him to go to an event that he really enjoyed (i.e., “The Thrashing Day in Linden”) because it took place the same days as his dialysis runs. As noted earlier, because dialysis must follow a set schedule, socialization may suffer. Plans that have been set by others cannot always be changed to suit someone’s dialysis schedule; thus, activities with friends can diminish. Olive, for example, was very active socially before she began dialysis therapy. Now her social life is severely curtailed: “I have no social life now and I haven’t been even in the store since a year ago August to buy new clothes or shoes or anything.” She no longer played bridge, couldn’t do the entertaining that she once did, didn’t go out to the golf club, and no longer went to the symphony, all of which were activities she enjoyed before the dialysis therapy. Similarly, dialysis and the consequences of living with renal disease have hindered Bassan’s social activities:

...nearly 98% cut off, 98%. The three days here, I’m wasted mine here....Where I used to go to church at least four or five time in a week now I hardly make it once a week...I was happy go lucky, I was running around enjoying my visits to all the senior clubs and the multi-cultural society and church and the library, I was helping the library, I was helping in the church...everyday I would hardly stay home. No, I kept my life active and I was always enjoying it. Until the last minute, until the day I went for surgery with the Dr.

Dialysis can also interfere with activities of daily life. Olive, for example, used to cook and clean for herself, and now finds that she needs help to complete these tasks. Pearl noted that dialysis even has an influence on the clothes she chose to wear.

...when you’re getting dressed in the morning for the days of dialysis, like Tuesdays and Thursdays when I go to work. When you’re getting dressed you kinda have to think about
what you’re going to wear because you are going to have to wear it to dialysis, unless of course you bring a change of clothes. But um, like you don’t like to wear necessarily like nylons because all the fluff from the blanket get stuck to it, then you know, you’ve ruined a perfectly good pair of nylons. Skirts aren’t too flattering sitting in a chair when you’re sprawled all over, jeans are uncomfortable. So you usually gotta think about that.

Further, Pearl found that she was reticent to do some of the things that she wanted to do because of her fear of being injured. As she put it,

I mean your bones are [weak], so I think there are some things you tend to stay away from. Like, I’d love to go sky diving, bungi [jumping], I’m not so sure I could do that, but I’m afraid what the jarring will do to me.

Thus, having kidney disease and undergoing dialysis therapy hinders many desired activities.

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<th>Dialysis Therapy (1993)</th>
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<td>Abundant evidence exists that despite advances in dialysis therapy, a high proportion of ESRD patients on chronic dialysis have coexisting medical conditions, ongoing chronic medical symptoms, and incomplete restoration of their premorbid physical health status. Likewise, significant percentages of patients report chronic psychological symptoms, impaired activities of daily living and social functioning, and incomplete occupational rehabilitation. Finally, many manifest psychiatric disorders, treatment regimen noncompliance, and/or problem illness behaviors which may complicate or threaten the success of chronic dialysis treatment. (Wolcott, p. 335)</td>
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Loss of independence.

People on dialysis must depend on a machine for their survival. This is something that can be very difficult to get used to, because it is not a typical aspect of life. Further, people on dialysis are also dependant upon a system and the people in that system to run and maintain those machines. As Bassan put it:

Before I was free man, now I’m a slave. My position is like a slave, slave of the machine, slave of the nurses, slave of the Handy-dart, every ways. Even, even the tone of my wife has changed.
The symptoms of kidney disease may also be a cause for a loss of independence. Olive, for example, found that she had to depend on someone to help her cook and clean around the house, as well as to help her dress and bathe. She also was unable to drive and, thus, had to depend on others to go places.

Issues of disclosure.

People with renal disease must not only deal with changes in lifestyle; they must also deal with issues of disclosure. That is, they often must face having to decide who and when they will tell about their illness. In a model of disclosure proposed by Joachim and Acorn (1998), it is indicated that there are consequences of both disclosure and nondisclosure of chronic conditions. For example, people with renal failure who disclose their kidney disease may have to face “stigma” such as being “discredited,” “rejected” and/or “isolated” (Joachim & Acorn, 1998). On the other hand, disease disclosure may also result in support. Persons who choose nondisclosure may avoid the stigma of having a disease, but they also do not receive the support they might need. Other consequences of nondisclosure include the stress of worrying about passing for “normal” and being “discreditable” (Joachim & Acorn, 1998).

The consequences of disclosure and nondisclosure are situated in the world in which the people with renal failure function. For example, in our society it is accepted, even expected, that older people experience illness and, therefore, it is not surprising that Olive and Bassan were quite open about their disease. On the other hand, George chose to tell very few people:

Shawna: Do most people know that you have this disease now?
George: No.
Shawna: No. Lots of people, you haven’t told them?
George: No, lots of people, I haven’t, I haven’t even told some of the people in my own family (laughs).
Shawna: How come?
George: Well, mainly, I don’t, they live in other provinces and I don’t communicate with them anyway, so I didn’t bother ever telling them. Uh, I don’t know, I just, um. I don’t know if you feel uh, you know, I just, a lot of times, I just think that it is none of their damn business, you know.
Shawna: Right, yeah. It is an issue that comes up for other people as well, you know, if you meet somebody, or you’re, when do you tell them? Or do you tell them, that kind of thing.

George: Well, I don’t, I don’t know about, I’ve never told any of my neighbours, except the one neighbour that knows, that had the kidney bladder problem. But I’ve never ever told any of my neighbours, it’s just, unless it is somebody that you’re, you and your family that you are close to, that you associate with often. I didn’t, just didn’t go out of my way to tell anybody. Yeah, I don’t know, no particular reason why you shouldn’t, I guess. I have a couple of sisters that I have told, that you know, that are aware of it. But I’ve got a couple of brothers, one lives in Saskatchewan and one lives in Alberta and I’ve never told them. I don’t associate with them that much, I just...

While George believed that this decision was the best one for him, it was not without its consequences. He sometimes made up excuses for the time he spent on dialysis and for the times that he was unable to be at family functions, especially for functions that were out of town.

Frieda believed that one of the reasons that he hadn’t told many people was because,

Oh he doesn’t, I don’t think he likes anyone to feel sorry for him, he doesn’t want anyone to have to give him sympathy or “poor you.” Like he was a long time telling people. He used to work with a man, he used to say, “Oh I just have a kidney problem, but it’s getting better.” Yeah, he’s very funny about who knows.

Pearl, too, struggled with issues of disclosure. While she chose to be open about her disease so that “basically everybody knows,” this, too, had consequences. For example,

Yes, it’s not really anybody’s business, what really bothers me sometimes is why my friends start telling their other friends or their boyfriends, and it’s like something exciting for them to talk about... “I know someone who’s on dialysis,” like and I’m sure, and I just don’t think it’s any of their business, you know. And I tell a lot of my friends that, you know, like right from the beginning of my friendship with them. ...It’s not something I’d do so I just don’t think it’s anyone’s business to unless there’s a real like, unless there’re in the professional setting or something comes up, “Well I’m worried about my friend,” you know, “I’ve got to see her,” or something. But other than that, it’s like, don’t tell everybody that meets me. You know, like, I meet someone and it’s “she’s on dialysis” because that’s what it almost feels like sometimes.

She also needed to make decisions about when (and if) to tell the new people in her life. She found that she wouldn’t tell someone until she knew them well, because often if they knew about the disease “all of a sudden that’s who you become.” Disclosure was an especially large issue for her when she was dating. As she put it,
But I think it affects your relationships. I think, you know, especially like with a man or something. It's like, you know, if you start getting serious, I mean at what point do you tell them? You know, and then if you tell them too soon then they're going to like run or and they usually do. If you don't tell them, at what point do you tell them? ... But it's the ones that you know, the guy you just meet and you start dating. It's like, want to go out Tuesday night? No, I'm busy. How about Wednesday or how about Thursday? No, I'm busy. What are you doing? Going out.

Thus, Pearl was “struggling with being single” and wondered how much her kidney disease had an effect on her relationships with men. She was once “dumped” by a guy because he believed that she had a lot of problems because of her kidney disease and he was unwilling to “deal with her problems.” Pearl’s “hackles just went up, it was like, deal with my problems, I don’t have any problems.”

As was noted previously, George kept his illness a secret to avoid people feeling sorry for him. Although Pearl, too, did not want people to feel sorry for her, she chose to be open about her illness with most people. Pearl’s main concern related to being seen as “a disease” and, thus, someone with problems and in need of care. These two different approaches to disclosure suggest that there may be different issues at work for men and women. Culturally, men are expected to be robust, strong and healthy in order to be considered masculine. Because most men value their masculinity, having a serious illness may be felt as a direct threat to their value as a person. On the other hand, because women are expected to be weak, having an illness may not be a direct threat to their femininity. However, because in our culture women are expected to fulfil a care-taking role, having an illness may be perceived as a threat to a woman’s ability to carry out her societal role and, thus, pose a threat to her value as a person. It is interesting to note that while the men in Pearl’s life have had difficulty accepting her as “a person and not a disease,” she noted that the women have not had this problem.
Losses in mobility.

One of the vexing things, to the study participants, about living life while undergoing dialysis therapy was the restriction on freedom of movement. That is, people on hemodialysis must always be within a day or two of travel from a dialysis centre. Any travel must be done to places that have a dialysis centre and there must be some available spaces in that centre. Although dialysis is becoming more common all around the world, it seems to be increasingly more difficult to get spaces in these dialysis centres. According to George, “travel is very, is very restricted. I find it a lot harder to get dialysis in Canada than it is elsewhere.”

When I asked Pearl what was the worst part of having kidney disease she answered:

Being tied to, being tied down. Like not having the flexibility to like take off for a weekend. One of the biggest things right now that’s really frustrating is going back to [city name]. I didn’t get to go back for Christmas. Every time I want to go back it’s a fight to get a machine and I’m still a Manitoba resident....

George had the same difficulties with travel:

George: ...you’re so restricted in what you can do and mainly you’re really restricted in your travel and it’s hard to, you know, make plans. I mean you can’t plan to go away for a week or to go on a camping trip or go out for a driving holiday or anything like that, without having a contingency plan at the end to get a dialysis session or so.
And as I was explaining the other day, it’s becoming increasingly difficult, especially in Canada, to get dialysis where you want to go.

Shawna: Right.
George: It doesn’t seem to be difficult in the States, although there are problems with that. They only dialyze you for two and a half to three hours and they get, their death rate down there amongst dialysis patients is really high compared to Canada.
Shawna: Oh really.
George: Oh, oh yes.

Even when travelling is done, it can be a difficult process. George and Frieda went on a trip to England and although they had a good time they were restricted in where they could travel.

George: I’m mean you’re very restricted in your movement and travels, you’re, it’s like you’re stuck on an umbilical cord and you have to stay within reach of a dialysis clinic. Like I guess it’s three years ago now, we went to England and I got dialysis in London and in Bristol. But you always had to stay within travelling distance to those clinics.

Shawna: Right.
George: We rented a car and drove around there, but we always had to stay within, you know, so we'd get back to those clinics for dialysis.

He found that it was "hard for you to arrange all these things on your own and go over there and find your own way... I think it takes a lot of pleasure out of travelling..."

There are other difficulties related to dialysis and travel, one of these being cost. Because people with renal failure must accommodate their travel to their dialysis schedule, they are unable to capitalize on last-minute travel specials, charter flights and more. For example, Pearl wanted to go to Manitoba for Easter but couldn’t find a cheap flight that would accommodate her dialysis schedule.

I’d really like to go back to [city name] for Easter, but trying to find a cheap flight, um. Canada 3000 only flies Tuesday, Wednesday, Thursdays. A lot of these things you have to stay for a week, and what’s my problem you ask? Being on dialysis! Because I can’t get dialysis in [city name] because they’re so ass-backward there that they just don’t have any space. So basically I would have to dialyze on a Friday morning, hop on a plane, go to [city name] and come back on a flight Sunday night so I could dialyze again Monday morning. But there aren’t any cheap flights like that. So that’s inconveniencing, to say the least.

Another cost issue relates to the dialysis therapy itself. George, for example, wanted to go with his son to Paris "real bad" but when he and Frieda checked into it, dialysis was too expensive.

George: I was going to go to France until, and I don’t know about now, somebody says it’s different now, but when I was anticipating going to France I found out that it was, dialysis was going to cost about six hundred dollars Canadian a day, of which you could only recover about half.

Shawna: Right, it’s still a lot of money.

George: And so you’re spending three hundred dollars out of your own pocket three times a week, that’s nine hundred dollars. That really adds up to your travelling expenses.

The quality of the dialysis is also a prohibitive factor when it comes to travelling. For example, in the United States most people on dialysis only dialyze for three hours, whereas in Canada the accepted dialysis running time is four hours. This makes it very difficult to travel in the U.S., especially for someone like George, who is used to running for 4½ hours. Finally, the
large number of tests and paperwork needed for travel make it “discouraging” to travel.

According to George,

It really is [frustrating], you know. I just, I’ve just more or less given up and I say to hell with it, to hell with travelling because of the roadblocks that they throw in your way. They don’t really want to take you so they, you get increasing little roadblocks along the way. And they now want you to take certain tests, smear tests and so on and have an x-ray before you go there, and so if you travel a lot you have to have more x-rays than you ever want to have, you know. ...I always think that it’s meant to discourage your travelling rather than having a real purpose in the system.

Because of the dangers and difficulties of travel, Bassan had not travelled since he began dialysis. Although he used to enjoy travelling, especially to visit his daughter in Toronto, he no longer felt comfortable being that far away from his doctors.

There are more consequences to a reduction in mobility than increased costs and decreased pleasure. Pearl, for example, found that sometimes family relations were strained by her lack of mobility. She found it very difficult because she was unable to get home for many important family occasions.

Shawna: Can you talk a little bit about trying to get a bed in Manitoba?
Pearl: Oh geez. Well, its impossible basically, um, they’re full. They don’t see me, they see me as a transient although I’m still a Manitoba resident. Um, at first they just had a policy that they didn’t do anybody outside of Manitoba, but they didn’t have any reasons or, or anything. So [I] had to get over that hurdle. But no, it’s just, they’re so unorganized, they get money and they put it in the wrong spot, or they just don’t, it’s not managed properly. Like they got money to increase the, eleven million dollar increase so they got room for expansion for six beds but they’re only putting two in and they’re losing two from another part of the unit so eleven million dollar expansion, its like no expansion, and they just...

Shawna: What are they doing with that eleven million dollars then?
Pearl: Good question, good question. No idea. So it’s just, it’s just really frustrating because you know, my family is there, my pets are there, my friends are there. You know, even just going back for my dad when he was sick, and he just passed away. I mean the day he dies they phone up and tell me they can’t accommodate me and I have to go back to [British Columbia]. It’s just, it’s just ridiculous! I mean it’s bad enough having to be living this way, secondly being inconvenienced as it is, like today. I was like, I just don’t have time to be here, I’ve too much work to do.

Shawna: Right.
Pearl: And then to have to, like have things like that thrown into your, it’s just, it’s, very frustrating, you know. And the way Manitoba looked at it was well, she chose to study in B.C. Yeah, but did I choose to be on dialysis?
Shawna: Right.
Pearl. Shouldn’t I have that right to choose to study where I want but yet still be able to come back to where I live? Like in the summer, or for Christmas or...
Shawna: And what you chose to study isn’t available in Manitoba.
Pearl: Well, exactly, exactly. All those, so now I’m, you know, fighting to get home for a vacation this summer. It’s just, losers, losers.

Another serious concern is delays or difficulties while travelling. For example, for a person on dialysis, a flight delay or cancellation is more than just an inconvenience, it may mean that they will not be able to get to their dialysis centre for treatment. Depending on the length of the delay, the consequences can range from mild (feeling ill and uncomfortable) to severe (serious threat to health or even loss of life). Pearl once had a flight cancelled because of a blizzard in Calgary. Although she was fortunate enough to not miss her dialysis session entirely, delayed, cancelled, or missed flights are always a serious threat when travelling. In fact, it is enough of a threat that Bassan was reluctant to travel at all. On the other hand, Olive felt that she is lucky because she had already done all the travelling that she was interested in doing. She did, however, understand how the “younger people” could be upset about travel.

Living With Kidney Disease (1990)

Many people on dialysis have avoided travelling simply because the idea of going to another unit where procedures and techniques may be different is just too threatening. Once they’ve travelled, however, most people change their minds and become real travel buffs.

In fact, having this extra contact often makes the holiday special. You’ll get interesting tips while dialyzing in a visiting unit—tips on local transportation, hotels and restaurants, sight-seeing, and local attractions. This often leads to experiences that you would not otherwise have. (Kidney Foundation of Canada, p. 6.16)
The Work of Others

As we have seen, there is much to which people with renal failure must adjust while undergoing dialysis therapy. It is a mistake, however, to believe that it is only the people with renal disease who must adjust to these changes. The choices that people with renal failure make and the difficulties they encounter have a profound effect on the significant people in their lives. Along with having to deal with changes in their lives due to a significant other's renal disease, friends and family are also called upon to provide support. For people with renal failure, one means of facilitating adjustment to their disease is to seek the support of others. Each of the participants in this study had at least one person upon whom he or she could rely for both physical and emotional support. Sometimes those supports came from family members, friends, health care professionals and sometimes even inanimate objects. For example, Pearl relied on Cornelia (a stuffed doll) as a support to her when she had to have surgery.

While people living with kidney disease do the bulk of the work with regards to their disease, there are other people who work to support the people with kidney disease in their everyday lives. The work of the health care practitioners often gets the highest recognition and valuation. Less publicly lauded is the work of friends and family. Outside of the dialysis ward, and for the majority of the time, it is friends and family who can have a profound effect on the lives of people with kidney failure. Further, it is the people in the lives of those living with renal failure who can provide health care practitioners with vital information on the lives of the people with renal failure outside of the hospital setting. However, as noted earlier, the medical community does not often seek out this information in any meaningful way.

Work of the Family

When someone in a family is diagnosed with kidney disease and is undergoing dialysis treatment, life changes not only for that person, but also for the entire family. Family members
often have to take on new responsibilities in the household, give emotional and physical support and must learn to adjust to the changes (and limitations) that this disease has brought. Further, family members are often asked about their willingness to undergo major surgery to donate a kidney, should they be eligible donors. These are no small tasks.

When a family member is diagnosed with renal failure, there is new knowledge to be learned. Family members learn about the disease, the symptoms, different forms of dialysis and what life is like with this disease. They must also learn to accept the fact that their family member is in a life-threatening situation. When Miriam, Pearl's mother, first learned about Pearl's disease she found that, "It was shocking, it was horrible. I thought my life was ending. I was very scared." In Frieda's case, she found that there was so much to learn that she decided to put this new knowledge to work for her and specialized to work with people on dialysis. She was, thereafter, able to provide George with both support and disease-related information.

Family members often accompany the person with renal failure to the doctor and take on partial responsibility in the decision-making process for selecting a mode of dialysis. The various types of dialysis will have very different effects on the families' lives and, thus, family members usually want to have a voice in the choices made. An example of this was noted earlier when Bassan's family fought against his doctor's recommendation that he undertake home dialysis. Bassan's spouse and children helped him to convince his doctor that PD would not be an option for Bassan, despite it being the "best medical alternative."

Diet may also be a responsibility that is partly taken on by the family. In George's case, when he began dialysis he wouldn't eat anything unless he checked with Frieda first. Thus, Frieda was responsible for learning about the renal diet and the contents of all foods. After a while George became more self-sufficient in his diet and Frieda's job was to step back and allow him to control his own diet (even if that meant he was eating things he shouldn't).
Shawna: Right, and how do you find that at home, do you follow the diet as well or...?
Frieda: Well, I used to but he doesn’t, he eats whatever he wants, so I don’t bother anymore.
Shawna: No? He doesn’t really follow it?
Frieda: He used to eat nothing unless he asked me if he could eat it. And then he just got so he, yeah, he eats what he wants. And he seems to be okay, I know his phosphate is high but he has a real, he’s, I know he’s not buying the big chunk of cheese anymore, but he’s pretty good. But you know, like one time he said, “Oh I think I’ll buy a banana cream pie, or what do you want, or would you rather have coconut cream?” And I said, “Well, I love banana cream”, I said, “but you shouldn’t eat that.” He said, “Who said, must like, says who?”
Shawna: Yeah.
Frieda: I says, “no one, but it, if you want, you know.”
Shawna: Yeah.
Frieda: If you want it, buy it, I don’t, it’s up to you, it’s you.

George’s daughter also gets involved in his diet.

Frieda: ...but my daughter can just make him do anything. I just can’t believe it, one day I was working at KDS and this nurse said to me, “You know” she said, “I can’t believe a child can have so much, so much control over their father.” She said, “One day I was putting the dressing on, he was drinking this awful green stuff.” And she said, “He just hated it, and I [the nurse] said, Well why are you drinking that?” and he said, “because my daughter told me I had to drink it (laughing) ground wheat.”
Shawna: Oh, wheat germ or something like that?
Frieda: Oh yeah, he was drinking and she would bring him this stuff and she brings him a lot of stuff and he doesn’t eat it, but he brings it home. All this good stuff for him.
Shawna: Right.
Frieda: Yeah, she’ll, or if he has extra fluid on, she just goes down to KDS and just blasts him, eh (laughing). I don’t know if he listens or not but she does. She’ll get right after him, so.

Anshu, too, was responsible for all Bassan’s meals. This was not an easy task for her; besides learning all about the renal diet, Anshu had to learn to cook differently than she was accustomed to, and if she and Bassan wanted to eat together she felt that she, too, had to follow the renal diet.

One consequence of this has been that Anshu ate more meat than she would have liked.

Salima: Like they need special food, they need this, they need that, everything and I can’t ask Mum to cook two or three different meals, so whatever he eats, she eats, whether she needs it or not.
Shawna: Right.
Salima: So it’s a big, big support there. It’s a kind of a sacrifice; I wouldn’t even call it a support. It’s a kind of sacrifice that the other partner is making, but you do it.
Shawna: Do you find it difficult to cook according to what they tell you he’s supposed to eat?
Anshu: Yeah, sometimes it’s okay, but sometimes I don’t like everyday meat and chicken and like this, you know.

Shawna: Yeah.

Salima: Because of her digestive problem, but because Papa, he’s losing lots of protein, he needs protein.

Shawna: Yeah.

Salima: So he’s been asked to eat lots of meat, so its kind of, you know...

Shawna: Yeah.

Salima: I mean those are little things, but if you’re doing it everyday, then it kind of strains you. But she’s adjusted; she’s adjusted, so that’s fine.

Both Olive and Pearl were responsible for their own diet. It is interesting to note that both the men in this study had family members (women) to help or take care of their dietary needs and both women did not. It is possible that this was a result of the fact that both women lived on their own and both men were married; however, there are other plausible explanations. If one considers the prevalent cultural notion of woman as caretaker, it is not surprising that in all the above cases it was women (whether the female participants themselves, participants’ wives, or their female children) who were responsible for participants’ diets. This is especially true for a society where women’s traditional role includes household chores such as cooking and cleaning. Overall, of all the kinds of support needed by the participants, it was mainly female members of the family who provided that support.

Family members also provide emotional and other kinds of support. Bassan, for example, became very nervous when he had to go to dialysis, and so Anshu spent time calming him down and reassuring him. According to Bassan:

She is my main support, she does the cooking, laundry, ironing, cleaning everything she does. I, I only do the shopping and, well, she takes care of me a lot. And in fact when, during my serious attacks on my health, I remember last year, I would say that if I survive little bit, is because of her. She took lots of day and night, she was by my bedside.

Thus, Anshu took care of all the household chores, visited him in the hospital when he was ill and helped him to do things when he was unable to do them alone (e.g., bathing). Anshu also had to deal with the guilt that she felt over Bassan’s illness.
Salima: She [Anshu] feels guilty that he has all this.
Shawna: Yeah, that’s normal human nature.
(Translating)
Salima: But you shouldn’t feel guilty.
(Translating)
Salima: And the problem is the biases she has. Her own pains and aches, but in front of his she just thinks that they are nothing. And I think that is wrong. You have your aches and pains and they are just as bad as anybody else’s, so yeah. You have to take care of yourself at the same time because...
(Translating)
Salima: I keep on telling mother if you don’t take care of yourself, you won’t be able to take care of dad. And my father is in no condition to take care of anybody.

Thus, since Anshu was focused on Bassan, she was not taking care of herself and/or was minimizing her own “aches and pains.” If it is the women who are doing the supporting, who then provided support for the women?

Frieda too, provides support by listening to George’s complaints:

I listen to his complaints, he complains all the time when he comes home... ...but he just, um, and he tells me if things go wrong. And I've helped him with things like wrapping his sodium. But, he was, his blood sugar was always low like, if he has a problem he just comes and asks me what to do.

Further, when George first began dialysis, Frieda went with him to dialysis for three months. At that time, he had a neck-line and couldn’t move so she also had to feed him during dialysis.

Olive received support from her daughter and grandchildren. Her daughter, for example, called her twice daily, did her banking and ran other errands for her. Miriam, Pearl’s mother, was Pearl’s main support. Miriam said that she provided both emotional and financial support for Pearl. She also provided indirect support for Pearl through her work with the Kidney Foundation, where she worked to raise funds and awareness of kidney disease. When Pearl came home for a visit, Miriam often had to fight to get Pearl into dialysis in Manitoba. This meant that she sometimes had spoken to doctors, politicians and the Kidney Foundation in an attempt to get Pearl dialysis treatment in Manitoba.
Miriam: But I’ve been told by my MLA that one of the reasons that they got an injection of eleven million dollars for dialysis in [city name] was because of me making them aware of the problems here, making her aware.

Shawna: Right.

Miriam: Like the last time when she came, last summer, the doctor phoned me the night before she was to come to tell her not to come. And I told them that I refused to do that.

Shawna: Not to come to [city name] you mean?

Miriam: Yeah, to stay in [British Columbia], that they had no place for her to dialyze. And I told him that that was his problem, to find a place for her and she would be coming. And with which I phone my friend, the Premier.

Shawna: Right.

Miriam: And they did make, you know, allowances for her, but we did have to go to Kenora.

Shawna: Wow.

Miriam: I don’t think they like me here.

Shawna: (Laughing) Well, too bad.

Miriam: But, you know, as my MLA will say, I’ve done an awful lot of work for kidneys in this province. And that shouldn’t make a difference but the point is that if my daughter wants to come home, she’s still technically a Manitoba citizen.

Further, and most significantly, Miriam provided support by donating a kidney to Pearl when she was 12 years old. Again, it was the female member of the family that was selected to undergo the pain and self-sacrifice of giving up a kidney. Despite both parents being equally able, and having equally suitable kidneys for Pearl, it was Pearl’s mother who donated the kidney. It is important to note, however, that after Pearl’s second donated kidney failure, her brother was willing to donate his kidney; unfortunately, it was not a suitable match.

Contemporary Nephrology Nursing (1998)

Flaherty and O’Brien (1992) studied 50 family members who were willing to discuss adaptation of families who had a member receiving dialysis therapy. They found that five family coping styles emerged from content analysis of the data. These styles were labelled: remote family style, enfolded family style, altered family style, distressed family style and receptive family style. A remote family style was characterized by responses that suggest that the disease had not interfered with the life of the family member. In contrast, the enfolded family style was characterized by responses suggesting that the disease had strengthened the bonds among family members and that the disease
had become a family affair. In the altered family style, responses suggested major changes in the family members' daily activities. The distressed family style was characterized by responses that suggest sorrow or grief regarding the disease and its impact on family life. The receptive family style indicated some degree of acceptance of the diagnosis and adjustment to it. (Molzahn, p. 277)

Life changes.

When a family member begins dialysis, life changes for the entire family. Some of these changes resulted in positive outcomes for family members. As mentioned earlier, George's kidney disease influenced Frieda to go back to school so that she could specialize in renal care, a profession that she really enjoys. Miriam began working for the Kidney Foundation and has learned a number of new skills such as canvassing and fund-raising.

Personally I've, I've grown as a human being because I got so involved in, you know, trying to make the lot of a kidney patients better for patients. Generally through my commitment, I guess to the Foundation and sitting on the national board for so many years. I know that I grew with that as a human being. I gained in self confidence... ...But at the same time, um, I guess it helped me through a very difficult time in my life when my husband became alcoholic and I was trying to, because of his disease drag me down. And I think in many ways, the Kidney Foundation, my work, my friends across the country and so on were my salvation. It made me a better person and survive the ordeal.

Most changes attributed to a family member's kidney disease, however, are not so positive and many of these have been noted earlier. Socializing can be cut down by the family member's dialysis schedule. Any event taking place during dialysis treatment cannot be attended as a family. Bassan's daughter Salima said, "It's difficult to always follow one person's schedule." Olive finds that the days she has free are often the days that her family is most busy. Sometimes friends do not understand about dialysis schedules and, thus, may drop out of people's lives. As well, community activities cannot follow a dialysis schedule. Anshu feels that her "social gathering and outings and all that has been really curtailed." Both Anshu and Bassan come from
a culture in which it is the wife’s job to attend to her husband’s needs. For this reason, Anshu felt that she must be at home when Bassan was at home. Because Bassan often did not feel well enough to go out, Anshu was stuck at home and could not socialize. She also was unable to drive and her English was poor; thus, when Bassan was on dialysis, Anshu felt limited to activities close to her house.

Travelling can also be a problem for a family living with kidney disease. As mentioned earlier, it is not always easy to get dialysis, and family members must arrange their vacations around the dialysis. Anshu found this one of the most difficult things about her husband’s dialysis. Bassan wouldn’t travel and so Anshu felt that she also couldn’t travel, even though she would have loved to go to Toronto to visit Salima. Further, a person on dialysis may not have the energy to keep up with a hectic travel schedule, or do more physical types of travel. Frieda began to travel on her own because she enjoyed going on cycling and hiking trips and George couldn’t join her. George has also become more reticent to do things and as Frieda got tired of “pushing” him, she had begun to do more things on her own.

Shawna: Em, so how, how has your life changed since your husband was diagnosed with kidney disease and started dialysis?
Frieda: Uh, I just sort of have to plan my own things to do and my own trips and that. Because I mean I think I’d go nuts if I had to stay home all the time and not do anything.
Shawna: Right.
Frieda: And I, because I belong to a cycle club, we do lots of cycle things. All my cycle trips I go with them, you know. We just don’t go anywhere, like you don’t go away for the weekend or…
Shawna: Right.
Frieda: …or stuff like that.
Shawna: You need a lot more planning for anything that you do basically then?
Frieda: Yeah, I just, I just do my own thing, so, you know. Otherwise I would think I’d go nuts because I just, for one thing when I get up in the morning, I like to do a whole bunch, get a whole bunch of work done. Well, he gets up and he eats, then he goes and lies down again. That just drives me nuts, so that’s why I like it if I’m here by myself, I can do it and I don’t have to see him sitting and a chair and then going and lie down.
Or when she did do things with George she found that she had to adjust to his pace, which was much slower than hers, due to his kidney failure. Overall, Frieda said,

I find it hard at work when I like, everyone I work with is sort of my age and they talk about they’re going to go, like one girl is going to retire next year and travel across Canada. And you know, they don’t think, you know, they don’t even think about how lucky that they are that they can do that. And one girl retired at fifty-five and they like she just came back. They were six months travelling all around the States in a mobile home and they don’t, they do say they “realize how lucky I am”, how lucky you know, they are you know. They should do it while they can, so yeah, that bothers me sometimes.

Miriam, too, found it difficult to adjust to fewer and shorter visits by Pearl (since this round of dialysis) because of the restricted access of travellers’ dialysis in Manitoba.

One of the most significant changes that families may have to work to deal with is a change in participants’ personalities. For example, George and Frieda’s relationship had changed. Frieda found that George wanted to do less and less and so she had begun to do more things on her own. They no longer slept in the same room because of George’s restlessness and “crazy” sleep schedule that kept Frieda awake. They didn’t talk to each other as much as they used to, and, as mentioned earlier, they hadn’t had “intimate relations for three or so years.” It is as if they live in the same house but lead separate lives. George’s kidney disease had turned them into virtual strangers.

Anshu said that Bassan’s “character is changing.” She believed this was because he was “losing the control of himself, of his life, so he wants to control the people around him.” I was quite surprised to learn that despite his sweet and gentle image, Bassan was actually a “tyrant” at home. In the hospital setting he appeared calm and controlled; at home, however, it was a very different story. According to both Anshu and Salima, Bassan had the tendency to lose his temper and “blow up” over nothing.

Shawna: So you’re providing a lot of emotional support?
Anshu: Yeah, and these days every time he come home, so I don’t know, he just seems to come maybe hyper temper.
Shawna: Oh.
Anshu: High temper, it's a small thing, he just blows up. It makes it difficult to...
Shawna: Yeah, and he wasn't like that before?
Anshu: Well, he was but not like this.
Salima: But not he's getting, that's why, you know, its kind of good he's going to the hospital.
Shawna: Right.
Salima: It's getting really out of hand, he's a nice guy, but...

He had become very controlling and demanding, which led to extra tension in the house. Bassan and Anshu "used to sit around, watch programs and do a lot" but at the time of the study they didn't do these things because

he's tired or he comes from the dialysis and he's just, you know, not handling it properly or whatever. And some days his pressure is low, some days it's this and that, so then all those things are affected. If it was for a short period you can say, "Oh it's okay, it's for a short period." This is a lifetime so then it bothers you.

Anshu had great difficulty sharing this information with me as she didn't want me to think that Bassan was "bad" and, thus, repeatedly mentioned that he was "a nice guy." It appeared to be taxing for Anshu always to be the caretaker, to have to bow to Bassan's needs and to feel "guilty" when she became upset about things. It is interesting to note that from Bassan's point of view it was Anshu's "tone" that had changed and not his attitude; he believed that she no longer respected him as much as she once did. These differing points of view connote the need for obtaining more than the perspectives of the people living with renal failure. If we truly are to understand the lives of those living with renal disease we must include all the relevant information, which, as mentioned above, includes the knowledge of the significant others of those with renal disease.
Social problems in dialysis patients include strains in intimate relationships, loss of vocational function, and restrictions of social and leisure activities.

Dialysis patients who were not in intimate relationships prior to the onset of ESRD often find it difficult to establish long-term, stable, intimate relationships. The incidence of marital strain, sexual problems, and dissolution of intimate relationships in dialysis patients appears to be quite high. Parental role dysfunction and psychological problems in children of adult dialysis patients have also been recognized. (Wolcott, p. 338)

It seems that it is the men in this study who require more support than the women, and who have more difficulties adjusting to their disease. As noted earlier, society’s role for men may have an influence on how men react to their circumstances. For example, it may be harder for men to accept that they have a disease because they then must accept that they are vulnerable, that they are not in control of their lives. Bassan’s attempt to gain back some control by controlling his family is a prime example of this phenomenon. It is clear that people with renal failure are not the only ones whose lives change as a result of kidney disease; families, too, must live with kidney disease. Family members are relied upon for support, advice and more, yet often they have little support themselves. This is especially true for female family members who take on many of the support needs of those living with renal disease.

**Work of Friends**

For the most part, the participants in this study relied on their family for support. However, friends are an integral part of their lives. Friends, like family, must learn to adjust their schedules to fit a dialysis schedule if they wish to include the people living with renal failure in their lives. Olive said that her friends were “very good and they understand and they know that I’m not available on Tuesdays, Thursdays and Saturdays.” Overall, Pearl’s friends
also understood, but occasionally she found it frustrating when they didn’t understand or became frustrated by her dialysis schedule.

Pearl: Yeah, because I mean let’s face it, when you’re planning stuff with people they don’t often think about your dialysis schedule.

Shawna: Right.

Pearl: Oh Sundays, everybody’s got Sundays off, so let’s have it on Sunday.

Shawna: Right.

Pearl: You know, or let’s go out Thursday night, or something, you know. It’s like, well I can’t Thursday night, oh well, can’t you switch it? That’s what a lot of people say to me, “Oh can’t you switch it, can’t you change that, do you have to go?” No, seriously, it’s like well yeah, “couldn’t you just leave early?” It’s like well, um, no, let me see what I can do.

Shawna: I’ll just bring my blood along with me.

Pearl: Well yeah, and it’s like, you’re looking at them like, and you know. Just, just recently when I was out in Langley I asked my friend’s husband, I said, “So are you going to take me fishing this summer?” and he says, “Oh sure,” he goes “What are you doing on the Labour day, that week?” And he goes, “We’re going to go for a week.” And I’m like, “Yeah, but I can’t go for a week” and he’s like “Oh yeah, well maybe you can drive up for a day or something.” So a lot of people just don’t think, like they know you’re on dialysis but they don’t really realize what that means.

Shawna: Yeah, or they forget.

Pearl: And sometimes it’s frustrating, you know, because people plan things and you say, “no, I can’t do that” and they don’t understand why.

Shawna: Yeah.

Pearl: “Why can’t you switch it, why can’t you this, why can’t you just, do you have to go, do you have to?” It’s like, “Well yes,” so.

Pearl did, however, have some very supportive friends, including some who had gone with her to hospital, helped her when her mother was not around, volunteered for the Kidney Foundation and even offered her a kidney.

Bassan felt that he received a lot of “moral support” from his friends. Although he wasn’t able to see them, they often would call to check on his health. George, too, didn’t see his friends often. He found that after a while his friends drifted away because “they think it would be better if we left him alone, you know, because he is pretty sick.” He thought that his friends also didn’t understand how difficult it was to have to go into dialysis three times per week. “They think, oh well it’s a, you know, you’re lucky all your problems are solved.” On the other hand, Olive believed that her friends had taken the time to understand what she was going through. For these
four participants, age may be a factor in how supportive and accepting friends are. As noted earlier, in our society, it is accepted, even expected, that older people experience illness. Therefore, Pearl’s and George’s friends may have had more difficulty accepting their illness than did Olive’s and Bassan’s. As well, culturally accepted activities for different age groups may also have an influence on the acceptance of friends. Seniors, for example, are expected to participate in sedentary activities and these may be more easily accommodated to dialysis schedules than the more active pursuits of the young (such as camping, ski trips, etc.).

**Participants’ Final Thoughts**

Living with kidney disease is very difficult. While this study participants’ attitudes towards their renal failure vary, their desire to live a “normal” life appears to be constant. However, despite all of the difficulties, the participants in this study somehow managed to enjoy their lives and would not even have considered foregoing dialysis therapy — thus, choosing to die. In order to make sense of their disease, these participants often compared their situation to people around them, and to those with other diseases and other medical systems. Further, their individual personalities, social situations and cultural histories influenced their attitudes towards their disease. Each individual’s overall attitude to life with kidney disease will be discussed in turn.

**Bassan**

Bassan was still in the initial stages of adjusting to his disease at the time the data were collected. Bassan believed that kidney disease was “the most serious disease of them all,” and said that it has changed his life “considerably.” He would rather have had a disease that wouldn’t have required him to come to the hospital three times a week. Bassan felt that he had lost his “freedom” and was under the “command of [the dialysis ward].” Dialysis consumed his life: “At the moment your whole direction is in that [the disease], the rest is in ‘B’ and ‘C’. ‘A’
is the dialysis.” He said that the commitment to the dialysis schedule and the “food” were the things that affected his life the most. He stated that he felt “mentally worn out” by the whole thing. Further, he became “a little irritated with all the sickness” and he believed that this led him to be short-tempered with those around him.

The stress of living with this disease sometimes led Bassan to wish that “I would see a heart attack and I should have gone, [not] to face all the problems.” He felt that he was causing “trouble for doctor, for nurses, for my family, for my everybody.” However, he was not willing to forgo his dialysis therapy and when probed, he said that he was coping with his situation and attributed this coping to there being “no other solution.” When I asked Bassan what was the worst part of having this disease, he answered: “You see the worst part is that, let’s say that you lose your independence. ...you are all the time like a beggar, stretching, please, please, please.”

For Bassan there were some “good” things about dialysis. He said that the best part was that dialysis keeps him alive. He was also very grateful to be living in a country like Canada:

I have to think and compare my life with people in the Third World and then I say thanks God that I’m in a good country and good people. And everything is fine. You see I come from Africa, I know the situation there. If I had been there as dialysis patient they throw you in the garbage. It’s lucky it work out, very fortunate and you should be grateful to the government of Canada for that.

In terms of his future Bassan was aware that a transplant was not an option for him, and he, therefore, hoped that his health would stabilize on dialysis. His goal was to get healthy enough so that he could help build a dialysis centre in the city that he lives.

George

When George first found out about his kidney disease he was “totally devastated” and was “practically throwing in the towel.” Five years later, he still did not consider himself successfully adjusted to his disease. He believed that the only way for him to adjust to his disease was to get a transplant, which he believed would be the closest he would get to living a
“normal” life again (George did receive a transplant in May 1998). George had difficulty understanding why he got kidney disease and had to go on dialysis. As he put it, "...why did this happen to me? I lived a, you know, I consider I led a clean life. I never smoked and I didn’t drink inordinately or excessively.” He blamed his kidney cancer on a blood pressure medication given to him by his family doctor, but still thought, “Why did this have to happen to me?”

George said that he became “very exasperated” with his “physical limitations,” especially as these pertained to his ability to travel. As he put it, “It’s really agonizing in that sense that, you know, you realize how restricted you are from moving about. It seems like you’re on a, it’s exactly like being on an umbilical cord, you know.” He found it very difficult to cope with his situation and became a little depressed at times. Dialysis consumed George’s life; he said that he is “always thinking about” it, that he “can’t do anything without knowing that in the next day or so you’re going to have to go on dialysis again.” He also said that his “restless legs” kept him from doing things he enjoyed such as going places like the theatre or out to dinner. However, he said that he did cope with all of this because “the second choice, or the alternative, isn’t very good.” He never seriously considered choosing not to undergo dialysis therapy, though he said that he “mutters about it” once in a while. George had reconciled himself to the routine of his dialysis; he found that he was “comfortable” with it, and has “made allowances” in his life for it.

In terms of his future, George finally got his wish for a transplant. Since being transplanted, he has had the pleasure of “a good pee.” He has also realized how much his family worried about him during his time on dialysis when he saw their reactions to his transplant. When he got the message about a donor kidney from his daughter, his daughter was so excited she could hardly contain herself. Frieda was working when she found out about the kidney and she yelled out to the entire dialysis ward, “My husband got a kidney!” George’s son was out in his truck trying to find his father to let him know about the kidney. When he saw his father’s
car, he drove over the median, got his father to pull over and was crying when he told him the news.

George felt like he was finally off the “crutch” of dialysis and was looking forward to living a normal life. While he must take a large number of medications for the rest of his life (or for the life of the new kidney), he believed that he would be a much happier person. He already had lost many of the unpleasant symptoms that accompanied dialysis. For example, he was no longer itchy or restless. After the transplant, he was having trouble drinking all the water that was prescribed, something that on dialysis he just dreamed of. George was looking forward to having his bladder stretch back to normal size (it shrank from non-use) and to going travelling without having to plan for months prior to departure.

While most people would agree that having a kidney transplant provides a much better life than does dialysis therapy, it does have its difficulties. It seemed that George and his family were still revelling in the excitement of his transplant and had not yet grasped some of the realities of living with a transplanted kidney. Life with a kidney transplant is freer than life on dialysis; however, it still is a life with many difficulties. As Pearl will attest, living with the large amount of medications, the side effects of these medications and the constant threat of kidney rejection is no easy task.

Pearl

Of all the participants, Pearl had the most positive attitude about her disease and to life on dialysis. She didn’t believe that having this disease had a negative effect on her life. She said, “Well, I don’t really think it [kidney disease] affects me really, much. I don’t know; I’ve gone on in school, I’ve gone farther in school than most people. I’ve done more travelling than most people….” In fact, she believed that it had made her a stronger, “more positive person,” and had
drawn her closer to her mother. This positive attitude, however, does not mean that she was in denial about her loss of freedom or the inconvenience of having to go to dialysis:

...of course, I always try to focus on the good and I have to really think about the negative, but obviously, you know, it's inconveniencing, it's boring as hell sometimes. ...I'm really surprised at myself because sometimes I wake up in the morning and it's like I don't want to go to work today, like I just hate it, I dread it, or there's something I have to do, I just hate it. I've never had that feeling about coming here [dialysis centre]. ...it's not like I enjoy it here, it's just kind of like, you accept it, you're doing that whether you like it or not. I've never had that, you know, kicking, screaming, "you can't make me, you can't make me go", type thing.

Pearl tried to plan dialysis around her life rather than planning her life around dialysis: “I try not to let dialysis run my life.” She believed that it was imperative to have flexibility in her dialysis schedule and appreciated that this was possible at the centre where she dialyzed. She also believed that she was “doing a pretty good job” of keeping herself healthy and thought that she had a “good quality of life.” Pearl has, therefore, never even considered choosing to die by foregoing dialysis therapy and would have been insulted if this option was ever presented to her by the health care practitioners — she believed that she was a “healthy” and “productive person.”

For Pearl, having this disease was:

not who I am, it's not in the forefront of who I am. It's kind of way in the back and sometimes you need to take it out, put it in the forefront and deal with whatever, but then I always throw it back there. So, I don't dwell a long time on it, I don't really think about it.”

Therefore, Pearl did not consider herself a “patient”; rather, she was a person who just happens to have this disease.

In terms of her future, Pearl was happy to stay on dialysis. Pearl said that she was feeling good (at the time of the data collection). Since she had already had two transplants she would like to “get some answers” before she had another. Pearl was concerned that if a third transplant failed, health care practitioners wouldn’t allow her to have another kidney. However, she still looked forward to the time when she would receive a new kidney so that she would have
"another chance and some freedom." Pearl also had high hopes for medical and technological advances in the future. She believed that in 10 or 20 years "dialysis will be obsolete." She was looking forward to the day when an artificial kidney could be implanted in the body.

Olive

For Olive, having kidney disease was nothing new; she had been living with this disease for more than 10 years. However, undergoing dialysis was a "whole new life" for her. She found dialysis very "confining" and felt limited in the things that she was able to do (e.g., socialize, do housework). However, Olive did not feel sorry for herself. She said that the "'Why me'? people give me a point right where I sit down because there's always somebody worse off than I am...." She felt "fortunate" that she didn't have a terminal illness like cancer and believed the best part about renal disease was that there was a life-saving treatment. As she put it, "I mean after all, there are worse things than dialysis." She was also grateful that she wasn't on dialysis 10 years ago because had she started then, she believed it would have been much harder, as she "would have had to give up just that much more and for that many more years."

When asked if she has successfully adjusted to her disease, Olive replied that she "had no other choice." She believed that accepting it was "about all you can do. Either that, or you can not accept it and die. And I don't know of anybody who would be foolish enough to do that." She believed that her determination helped her cope with her "new life." She said that having kidney disease and undergoing dialysis therapy wasn't "something that you'd choose" and that she would "rather have something I didn't have to stay in bed for four hours three times a week." Olive found that her life "revolves around dialysis" because "you can't do anything but this [dialysis] on Tuesday and Thursday and Saturday" but dialysis did not consume her life. She tried to do as much as possible on the days off from dialysis. Her overall attitude toward dialysis was summed up when she said, "Well, if you've got to do it, you've got to do it."
In terms of her future, Olive knew that she was not eligible for a transplant. She believed that transplants are meant for younger people and did not feel that this was a good option for her. Her goals were to get feeling better so that she could spend more of her time doing the things that she likes — housework, socializing, and playing bridge, for example.

**Pulling It All Together**

This research has shown that for these four participants, life with renal failure was work. The work of renal failure took place both inside and outside the biomedical community. Within the medical community, participants worked to learn about and choose a dialysis therapy, adjust to the hospital or dialysis environments, and learn to live with dialysis therapy and all the inconveniences and pain that this entailed. Outside of the medical community, participants worked to monitor their diet and fluid intake, get exercise and take medication. Finally, the work of participants included adjusting to and living with the losses related to their renal disease. These losses included declines in physical health and psychosocial losses. Although it is commonly accepted that people with kidney disease experience losses in cognitive function, these participants did not experience cognitive decline. The work of living with renal failure is not only in the hands of the participants, but falls into the hands of family and friends as well. Family members were most often participants’ primary supports and, thus, experienced many changes when kidney disease became a part of their lives.

Participants in this study did not live their lives in isolation; there were cultural, historical and institutional milieus that were important in understanding their lives. Smith (1987) argued that reality is created by the historical practice of those involved. It is unfortunate that many of the historical and cultural practices of the people living with renal disease have most often been ignored both in medical research and practice. This research is an example of a different model, one that includes many of the salient communities and the contextual backgrounds in the lives of
people with kidney failure. I have argued that the best knowledge comes only when the relevant sources of knowledge are consulted. It is for this reason that I included the knowledge of those with kidney disease, health care practitioners and significant others. Each area informs a critical piece of the lived experiences of people with renal failure. For example, it was only by bridging the discourse of these communities that it became apparent that although medically Pearl may have been the best candidate for a transplant, personally this was not a good option (at the time of the study). Similarly, although Bassan may appear to have adjusted to his disease, it was only by consulting his significant others that we could gain a more complete picture of the story.

Understanding the lived experiences of people with renal disease also requires an understanding of the historical and cultural milieus in which they live. For example, both age and gender appear to have an important influence on the live of people with renal failure. Further, a look at our history and culture in relation to the lives of people with renal disease revealed that the position of power of health care practitioners may constrain the discourse between those living with renal disease and health care practitioners. For example, the authoritative voice of the health care practitioner limits both how people with renal disease speak and how they are heard. It also limits the transparency of the dialysis tools and, thus, the agency of the people with renal disease. In sum, when people are diagnosed with renal failure and thereby enter the medical arena, they are changed from people to patients. This research illustrates that the change is not just one of semantics, nor is it solely a change in health status. As we have seen, becoming a patient results in a loss of status, power and independence.
CHAPTER FOUR

Discussion

Summary and Reflections

The goal of this research was to gain an integrated understanding of the lives of four people living with renal failure. By all accounts, renal failure is a devastating illness. People who live with renal failure learn through experience that so-called "normal" life is irrevocably changed. Living with renal failure requires medical machinery to sustain life and, thus, people's lives and identities are of necessity inextricably connected to hospital and/or dialysis settings. Life with renal failure also alters connections and interactions with family and friends. There has been virtually no research that sheds light on life with this illness in its institutional and cultural contexts. In this study, four participants gave me the opportunity to share in their lives and their experiences both on and off dialysis therapy. I was also able to share in participants' lives by interviewing family members and hospital staff, and by observing both their home and dialysis environments. What emerges from this research is a situated account of life with renal failure, one that brings new insights, and challenges current models upon which medical and educational practice are based.

I begin this chapter with a summary of the research that supports the current medical and education practices. This summary leads into a discussion of the importance of this study and examines how it can broaden our knowledge of life with renal disease. The means and method of this study are reviewed and defended. Then, the findings (in terms of life with kidney disease both inside and outside the hospital setting, as well as life for the significant people in participants' lives) are discussed. These findings are linked to and interwoven with relevant existing research. The implications of these findings are described, most especially in relation to
hospital educational programs. Finally, limitations of this research are outlined, as are suggestions for future research.

A review of the existing research revealed that the self-management model dominates renal failure research, educational practice and theory. The self-management model is cognitively based and relies on a representation of an autonomous and rational self, and on assumptions about individuals' ability to master their environment (Coates & Boore, 1995; Linn, Skyler, Linn, Edelstein, & Sandifer, 1985). In psychology, focus on “the self” can be seen in theories of self-determination (Clark & Zimmerman, 1990), self-regulation (Thoresen & Kirmil-Gray, 1983; Pintrich, 1995; Zimmerman, 1986, 1990), self-efficacy (Bandura, 1982; Rosenstock, 1974; Zimmerman et al., 1992), and in lay terms is expressed in the proliferation of self-help groups (Bartlett, 1983). Self-management and educational programs to which this focus has given rise, incorporate these notions of “self” and are appealing because they seem to give more control to the people living with illness than did previous medical and educational models (Coates & Boore, 1995; Strowig, 1982). Further, self-management has been interpreted as an improvement on previous models because it appears to move beyond the strict medical focus to include both personal and environmental influences on the well-being of people with renal failure (Clark & Zimmerman, 1990; Sciarini & Dungan, 1996). Interest in self-management seems due in part to the belief that this type of program improves the agency of people with chronic illness, as well as reduces their position of relative powerlessness in the medical setting (Bartlett, 1983; Coates & Boore, 1995; Strowig, 1982). That is, the self-management model envisages people with illness as causal elements in the success of managing disease. It positions people living with renal failure in “the driver’s seat.” From this perspective, kidney disease is considered a manageable problem where the most efficient way to manage it is to learn, understand and follow the regimens prescribed by health care practitioners. Further, in order to
self-manage, people with renal disease must have the "right" beliefs about their illness (Bandura, 1993; Rosenstock, 1974). That is, they must believe that positive health-related results outweigh the difficulty of following a strict regimen.

Research framed in this perspective has typically focused on improving the abilities of people with illness to manage their disease. The result has been a proliferation of research on the symptoms of renal disease (Burton et al., 1989; Corkadel & McGlashan, 1983; English et al., 1978; Lindsay et al., 1985; Speers, 1989); the effect of these and other influences on self-management abilities (Baldree, Murphy & Powers, 1982; Berkman & Syme, 1979; Brown, 1992; Burton et al., 1986; Lachman & Leff, 1989; Speers, 1989; Wolcott et al., 1989); and on educational programs to help improve different aspects of the self-management abilities of people living with disease (McCain & Lynn, 1990; Tabac et al., 1991; Wilson-Barnett & Osborne, 1983). Each piece of research attempts to add to the understanding of life with kidney disease so as to help people cope with their disease. However, self-management research projects an image of life from a particular theoretical toolkit — one that is empirical, cognitive, factorial and individually focused. Self-management theory is based in a particular language and research tradition that fits closely with that of the hospital institution. The focus on management of illness coincides with the preoccupation of hospitals with efficiency and rationalization. From this perspective, it is argued that self-management research is important because it increases practitioners' knowledge, as well as their ability to help people living with illness improve the management of their disease (Bartlett, 1983; Clement, 1995; Day, 1995). Proponents of self-management argue that a cognitive approach is more effective (and hence efficient) than a behavioural approach when teaching self-management skills.

Self-management is framed within an ideology of an efficient and rational self, and expresses an unquestioned faith in people's ability to "self-manage" their care. However, the
defining feature of renal failure is that there is no “self” — that is, no “self” in the sense of an autonomous body. People living with renal failure are connected to machines in a profoundly significant way—their bodies are no longer autonomous agents. People with renal failure epitomize Haraway’s (1991) notion of “cyborg,” in that they are both organism and machine. In Haraway’s work, the distinction between body and machine was blurred. Organisms and machines do not occupy separate spaces. She argued against the anti-science/technology view where a kind of excessive naturalism pits bodies against machines. A new view of our bodies and ourselves is needed to ensure that the world in which we function is included in who we are, and who we are includes the machinery of science and technology. People living with renal failure cannot separate themselves from the machinery needed to sustain their lives. This machinery is a part of a reality based in biomedicine, which has its own language, social forms and technologies. Living with renal disease necessarily means not only being a part of this medical and technical community, but accepting this reality as a part of “self”.

It is not possible for people living with renal failure to “manage” apart from the medical technology and institutions that keep them alive. If people with renal failure attempted literally to “self-manage,” they would certainly die. This reliance on medical technology and institutions renders it unintelligible to talk about “self” and “self-management” for people living with this illness. Therefore research based in such notions of “self” necessarily results in misconceptions about life with renal failure. Further, the pedagogy that results from this point of view is situated in the hands of health care practitioners, takes place in the hospital setting, focuses on training people with illness to follow medical regimens and does not necessarily take into account the voices of those living with renal failure. What is required, therefore, is a more ecological or situated portrait of life with renal disease.
The inextricably connected character of people and the milieus in which they live argues for the utility of a sociocultural approach to research (Wertsch, 1991). This kind of research offers, I argue, a more adequate foundation for implementing research that aims to describe the lives of people living with renal failure, who by the nature of their disease live lives dispersed across multiple institutional locations. From a sociocultural standpoint, both person and environment combine to create the action taking place and the agency by means of which it is accomplished—there is no such thing as person in isolation (Engeström, 1993; Wertsch, 1991). In this way, the focus moves away from any notion of an autonomous self and supports, instead, a situated account of lived experience. This research utilized a qualitative perspective as a means of gaining insight into the worlds of participants. Such a perspective can provide a detailed view of life in its "natural" setting (Creswell, 1998). The lived experience of four people with renal failure was investigated using a multiple case study design. Others have also used sociocultural research design as a means to describe—in a culturally sensitive way—the lives of people who hold a devalued position in society (Dehyle, 1995; Heath, 1983). The studies by Dehyle and Heath, although on different "at-risk" populations, came to the same conclusion—that power is distributed more equitably when the culture of the groups at risk is valued.

There is a decline in the status of those diagnosed with illness, especially chronic illnesses (Charmaz, 1991; Kagawa-Singer, 1993). Like other populations in devalued positions, people living with illnesses are at risk of social and institutional subjugation (Foucault, 1963; Fox, 1993; Strauss, Corbin, Fagerhaugh, Glaser, Mains, Suczek & Weiner, 1984; Waxler, 1981). A sociocultural case study research design is, thus, an appropriate method for describing the experience of people living with a chronic illness. Some examples of this type of study conducted with people living with other illness include studies on AIDS (Ezzy, 1998), peripheral vascular disease (Gibson & Kenrick, 1998), diabetes (Hernandez, 1995), spinal cord injury
(Carpenter, 1994), and cancer (Halldórsdóttir & Hamrin, 1996; Pelusi, 1997). In these studies the voices of the people living with disease are at the forefront of the exploration of the experience of living with a particular illness. For example, in her study on breast cancer, Pelusi (1997) moved away from the more common focus on symptom management and focused on the lived experience of the people with breast cancer. Through in-depth interviews, she was able to construct the "essential structure" of breast cancer from the point of view of those who lived with it. Similarly, Halldórsdóttir and Hamrin (1996) focused on the feelings and the experiences of living with cancer expressed through the voices of that study's participants.

The nature of kidney disease makes this lived experience different in significant ways from that of other chronic illnesses. Not only are people living with renal failure dependent upon the medical system, they are also continually dependent on the machinery in that system. Since it is the medical system that has control over the machines upon which their lives depend, people living with this disease are left with little control over their lives and care. This lack of control, and dependence on the medical system, point to the need for a contextually valid understanding of the lived experience of this population. The sociocultural basis for this research allowed for an investigation of the lived experience of renal failure from the point of view of those with this disease and at the same time included centrally important cultural, historical and institutional settings. Two studies have been done that looked at the lives of people living with renal failure. The first, a longitudinal study by O'Brien (1983), revealed many insights into people's lives such as the importance of people's social world and the importance of courage. However, much has changed since O'Brien began her research (in 1974): dialysis technology has improved, medical regimens have changed and the sociocultural world in which people live has changed. The second study on the lives of people living with kidney failure by Rittman et al. (1993) revealed the need for a shift away from the focus on technology and compliance. They advocated a move
toward understanding the experience of living with technology. This second study is more current, and, thus, overcomes the weaknesses of O'Brien's research; however, because the second study was restricted to the hospital environment, it is possible that much of the important parts of the lives of people with renal failure was omitted. My research, which builds on past research, adds to our understanding of life with renal failure in a contemporary and situated manner.

This study's findings support the argument that living with kidney disease is work. While health care practitioners may not refer to or recognize what people living with renal failure do to take care of themselves as work, it can be characterized as work nonetheless (Strauss, 1991; Strauss et al., 1984). A look at the lives of the four participants in this study suggests that the work required to live with kidney disease is a difficult and pervasive part of their lives. This work began when participants were diagnosed with kidney disease, when they learned about and began learning how to live with kidney disease. Participants then worked to understand the different dialysis therapies and chose a therapy that best suited their lives. Once a dialysis modality was chosen, the work then involved coping with hospital or dialysis settings and submitting to dialysis therapy. Undergoing dialysis therapy often required that participants work to endure pain and discomfort. Outside the hospital or dialysis settings, participants worked to monitor their diet and fluid intake, took medications and attempted to get regular exercise. No matter how well participants followed medical regimens, they still had to work to accommodate the losses associated with kidney disease. One of these losses is a deterioration of physical health, as people living with renal failure never really feel "100%" well. Another loss is psychosocial functioning. Living with renal disease placed limitations on participants' abilities to socialize, move about and travel freely. Renal disease also limited participants' independence, and forced them to deal with issues of disclosure. None of this work was done in isolation;
others had an influence on, and were influenced by, the work of participants. Participants' families and friends, as well as their health care practitioners, were all involved in the work of living with kidney disease.

There is a great deal of work, then, that is performed in the everyday experience of living with kidney disease. The bulk of this work falls in the hands of the people living with the illness and, thus, I have argued for a need to change the way we look at and describe people living with disease. If health care practitioners were to recognize and value the work that people with renal disease do for their own care, practitioners could no longer look at people living with this disease in the same way. That is, they would no longer be able to maintain the belief that people with kidney failure hold no important disease related knowledge and are merely passive recipients of care—that they are “patients.” More than just changing how practitioners talk about people living with renal failure, however, a change is needed in how practitioners talk to people living with renal failure. This research suggests that a change is required in the community of practice so that the discourse between people living with chronic renal failure and practitioners is dialogical rather than monological. The authoritative voice of health care practitioners should no longer rule the dialogue; rather than talking to people living with renal failure, health care practitioners should talk with them.

Other researchers have also called for a distinctly different relationship between people living with illness and health care practitioners. This “new” relationship would give more power to the people living with illness and allow more of their world into the medical arena. For example, Hernandez (1995) asserted that what is needed is a move away from health care practitioners that ‘prescribe’, to practitioners that ‘collaborate’. Similar sentiments have been espoused by other researchers who label the new role of the physician alternatively as facilitators or resource persons (Carpenter, 1994), or consultants (Thorne, 1990). This way, the relationship
between the physician and people living with illness can move away from fear and distrust (Mishler, 1981e), toward mutual trust and respect (Hernandez, 1995). In this type of relationship, people living with illness are the experts who define the symptoms of their diseases and are key participants in designing and acting on their own care (Carpenter, 1994; Hernandez, 1995; Thorne, 1990). Thus, while the health care professionals may be the experts on the illness, typical symptoms and manifestations, it is people living with renal failure who are the experts on the experience of illness. There is a difference between understanding an illness and experiencing that illness. This experience needs to be a part of the medical discourse. Thus far, most medical research and practice focuses on only one voice, that of the health care practitioners.

While the health care practitioners understand illness and medical technologies, this information is not sufficient upon which to base life-altering decisions. People living with renal disease and their families need to have input into the decisions that will affect them. I argue that a new type of discourse is needed, one that is dialogical rather than monological—one that facilitates choices rather than constrains them. One way for participants in this study to have more of a voice in the medical discourse was to perform a form of self-care dialysis. The extra training, as well as the increased activity on the part of the participants, allowed them greater access to, and understanding of, dialysis technology. This training included not only the workings of the dialysis machine, but also allowed the workings of the dialysis ward to become more transparent. However, as noted, not all of the participants had equal access to self-care dialysis and, thus, to an increased level of participation in the dialysis community. According to Lave and Wenger (1991) access is the key to becoming full members of any community. Thus, we can see that historical and cultural influences also need to be taken into account when attempting to facilitate the choices of those living with kidney failure.
The roles of both people living with renal failure and health care practitioners are culturally defined and shape the way that members of these groups relate to each other (Mishler, 1981c,e). In the medical setting, there is a clear division between people living with renal failure and the health care practitioners. This division is apparent not only in the roles that each fulfills, but also in how social interactions take place. In my observations, the social interactions between practitioners and people on dialysis were almost exclusively restricted to medical topics, yet practitioners commonly socialized amongst themselves. It is possible that different cultural roles and power relations between people living with renal failure act to constrain their social interactions. Historically, health care practitioners have been accepted as the “voice of authority” and, thus, have held positions of power and prestige (Foucault, 1980). People living with disease, on the other hand, held no power. They were thought to be less knowledgeable than their health care practitioners, and were expected to follow their health care practitioners’ advice (Hauser, 1981; O’Neill, 1985). The result of this power dynamic is that health care practitioners’ concerns dominate over the concerns of people living with disease. It is true that, more recently, people have begun to question their physicians, and seek second opinions. However, the relative power positions have not changed. It is the practitioners who prescribe for the people with kidney failure, even though they are prescribing from a limited viewpoint — a view based in the medical model of illness that is framed in only one perspective, that of the practitioner.

The current biomedical model of illness, it was argued, is based in our cultural understanding of health and disease. This medical model of illness, which is based in the science of biomedicine, dominates research and medical practice. It is within the constraints of this model that health care practitioners make diagnoses and decide upon medical regimens. However, medical diagnosis is interpretative work that is influenced by culture (Payner, 1996). Similarly, medical regimen recommendations are steeped in cultural and historical practices and
traditions. As was shown, the type of dialysis recommended by practitioners may be influenced by factors such as our cultural understandings of age, learning abilities, and gender and race expectations. Further, medical regimen recommendations are often influenced by historical precedents rather than by medical "discoveries." It is clear that in spite of the appearance of an "exact science" of medicine, what constitutes good medical practice varies with culture, medical setting and even with different practitioners. So, while the science of medicine must certainly have a strong influence over medical practices, historical and cultural influences over both medical science and everyday practice of medicine cannot be ignored.

Many researchers have argued that the biomedical approach, while useful, has been over-emphasized and has led to the exclusion of other approaches (Brown & Williams, 1995; Carpenter, 1994; Mishler, 1981a,d). Biomedicine ignores important aspects of disease including the social, cultural and institutional world in which the disease takes place (Brown & William, 1994; Charmaz, 1983; Mishler, 1981a,d; O’Neill, 1986). Only certain concerns are seen as legitimate and pertinent to illness, and it is physicians who decide the legitimacy of the concerns of people living with illness (Loveys & Klaich, 1991; Mishler, 1981e). In the biomedical perspective, physicians are not interested in the social or psychological aspects of a disease because these attributes do not fit with the conception of disease, and because they are not trained to deal with this kind of information (Foucault, 1973; Mishler, 1981e; Waitzkin, 1989). However, there is much more to a person and their illness than physical disability and discomfort (Carpenter, 1994; Charmaz, 1983). There is also the fact that people do not experience their illness alone. According to Fox (1993), both health and illness occur in a family setting.

Further, Monks (1995) argues that you cannot extract the body from the social world in which it functions. The biomedical approach has limited people’s input into the construction, evaluation and experience of their disease (Brown & Williams, 1994; Carpenter, 1994). To date, much of
the research in medicine is conducted with a focus on illness rather than on people's experience
of illness (Brown & Williams, 1995). By decontextualizing disease, biomedicine has limited
potential to truly understand and treat illness.

An examination of medical and nursing textbooks illustrated how greatly the science of
biomedicine is emphasized in medical training, and how the "unscientific" lives and concerns
of people with renal failure are either totally ignored or are only a minor part of these textbooks
(and are often concerned only with improving compliance with medical regimens). Medical
textbooks are, then, constituted by culture and history, and these cultural texts in turn shape
medical practice. The resulting gap in health care practitioners' understanding of the lived
experience of people with disease compromises practitioners' abilities to inform and support
the necessarily collaborative work of living with renal failure. The consequence is a dichotomy
between the standard in the medical field and the experience of people living with renal
disease. Even, for example, the current medical definition of health as absence of disease
belyes people's understanding of health. As noted earlier, participants in this study recognized
that they had a chronic illness for which there was no cure, yet all of them considered
themselves "healthy".

There is, as I have tried to show, a world of difference between listing symptomology and
understanding how these symptoms manifest themselves in participants' lives. For example, as
was discussed previously, medical research has long established that cognition declines with the
onset of renal disease (English, Savage & Britten, 1978; Fraser & Arieff, 1985; Kenny, 1983;
Osberg, Meares & McKee, 1982; Shea et al., 1965). But, while cognitive decline is accepted as
by researchers and health care practitioners as a typical by-product of living with renal disease,
the people in this study did not experience this decline. It is possible that the participants and
their families were not aware of this decline. It is also possible that the tests of cognitive
function reveal a decline that does not translate into deterioration in the daily functioning abilities of people with renal disease. Whether due to lack of recognition or to a difference between measured and experienced cognition, this study raises provocative issues regarding the notion of cognitive decline in people with renal failure.

Similarly, medical lists of symptoms cannot delineate the relative importance of these symptoms in the lives of people with renal failure. Participants in this research, for instance, found the “smallest” of symptoms the most difficult to live with. It is only by broadening the knowledge base seen as relevant that a ‘simple’ symptom (such as restlessness) be recognized as having profound consequences on the lives of people with renal failure. This research points to the importance of including the voice of people living with renal disease as a part of the knowledge base of a chronic illness. Other researchers have also found that how people experience and react to illness is often quite different than what is expected by health care and educational practitioners. For example, in their study on breast cancer, Jones and Greenwood (1994) found that people experienced stress in many of areas physicians thought of as unimportant (or did not think of at all). Similarly, Hernandez (1995) noted how people living with diabetes emphasize and focus on the “needs of their body” while practitioners emphasize the medical regimen (p. 35). The focus on the physical/medical aspects of disease does not match with people’s experiences of their illness. While scientific knowledge and familiarity of a particular illness may be helpful to practitioners, it does not make them experts in the life of an individual living with that illness. This is beautifully stated in a quote from Sir William Osler. He said, “You need to know what kind of person has the disease, not what kind of disease the person has” (taken from O’Brien, 1983). It is the people living with illness that are the experts on their body, disease and the many ways in which it manifests itself in their lives (Hernandez, 1995). It is interesting to note that, like the findings in this research, other studies have found
that many people who have chronic illness still consider themselves to be healthy (Kelleher, 1988). This is at odds with the health care profession’s definition of health as the absence of disease (Kagawa-Singer, 1993). Thus, biomedical studies do not provide the data necessary to understand and support those people who have to include a chronic illness in their lives.

The gap between health care practitioners’ understanding of disease and people’s lived experience may have many negative repercussions. One of these repercussions is a clash in goals between practitioners and those living with renal disease. The goal of health care practitioners is to improve people’s health and the focus of medical research and practice is on physical well-being. Conversely, people living with disease focus more on living “normal” lives. While these different goals may sometimes work in harmony, this research reveals that many times they do not. For example, the goal for the participants in this study was to live as normal a life as possible, which required some flexibility; however, the goal of the practitioners was to maintain some sort of order in dialysis scheduling, which restricted flexibility. I believe that increased transparency of dialysis scheduling would increase the mobility of those living with renal disease. If people with kidney failure were fully informed of scheduling procedures, resource availability and system operations, they could have more control over their own dialysis times. Although there has to be some structure in dialysis scheduling, this structure does not have to be foreign to those who must follow the schedule. For example, if dialysis scheduling was transparent to people undergoing dialysis therapy, they could take on the task of finding someone to switch dialysis sessions with themselves and then inform health care practitioners of the schedule change. This would alleviate the stress on health care practitioners and give people with renal failure more agency over their own lives.

Overall, however, because of the health care practitioners’ position of power, it is the people living with renal failure that most often suffer the consequences of the conflicting goals
between these two groups. That is, working towards the goal of improved health is considered to be the one "correct" and "logical" goal. When people living with renal failure do not follow medical regimens, they often are labelled "noncompliant" and/or deemed to be "in denial." According to Carpenter (1994), people with illness who do not "function within the system are frequently viewed as non-compliant, difficult, unrealistic, or poorly motivated" (p. 615). The notion of compliance is pervasive and problematic — it stems from a model of care where the knowledge and power reside in the hands of health care practitioner. When health care practitioners and researchers focus on compliance, they often deny the voice of people with renal disease to determine the perimeters of their own care. From the perspective of those living with renal disease, there are times when following health care prescriptions is not logical. In order to live more normal lives, the people in this study were often willing to suffer the physical consequences of not following their medical regimens. Unfortunately, in order to do this, participants were sometimes forced to lie or had to fight for their right to disregard health care practitioners’ prescriptions. When people with renal failure do not follow their medical regimens, health care practitioners often conclude that these people do not understand the consequences of their actions rather than recognizing conscious choice behaviours. Much of the research into hospital education and self-management continues to focus on finding the individual factors that relate to non-compliance (Rittman et al., 1993). These kinds of studies do not consider that compliance is connected to the worlds in which people function. Johnson and Morse (1990) noted that despite the clear concern over noncompliance there is very little investigation into the perspectives of those living with disease. Thus, compliance studies are aimed at getting people to follow regimens rather than to improve their lives.

Like all communities, the community of the hospital has its own distinctive discourse, conceptions and standards of practice. These standards are set by the health care practitioners
and focus on life in that community. Despite the significant amount of time that people with renal failure spend in this community, they are not “speaking subjects” within the discourses of their own care. Through the proliferation of scientific language, and the power of health care practitioners in this community, the concerns of people with kidney disease are often excluded or thought irrelevant to their medical care. This lack of attention to the concerns of participants was noted many times throughout this research study. The agency of people living with renal failure cannot help but be denied when the medical community does not include the knowledge of those living with this disease as part of the medical knowledge base. Recently, the trend toward interdisciplinary teamwork has involved more people in decision-making processes concerning medical regimens and procedures. This is considered a more adequate approach for people living with renal failure because of the complex nature of their disease. However, while this interdisciplinary team does include the knowledge of other health care professionals, it does not include the knowledge of the disease’s human “subjects.”

Whether utilizing interdisciplinary teamwork or a doctor-focused approach in determining medical diagnosis and recommended regimens, it is the medical-based knowledge that has been considered centrally important. As has been illustrated, however, this knowledge base lacks two of the relevant sources of information. The first of these sources is the people living with renal disease. It is the people with this disease who best understand the lived experience of renal failure, and it is they who were best able to provide knowledge on life with this disease and the work that this entails. The second of these sources of information is the significant people in the lives of those with renal failure — family members. It is the significant people in the lives of people living with renal disease who best understand the people living with this disease. Thus, it is the significant others who can best provide knowledge concerning the lives of people with illness both before and after renal failure, and both inside and outside of the hospital setting.
The hospital world is an important community to which people with renal failure now belong. However, an integrated look at the lives of the participants in this study revealed that they are a part of many other important communities. Living with kidney disease does not just occur inside a hospital or dialysis setting; in fact, most people with renal failures' time is spent elsewhere. The home world of people with kidney disease includes family and friends, and it is in this world that people with this disease really learn about, adjust to and live with their disease. Moreover, it is often here that the greatest difficulties facing life with kidney disease are revealed and these difficulties do not just "belong" to the people living with renal failure. Stein (1992) contended that a disease is located in many people, that is, there are many other people that are involved and contribute to the disease process. Family and friends must also learn to live with kidney disease. They both affect and are affected by kidney disease and are therefore vital sources of information when seeking to understand life with renal failure. Although it is most obviously the affected individual who must deal with losses in physical well-being, socialization, independence, disclosure and mobility, other people in the lives of those living with renal disease also experience these losses. The families and friends of people living with renal disease play key roles in their lives. It is they who provide the primary support for the people living with renal disease, and it is they who best understand the person with renal disease. Therefore, as argued above, they can best provide knowledge concerning the lives of people with renal disease both inside and outside the hospital setting. In arguing for the need to bridge the gap between the home world and the hospital world, I am arguing for the creation of a broader community of practice in which medical practice is based on the knowledge of three relevant sources of knowledge: the practitioners, the people living with renal disease and the significant people in the lives of those with renal failure (de Castell, 1980).
In summary, I have argued that sufficient knowledge depends upon all the relevant sources of epistemic authority being consulted. While the health care professionals may be the experts on the illness and its typical symptoms and manifestations, it is the people living with renal disease who are the experts when it comes to understanding the experience of the illness. Further, there is usually a significant other, whether family or friend, who is the “expert” on the person. These three sources of knowledge, when brought together, co-constitute an enlarged body of knowledge (de Castell, 1980); each perspective brings vital aspects of information in order to understand “renal failure.”

Studying kidney disease from a sociocultural perspective sheds new light on hospital education and health care practice in many ways. Unlike previous research, necessarily fragmented and restricted by its focus, this research has sought to provide an integrated picture of life with kidney disease. Further, by focusing on the perspectives of those living with renal disease, this study was able to investigate the work of renal failure rather than simply how best to “manage” symptoms. The result is a very different view of people living with renal failure, which considers their lives and the lives of those around them. This is a study, which calls into question the very nature of medical knowledge, how it is constructed and who holds the key to its best use. This study calls for diversity of perspectives by showing that the cognitive model of functioning is not the only possible (or perhaps even preferred) model for hospital educational programs. Together, these new insights suggest very different approaches on how best to support people living with renal failure.

Implications for Practice

This research has sought to reveal the limited scope of current medical practice by arguing the need for a change in perspective so that the complexity of life with renal failure can be comprehended. I have argued that the knowledge of people living with renal failure and their
significant others should be a vital part of the medical-knowledge base. Considering and incorporating multiple voices, I have argued, can help to bridge the communities to which people living with kidney disease belong — that of the hospital and the home world. Further, I have argued for a broader look at life with renal failure, one that is situated in cultural and historical contexts. An account of the lived experience of people with renal failure that includes these factors can inform “best practice” because it provides a richer and more authentic picture of life with this illness. It is from this perspective that health care practitioners can begin to broaden their understanding of renal failure as it is “lived”, and, so informed, can better provide the kinds of education and support that will enhance the lives of people who live with a devastating and fundamentally transforming condition.

“Best practice” begins, then, with a change in how practitioners see people living with renal disease. In order for practitioners to value the knowledge and voices of those they seek to assist, this change must be reflected in medical training and textbooks. Disseminating information about the lived experience of people with renal failure would go a long way towards helping practitioners discover that people with this disease do a considerable amount of work in their own care. Further, it is not possible to understand the lived experience of people with renal failure without including the cultural and historical factors (age, gender, and power roles, for example) that so greatly influence how illness is defined and treated.

This research has demonstrated that through their position of power and use of scientific language, health care practitioners often exclude people with renal failure from the discourse of their own care. If, as I have argued, a distinctive language creates a distinctive community, then people with kidney disease need full access to this language. The limited access of people with renal failure to “dialysis speak” is not sufficient to allow them to become full participants in a community to which they belong. People with renal failure need access to practitioners’
discourse, as speaking subjects and not simply as "auditors," in order to enjoy legitimate access to a community to which, through necessity, they are permanently tied. With increased access comes increased agency, power and, I would argue, improved quality of life. When people with renal failure have a legitimate voice and a legitimate role to play, their concerns, suggestions and knowledge contribute greatly to the medical-knowledge base in a way which cannot help but improve medical services. It is also important, too, for people with renal failure to have advocates. Interestingly, those with the greatest power in the medical community, the health care practitioners, have groups to advocate and protect their rights (unions, medical boards, etc.). Yet, those with little or no power (the people living with renal failure) do not. While the Canadian Kidney Foundation provides information and works to increase research and awareness of kidney disease, they do not involve themselves in the lives and problems of individuals. This means that if people with renal disease experience difficulties with the medical system, they may have no one to advocate on their behalf. An advocacy group, one that is run by and for people living with renal failure, could help increase the power of those living with renal failure both in and out of the medical setting.

Current hospital educational programs are based on a medical model and focus on improving medical outcomes. The medical model's pedagogy resides in the hands of health care practitioners, takes place in the hospital setting and does not incorporate all of the relevant sources of knowledge. Participants in this study all took part in this type of formal educational programs in the hospital setting. While these programs were of course found to be of some value (especially for learning self-care dialysis), participants reported that it was in the actual living with kidney disease that they really learned about their renal failure. That is, real learning is in the doing and living, not in the educational programs. As well, it became clear that many participants did not hold the kind of beliefs that are considered "right" in the self-management
model. For these participants, the difficulties or costs of following a regimen sometimes outweighed the benefits of improved health. When participants chose not to follow their regimens, they ran the risk of being labeled “noncompliant” and often had to face the negative responses of their health care practitioners. Educational programs that focus on compliance place power in the hands of practitioners, and erode and undermine the agency of those they aim to help.

Taking into account the experiences of people living with renal failure requires a rethinking of the structure and content of pedagogy, which, rather than being situated in the hospital, would be situated in the living with renal disease. The nature of knowledge, who has that knowledge and whose knowledge is seen as important would change (Deyhle, 1995; Heath, 1983). In his seminal work, Paulo Freire (1970/1993) argued that change could only take place though the voices of those marginalized. Since they live the experience of being marginalized, it is they who must be a part of the voice for change. Freire’s critical pedagogy, though based on a study of political oppression, has much to offer as a pedagogical model for the education of people with renal failure.

Freire (1979/1993) argued against a “banking” concept of education where teachers are the “depositors” of knowledge and students are the “depositories.” Within this framework, teacher quality is based on a capacity for filling “depositories” and student quality is based on a capacity to “be filled.” The result is a dichotomy between students and teacher, and a system of education that believes that people are “adaptable and manageable beings.” This model of education falls in line with self-management education, which I have argued is an inadequate model for people living with renal failure. Like the people in Freire’s research, people living with illness are marginalized and are in need of a different pedagogy — one that does not further their marginalization.
For Freire, real education only begins when roles of teachers and students are modified so teachers are both teachers and students and students are also both students and teachers. Both parties share in the development of the pedagogy, which forges a partnership in education rather than educational domination. In this critical pedagogy, knowledge (rather than being static and in a person’s possession) is continuously “made and remade” in the actions of people in the world (Freire, 1970/1993). This kind of dynamic knowledge incorporates both the world and the people in it, and argues for a dialectical process of education. This process is one in which students are “co-investigators in dialogue with the teacher” (p. 62). Further, this dialogue (and all authentic education practice) is mediated by the world in which it occurs. The language of the discourse must be relevant and transparent so that it may include all parties in the dialogue.

Educational programming for people living with renal failure, if based on Freire’s (1970/1993) pedagogy, might imbue power and legitimacy to those living with this disease. Pedagogy that is built by practitioners and people living with kidney disease cannot help but be an improvement over educational programs built exclusively by practitioners. As a means of broadening the knowledge base, these programs could also include the voices of the significant others in the lives of people with renal failure. When the voices of people with renal failure (and their significant others) are given legitimate access to the development of educational programs, the worlds and experiences of people living with this disease will become a part of the pedagogy. Since the worlds and experiences change, the pedagogy too must change. Education — no longer based on static information, confined to formal programming and restricted to medical settings — becomes a dynamic pedagogy centred on living with a chronic illness. Further, the inclusion of people living with renal failure in the development of educational programming will re-shape the goals of these programs. Rather than focusing on the goals of practitioners (i.e. getting people with renal failure to comply), it may be possible to align the often quite different
goals of those living with illness and practitioners. Overall, this kind of critical pedagogy may, for the first time, offer people living with renal failure a legitimate role as participants in the medical community, with a significant, authoritative voice in their own care.

Limitations and Future Directions

As with any study, there are a number of limitations that must be considered. Because the research reported here utilized case study as a central method, the number of participants might be regarded as being “too small a population” from the standpoint of quantitative methodology. Further, the study was conducted in one hospital and one community dialysis setting; therefore it may be argued that the findings are not representative of other people’s experiences of kidney disease. However, because the purpose of this study was to gain an in-depth understanding of life with renal failure, a case study design is justifiable. Understanding the lived experience of people with renal failure requires a methodology that can focus on individuals in the contexts of their worlds, address the complexity of life and experience, centre on the perspectives of these people while treating them in a culturally sensitive way. Multiple qualitative case studies framed in a sociocultural perspective are prime means of accomplishing these goals. This research design allowed me to create four portraits of life for people living with renal disease. These portraits made it possible to delineate, for these participants, ongoing issues of life, as well as allowing some reflection on medical education programs and the treatment of people living with disease.

As with most qualitative case studies, the generalizability of the results may be limited. However, these four participants comprised a diverse sample that included both men and women of diverse age and cultural backgrounds, as well as diverse disease histories. Despite this diversity, the results indicated that there were many commonalities in their experiences of this disease. Further, many of the findings about what the participants were experiencing in their
everyday lives were issues that other researchers have talked about in the literature on renal failure. Therefore, it is not unreasonable to assume that what was true for these four people may be true for other living with this disease. That is, both the diversity of the participants and the congruity with the findings of other research leads me to believe that these four people are not unrepresentative of others with this disease.

One of the difficulties of research in general, and this case study in particularly, is the notion of validity. In order to improve validity, this study utilized triangulation and member checking. Multiple cases allowed for triangulation of perspectives among and between participants. Further, because this study also included data from other sources (i.e. significant others, health care practitioners, medical records and researcher observations), it was possible to triangulate the data from many positions. The main emphasis, however, was on the ecological validity of participants' lived experience. Because the goal was to represent the participants' views of life with renal failure, it was vital to ensure that the researcher’s findings and interpretations represented the lives of the participants. For this reason, a number of member checks were conducted both during and after the data gathering. However, in any conversation, even if two people think they understand each other perfectly, there may be differences in interpretations. This is a difficulty encountered by every qualitative researcher and, while I endeavoured to minimize these misunderstandings (through member checks and triangulation), it is important to recognize that this study represents my perspective of participants’ lives. Thus, it is important to note that the theory of life generated by this study reflects a sociocultural perspective and that this particular perspective shaped how I both gathered and interpreted the data.

Limitations also result from the translation of people’s experience into text. With text, it is not possible to capture the richness, depth and complexity of people and the experiences that
they are trying to express. In the translation of these people’s lives into text, I was unable to
catch the nuances and the richness of what they were experiencing. I was unable to capture
exactly what occurred because words can never fully capture the situation—language is lived
and spoken and includes contexts, facial expressions and nuances that can never fully be
captured in text. This is the inevitable limitation of transcript-based reports. It is impossible to
capture the richness and complexity of the discursive situation because conversation is more that
just words.

Case study and qualitative work is always narrative. This is why it is important to pay
attention to the skill of the writer. In narrative work, the production of the account, that is, the
actual writing of the account is a large part of the research process. In this type of study, the act
of writing can be considered an act of research. Inevitably, there will be some awkwardness and
lack of skill in sufficiently richly articulating the narrative account of people’s lives. When I
reread what I have been able to say about the lives of these participants, I am conscious of the
relative thinness of the text of their lives when compared to the richness of their real lives.

A final point deals with the conclusions drawn from this study. I have argued that there
is a need for a change in medical and educational practices so that knowledge of illness is
constructed from a broader epistemic base. Healthcare practitioners often argue that within the
confines of the current medical system, data collection of such a broad scope would be
impossible. This argument is often used to maintain the status quo, and to justify a strict
biomedical focus. However, the difficulty of gathering information does not negate its
importance. When people living with illness and their families have a voice in medical care, care
will improve.

One study on its own is, of course, not enough to paint a complete picture of life with
renal disease. This research represents a first venture into uncharted territory and attempts to
begin to formulate an understanding of the lived experience of renal failure. More research is needed on the lived experience of renal failure from a larger and more diverse population in order to begin to chart the similarities between these participants and others as well as to note the areas that are idiosyncratic to these particular participants. As well, studies that implement and test the approaches to medical practice and education proposed here are warranted if we are to know with greater confidence that this research is indeed, a step in the right direction. My hope is that this research may have shed light on the reasons why such a pursuit might serve the best interests of practitioners and “patients” alike.
REFERENCES


Fife, B.L. (1994). The conceptualization of meaning in illness. Social Science and Medicine, 38, 309-316.


York, NY: Pantheon.

Foucault, M. (1994). Ethics, subjectivity and truth: The essential works of Michel

Press.


education programs. Diabetes Care, 18, 100-116.

Directions for Teaching and Learning, 63, 29-42.


Journal of Medial Education, 60, 745-756.

groups during family conferences on inpatient rehabilitation units. Archives of Physical
Medicine and Rehabilitation, 71, 699-702.

Language in Society, 12, 173-185.


APPENDICES

A: Sample Questions
Sample Interview Questions
For patients:
What has your life been like since you were diagnosed with kidney disease? What was your life like before you were diagnosed with renal disease?

What is it like to be a patient with kidney disease?

What does kidney disease mean to you?

How does kidney disease affect your everyday life?

How would you define your disease?

What is the worst part of having renal disease? What is the best part?

What is the hospital environment like? How much time do you spend in the hospital?

What kind of relationships do you have with renal program personnel? What (if anything) would you like to change about this relationship?

Someone who has just been diagnosed with renal disease has come and asked you for advice, what would you tell him/her?

For Social Supports:
What kind of support do you provide?

What kind of support do you often require?

What kind of support does ________ often require?

Has your life changed since ______ was diagnosed with kidney disease? How?

Has _______ life changed since he/she was diagnosed with kidney disease? How?

What does kidney disease mean to you?

For Medical Practitioners:
What does it mean to have kidney disease?

What kind of life changes does kidney disease require?

What kind of supports do you provide?

What kind of supports do patients need?

What is the hospital environment like?

What kind of relationships do you have with patients?
B: Hospital and University Consent Forms

and Participant Eligibility
Participant Eligibility

In order to be eligible to participate in this study a person must:

- be 18 years or older
- be able to speak and read English
- have chronic renal failure
- be undergoing dialysis therapy
- have participated in the hospital training program
- not be slated for kidney transplant within six months of study commencement
- have no other complicating illnesses (unrelated to renal failure)

The renal program manager determined participant eligibility based on the criteria above and those people deemed eligible were forwarded a request for participation letter.
C: Request for Participation Letters
D. Participant, Practitioner and Social Support Consent Forms
E: Data Analysis Summary and Coding Sample
**Procedure:**

<table>
<thead>
<tr>
<th>Data Gathering</th>
<th>Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hospital ethical consent obtained</td>
<td>• interviews transcribed verbatim, read and reread</td>
</tr>
<tr>
<td>• Program manager determine participant eligibility and request for participation letters sent</td>
<td>• transcripts divided into sections of talk and coded</td>
</tr>
<tr>
<td>• Initial data gathering</td>
<td>• analysis of basic characteristics to find 3 people with renal failure that vary on as many characteristics as possible (gender, social class, ethnicity, time on dialysis, etc.)</td>
</tr>
<tr>
<td>• observation of hospital setting</td>
<td></td>
</tr>
<tr>
<td>• medical personnel interviews</td>
<td></td>
</tr>
<tr>
<td>• Participant volunteers contacted</td>
<td></td>
</tr>
<tr>
<td>• further explanation of study</td>
<td></td>
</tr>
<tr>
<td>• consent forms signed</td>
<td></td>
</tr>
<tr>
<td>• Basic information gathered on participants</td>
<td></td>
</tr>
<tr>
<td>• 3 participants selected and 1 partial participant added to provide age and gender balance</td>
<td></td>
</tr>
</tbody>
</table>

**Data Gathering: Type One**

<table>
<thead>
<tr>
<th>Data Analysis: For Type One</th>
</tr>
</thead>
<tbody>
<tr>
<td>• initial interviews with selected participants</td>
</tr>
<tr>
<td>• home/hospital observations</td>
</tr>
<tr>
<td>• participant documentation reviewed</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>• interviews transcribed verbatim, read and reread</td>
</tr>
<tr>
<td>• transcripts divided into sections of talk and coded</td>
</tr>
<tr>
<td>• notes from observations and documentation read and coded</td>
</tr>
<tr>
<td>• questions formulated from missing or unclear information (to be asked at next interview)</td>
</tr>
<tr>
<td>Data Gathering: Type Two</td>
</tr>
<tr>
<td>-------------------------</td>
</tr>
<tr>
<td>• participant interviews (for five months)</td>
</tr>
<tr>
<td>• informal member checks</td>
</tr>
<tr>
<td>• dialysis observations</td>
</tr>
<tr>
<td>• observations at other relevant settings</td>
</tr>
<tr>
<td>• participant documentation reviewed</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data Gathering: Type Three</th>
<th>Data Analysis: For Type Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>• tape recorders given to participants (on three different occasions)</td>
<td>• interviews transcribed verbatim, read and reread</td>
</tr>
<tr>
<td></td>
<td>• transcripts divided into sections of talk and coded</td>
</tr>
<tr>
<td></td>
<td>• new (or changed codes) changed on other data</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data Gathering: Type Four</th>
<th>Data Analysis: For Type Four</th>
</tr>
</thead>
<tbody>
<tr>
<td>• healthcare practitioner interviews</td>
<td>• interviews transcribed verbatim, read and reread</td>
</tr>
<tr>
<td>• primary social supports interviews</td>
<td>• transcripts divided into sections of talk and coded</td>
</tr>
<tr>
<td></td>
<td>• new (or changed codes) changed on other data</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data Gathering: Final Type</th>
<th>Data Analysis: For Final Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>• participant interviews – formal member checks</td>
<td>• categories revised</td>
</tr>
<tr>
<td></td>
<td>• all data analysis using the cut and paste method</td>
</tr>
<tr>
<td></td>
<td>• categories determined and emergent theories postulated</td>
</tr>
<tr>
<td></td>
<td>• categories and theories revised from member check data</td>
</tr>
</tbody>
</table>
Codes:

<table>
<thead>
<tr>
<th>Pi = Personal information</th>
<th>L = Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pih = history</td>
<td>Lwk = life work -- knowledge</td>
</tr>
<tr>
<td>Pif = family</td>
<td>Lw = life work</td>
</tr>
<tr>
<td>PiT = transplant</td>
<td>LL = life losses</td>
</tr>
<tr>
<td></td>
<td>Li = life issues</td>
</tr>
<tr>
<td></td>
<td>Lf = life family and friends</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>R = Responses</th>
<th>S = System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rc = Comparisons</td>
<td>Sp = policies and procedures</td>
</tr>
<tr>
<td>Ra = Attitudes</td>
<td>Sw = system work</td>
</tr>
</tbody>
</table>

Example:

1186  P: Yeah, I suffer the consequences, you have good days and
1187  good stretches and bad stretches like today I only had two
1188  point five and I intend on having, I've had one coke and I'm
1189  having another one so I'm taking off more than I actually
1190  put on type of thing.
1191
1192  R: Right.
1193
1194  P: Yeah, a lot of times they'll look at the bottom line not
1195  to go, no, no, look up here, this is what I gained, this is
1196  what I'm having
1197
1198  R: Right.
1199
1200  P: So, I usually have it, you know, if you're eating or
1201  something, it's usually at the beginning of the run and so by
1202  the end of the run it's usually
1203  Gone
1204
1205  R: Gone already.
1206
1207  P: Gone already.
1208
1209  R: So that's when you have all the things you're not
1210  supposed to have, is that the idea or
1211  P: Yeah, yeah, like if I'm going to have a bag of potato
1212  chips, I'll have it on the way here or something and I don't
1213  know why particularly I pick potato chips as being worse
1214  than pizza I might have had the day before.
ENDNOTES

1 Dialysis is a method of treatment for renal failure that removes water and wastes from the blood. This removal of wastes takes place either through an artificial kidney machine or in the abdomen (through the peritoneal cavity) (Kidney Foundation of Canada, 1990).

2 Quotations are used to denote terms that, while accepted as part of particular models, are in reality, constructs of those models. For ease of reading and following APA style, each term will appear in quotation marks on only the first occasion it appears.

3 A fourth partial participant was added to help balance the age and gender of the participants.

4 Creatinine is a waste product of the muscles that increases as kidney function decreases. It is often used as a measure of kidney function. Normal creatinine levels range from 60-110 μmol/L (Kidney Foundation of Canada, 1990).

5 A fistula is a permanent access site for hemodialysis therapy. It requires that an artery and a vein be connected together to enlarge the vein and provide better access for the dialysis needle (Kidney Foundation of Canada, 1990).

6 A neckline (or Central venous catheter) is most often used as a temporary access when dialysis is needed quickly. A soft tube is placed in either the vein near the collarbone or in the jugular vein in the neck (Kidney Foundation of Canada, 1990).

7 In Hemodialysis therapy blood is taken from the body and passed through an artificial kidney machine. This kidney machine works much like a real kidney in that it cleans the blood of wastes and excess fluids (Kidney Foundation of Canada, 1990).

8 In Peritoneal dialysis therapy blood is cleaned of wastes and fluids while still inside the body. In the abdomen there is a peritoneal cavity which surrounds the intestines and other organs. It is in this cavity that a special dialysis fluid is placed. The blood vessels in the peritoneal cavity are exposed to the dialysis fluid and the wastes and excess water are drawn from the blood into the fluid. The fluid is then drained from the body and discarded (Kidney Foundation of Canada, 1990).

9 During the early phases of my data collection I referred to people with kidney disease as "patients." In order to faithfully represent my observations, I have used the words that represent my understanding at the time.