LIFE AND WORK: THE HEALTH-RELATED QUALITY
OF LIFE AND EMPLOYMENT OUTCOMES OF
RENAL TRANSPLANT RECIPIENTS

By

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ABSTRACT

This study was designed to investigate patient outcomes following kidney transplantation in terms of health-related quality of life and employment status. In addition it was designed to identify, in terms of relative contribution, the main factors or characteristics that are associated with employment from the perspective of the renal transplant recipient.

The study was conducted in two stages. In stage one, 216 adult renal transplant recipients from the lower mainland of British Columbia completed a mail questionnaire on their health-related quality of life and their employment circumstances. In stage two, using a maximum variation sampling strategy, seven adult transplant recipients participated in a personal interview.

The results from this work indicate that a person's health-related quality of life following renal transplantation is less than optimal. Limitations persist particularly in the area of physical functioning and the ability to perform usual roles at home, school and work. The area least affected is the transplant recipients' mental health. People with renal transplants generally adjust well to their condition and their mental health approaches the levels found in the general population. Employment prospects are diminished for people with kidney transplants. Employment rates lag behind the rates in the general population. The reasons for this finding are complex and reside in the individual as well as the socio-cultural, economic and political reality. When poor functional health is compounded by limited education, increased age, interruptions in work and the unavailability of suitable work, disadvantages in employment increase.

The health and employment outcomes of renal transplant recipients provide estimates of the need for social work services and allow monitoring of progress toward meeting the goal of full rehabilitation in this population. Identifying and
mapping the factors that contribute to employment using the PRECEDE-PROCEED model for health promotion planning and evaluation is a useful guide to selecting and directing intervention where it is most needed.

The findings of this study raise questions about quantifying a realistic employment goal for renal transplant recipients. It is recommended that further research be conducted to determine the barriers to employment found among other groups of chronically ill persons in order to develop a broad strategy for improving access and equal opportunity to jobs for all who desire them.
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CHAPTER ONE
Introduction

Background to the Problem

In today’s health care community, there is growing interest in using standardized measures of health-related quality of life to evaluate the impact of medical care and treatment on the patient’s life, from the patient’s perspective. This enquiry is labeled variously as patient outcomes research or quality of life evaluations. It represents a change in focus from the traditional biomedical outcomes of mortality and morbidity to interest in psychological and social outcomes. Kleinman, Eisenberg and Good (1978) describe this development as a shift from interest in the disease component of sickness to interest in the patient’s description of the experience of illness. How we perceive, experience and cope with disease and treatment are the pertinent questions today. For example, measuring the reduction of tumor size or counting the number of hospital days is too narrow a focus. We now want to complement this information with quality of life data - a description of what patients feel like following treatment, what they are able to do, how their lives are affected.

The emergence of quality of life as an important endpoint or dependent variable in evaluations of medical interventions can be attributed to several interrelated factors: (a) the increasing number of people living with chronic diseases where care of the patient, not cure of the disease, is the pertinent issue; (b) the practice of using new forms of technology that can keep people alive biologically but dead socially, challenging the concept of sanctity of life with the concept of quality of life; (c) concerns about health care costs and the need for information on the benefits gained, by whom and under what conditions in order to determine the cost-effectiveness of treatment; (d) a shift to a shared-decision
treatment model between patients and doctors with the accompanying need for outcome information that is relevant to patients in order to assist them in making informed choices about treatment; and (e) and an emerging alliance of biology with sociology and psychology in understanding treatment of disease - an appreciation of the interdependence of psychological factors and the functioning of the endocrine, nervous and immune systems and the important role of a positive attitude and hope in sustaining life and reducing susceptibility to disease (Holman, 1993; S. Levine, 1987; McClellan, Anson, Birkeli & Tuttle, 1991; Mahoney, 1991; O'Brien, Buxton & Ferguson, 1987).

End-stage renal disease (ESRD) is a life threatening condition that affects thousands of persons in Canada each year. ESRD is the irreversible shutdown of kidney function that can strike people of any age and any background, without warning. From 1981 to 1991, the new case rate per million of the population has increased at a compound rate of 6.8% (Canadian Organ Replacement Register, 1991, Table 31). The number of new ESRD patients per million of the population in BC is 86.6 per year (CORR, 1991, Table 29). There is no cure for end-stage renal failure. Current treatment options include maintenance hemodialysis, peritoneal dialysis or kidney transplantation. In British Columbia (BC), approximately 1848 persons received renal replacement therapy in 1991; 30.6% (566) were alive with a functioning kidney transplant, the remainder were on dialysis (CORR, 1991, Table 39).

Of the treatment options available, kidney transplantation is the treatment of choice (Keown, Shackleton & Ferguson, 1992). When kidney transplantation was first performed in Canada in 1958, it was viewed as an experimental, high-cost treatment suitable for only a select group of patients with end-stage renal disease. Today, it is a well-established and highly successful treatment. Patient and graft
survival is excellent. The success of kidney transplantation in BC equals that of major programs throughout the world with estimated graft survival rates in British Columbia of 90% at one year, a continued success rate of 80% at three years and an expectation that more than half of these grafts will survive over 12 years (British Columbia Transplant Society, 1992). Beyond survival, there is mounting evidence to support the claim that a person’s quality of life following a successful kidney transplant cannot be matched by any other form of renal replacement therapy (Bremer, McCauley, Wrona & Johnson, 1989; Devins et al., 1990; Evans et al., 1985; Martino, 1987; Morris, 1988; Simmons, Abress & Anderson, 1988). Whereas hemodialysis is associated with four-hour treatments on an artificial kidney machine three times a week, and CAPD is associated with regular exchanges of peritoneal fluid throughout the day, the treatment regimen for transplantation entails little more than daily immunosuppressive medications. It is viewed as the least intrusive form of treatment with the fewest restrictions and it offers the best potential for returning ESRD patients to a full and active lifestyle.

For many transplant recipients the ability to maintain an active, productive role in the workforce is a specific quality of life concern and historically studies have used return to full-time work as a clinically relevant index of improved quality of life following transplantation (Evans et al., 1985; Johnson, McCauley & Copley, 1982; Simmons, 1984). However, there is evidence to suggest that despite marked improvement in functioning and well-being, kidney transplant recipients are not returning to the workforce at the expected rate (Evans et al., 1990; Kinnaert, Vereerstraeten & Toussaint, 1985). Although employment may not be important for all transplant recipients, for those who do want to work and are able to work, it may be that transplant recipients, when compared to people with no chronic illness, are
in a disadvantaged position when seeking to enter, reenter or retain their position in the workforce.

**Statement of the Problem**

Previous studies have indicated that quality of life and ability to work improves for people with ESRD following transplantation, yet transplant recipients do not return to the workforce at the expected rate. Despite this observation, few studies have systematically examined the employment outcomes of patients following transplantation to determine whether in fact they are underemployed relative to the general population or to describe the factors that inhibit or contribute to employment following transplantation.

**Purpose**

The purpose of this study was to provide some descriptive information on the health-related quality of life and employment outcomes of BC residents following renal transplantation in order to define the extent of the problem and second, to identify, in terms of relative contribution, the factors or characteristics that are associated with employment from the perspective of the renal transplant recipient.

**Theoretical Framework**

The goal of renal transplantation is to improve, restore and promote health in the transplant recipient. The perspective used in this study was that the individual's health and employment outcomes are multifaceted phenomena and no one factor can explain the variance in individual or group outcomes. Transplant recipients will make judgments about their health and make choices regarding employment in the context of their individual and collective environments. A causal model describing the factors or characteristics associated with employment status must reflect the complex and dynamic interplay between the individual and the social, cultural and political influences of the larger world.
The theoretical framework for this study was based on the PRECEDE-PROCEED model for health promotion planning and evaluation (phase 4) developed by Green and Kreuter (1991, pp. 150-187). Phase 4 of the model examines the contributing factors affecting individual or collective health promotion behavior. The factors affecting behavior are classified as (a) positive or negative predisposing factors - which are those antecedents to behavior that provide the rationale or motivation for the behavior, (b) positive or negative enabling factors - which are the antecedents to behavior that enable a motivation to be realized, and (c) positive or negative reinforcing factors which are factors subsequent to a behavior that provide the continuing reward or incentive for the behavior and contribute to its persistence or repetition (Green & Kreuter, 1991, p. 151).

An adaptation of the Green and Kreuter model developed for this study is presented in Figure 1. In this model, employment activity is the dependent variable of interest. The independent variables associated with employment status reside in the individual (i.e. personal values and beliefs, physical health, psychological health, social health, age, education) and the external environment (i.e. the physical, social, cultural, economic and political environment). These independent variables are classified as predisposing factors, enabling factors or reinforcing factors. The arrows represent the causal pathways. The pathways are not strictly linear. Many of the independent variables are interrelated (such as health and the environment) and there is a complex and reciprocal relationship between the independent variables and employment activity. In this model, work behavior will occur and persist when: (a) the individual believes in the value of work and views it as an important activity (predisposing factors); (b) adequate resources are present, such as stable health, appropriate work skills, social support and access to a job (enabling factors); and (c) the behavior receives monetary and/or emotional
Figure 1. Conceptual model of the classification of factors associated with employment status.


...rewards such as self-fulfillment or recognition and status within the family and community (reinforcing factors). Although a highly motivated person might secure employment despite a deficit of resources and rewards, or a highly rewarded employee might choose to continue working in the absence of personal beliefs about its value, for the most part, the three conditions - predisposing, enabling and reinforcing - will be aligned for work behavior to occur and persist. When the rewards of work are positive they reinforce and strengthen the work behavior,
future resources and future motivation and today's reinforcing factors become
tomorrow's predisposing or enabling factors (Green & Kreuter, 1991, p. 152).

**Research Questions**

The specific aims of this study were to answer three major questions:

1. What is the health-related quality of life of kidney transplant recipients and how does this compare to the general population?

2. What is the employment outcome of kidney transplant recipients and how does this compare to the general population?

3. Which factors outlined in the conceptual model (see Figure 1) are the strongest predictors of employment in the kidney transplant recipient?

**Definition of Terms**

**Kidney transplant recipient:** an adult with non-functioning native kidneys who underwent surgery to implant a single healthy kidney donated from a person who had died (cadaveric) or by a living-related donor.

**Health-related quality of life:** a description of general health in terms of the person's physical, psychological and social functioning and well-being. In this study, health related quality of life was expressed as the scores obtained on the six dimensions of the Medical Outcome Study Short-form General Health Survey (Stewart, Hays & Ware, 1988).

**Employment outcome:** the employment status of the transplant recipient at the time of the survey. The categories of employment were those used in the 1986 Canadian Census Handbook such that (a) employed persons refer to those who were working for pay full- or part-time or who were temporarily on leave from a job, (b) unemployed persons were those who were not employed but were able to work and searching for a job, (c) active in the workforce refers to the unemployed and the employed categories combined, (d) the unemployment rate shows the
unemployed as a percentage of the labour force and the participation rate shows the labour force as a percentage of the population surveyed, and (e) not active in the labour force refers to those who were unemployed and unable to work or not looking for work (Statistics Canada, 1988, p. 60).

**Employed group vs. unemployed group:** The subgroup analysis in this study was based on the group of employed transplant recipients who were working full-time, part-time, or on temporary leave and the unemployed transplant recipients which included both those who were looking for work as well and those who were not looking for work.

**Importance of the Enquiry**

The potential applications of patient outcome data can be divided into three broad categories (a) use as a discriminative index to distinguish people with different levels of health/quality of life at a single point in time, (b) use as a predictive index to express the probability for a future outcome, and (c) use as an evaluative index to measure the magnitude of change within individuals occurring over time (Kirshner & Guyatt, 1985). These data are relevant to the patient, health care practitioners, private industry and public health policy.

In the health policy arena, research on patient outcomes is central to many of the debates in the Canadian health care system today over what medical interventions actually contribute to improved health of the patient and should therefore be funded and what interventions are disproportionately costly in relation to the health outcomes they produce. The British Columbia Commission on Health Care and Costs has strongly endorsed the view that the “the focus of the health care system must be on providing those services which improve health outcomes; these outcomes must be defined, measurable, subject to analysis and be able to be independently evaluated; services which cannot be shown to improve health
outcomes should not be funded by the health care system” (British Columbia Commission on Health Care and Costs, Volume 1, 1991, p. 6). Sophisticated medical procedures such as organ transplantation are high-cost technologies which dramatically improve, or occasionally compromise, patient survival and quality of life. Recognizing that the medical care system cannot afford to do everything possible for all people, choices are being made around what benefits or services will be provided and who will have access to these benefits i.e., decisions on the rationing and allocation of health care resources. The ultimate goal is to maximize the number of patients being treated, at the least cost, while providing the highest quality of life affordable (Evans, 1983; Kutner, 1987). Outcome data on quality of life contribute to this decision-making process about benefits gained, by whom, under what conditions and at what cost.

From the perspective of the public health sector, quality of life information is both relevant and understandable; to the extent that rationing and allocation of resources should reflect the views and needs of the society, it offers the potential for greater equity of provision relative to need (Hunt, McEwen & McKenna, 1986, p. 237). Quality of life data from population surveys and clinical trials represent a clear and significant guide to decision makers. Such research can distinguish differing levels of distress associated with the same medical condition and thus identify priority groups within a diagnostic category (Hunt et al., 1986, p. 237). Provincial health plans are expected to provide 100 percent coverage of all “medically necessary” services according to the Canada Health Act of 1984. The demonstration of effectiveness and efficiency of a medical intervention are key in the political process of interpreting what procedures are “medically necessary”, who should receive them, and under what conditions. The evidence from patient outcomes research provides clinical guidelines on the utilization, health impact and
dispersion of different health technologies, and offers a rational basis for the interpretation of Medicare's principles of comprehensiveness and accessibility.

Specifically to program planning and staff development within social work studies that provide baseline data on the health and employment outcomes of a population such as renal transplant recipients would provide estimates of the need for services and allow monitoring of progress toward meeting the goal of full rehabilitation for this population.

Private industry - pharmaceutical companies and manufacturers of medical devices - also benefit from quality of life information. Demonstration that a new treatment is both biologically effective and provides a benefit in terms of quality of life is a key observation and affords an important marketing advantage (Bergner, 1989). When quality of life information is factored into a cost-effectiveness analysis the results provide guidance to the manufacturer in setting a competitive price for new products.

For health practitioners, such as social workers, nurses, occupational or physical therapists, and doctors, outcomes research provides a firm set of standardized criteria to demonstrate more convincingly the clinician's contribution to patient health and well-being (S. Levine, 1987). In addition, the quality of life profiles that emerge from the research act as a clinical guide enabling health practitioners to direct interventions where they are most needed. Identifying and mapping the predisposing, enabling and reinforcing factors that contribute to, or inhibit, employment activity make it possible to group the specific features of the patient's situation according to the types of social work intervention available. If there were some attitudes and beliefs about work that were negatively impacting on the person's motivation or predisposition to work, individual counselling may be effective. If there were deficits in work skills, vocational training strategies may be
helpful. An increase in the proportion of the population who hold a favorable attitude toward employment of the transplant recipient would provide reinforcing support. If discrimination by employers or lack of social support were a concern, family work, public education, community organization or social action may be required to improve the environmental influences that were having a negative impact on employment of the transplant recipient.

Finally from the perspective of the patient, quality of life studies provide an opportunity for patients to voice their opinions about the human impact of disease or treatment. Some of the secondary benefits of a quality of life evaluation are the potential for increasing the amount of attention paid to patients by members of the health care team, increasing the perceived social support by patients. Information on the probable outcomes of treatment provide patients with a basis for informed consent (R. Levine, 1990).

Despite their importance, the health and employment circumstances of people following renal transplantation have not been the subject of systematic study in British Columbia. As an initial research endeavor, this study will describe the patient outcomes and develop a tentative model for the mapping of factors associated with employment. As we move into a post-industrial society characterized by high rates of structural unemployment, it is likely that minorities such as people with chronic health problems will be disproportionately represented in the workforce. Research of this kind will have important practical value as well as theoretical relevance for models of health promotion and planning.

**Organization of Thesis Content**

The thesis is composed of five chapters. In Chapter One, the background to the problem, problem statement, purpose, theoretical framework, research questions, definitions, and the importance of the enquiry were introduced. In
Chapter Two, a review of the literature is presented in relation to the two major concepts under study, health-related quality of life and the employment role followed by a review of the ESRD literature on patient outcomes in renal transplantation. Chapter Three describes the research methods and procedures that were used. In Chapter Four, a description and discussion of the study sample and the research findings are presented. Finally, the summary, conclusion, implications for social work practice, and recommendations for further research are developed in Chapter Five.
CHAPTER TWO
Review of Related Literature

Introduction

In this chapter, a review of the literature is presented in relation to the two major concepts under study, health-related quality of life and employment. The literature review is organized into three sections. In the first section, some conceptual, theoretical, methodological and measurement issues in the evaluation of health-related quality of life are discussed. The second section examines the role of employment in adult life. The third section reviews the ESRD literature on the quality of life and employment outcomes after renal transplantation.

The Evaluation of Health-Related Quality of Life

The literature addressing the evaluation of health-related quality of life begins with a discussion of some conceptual and theoretical issues. The next section examines methodological and measurement issues focusing on the relevant viewpoint to consider when conducting quality of life studies, whether a quantitative or a qualitative methodology is appropriate, and pertinent topics to consider in the selection of a standardized instrument including generic or specific instruments, mode of administration, consideration of the breadth vs. the depth of the coverage, the level of data dis-aggregation, the response scale, the range of measurement, question time-frame, instrument reliability, validity, sensitivity, and sensibility.

Conceptual and Theoretical Issues

Since 1975 when quality of life first appeared as a key word in the medical literature there has been much confusion over the meaning of the term and the appropriate attributes that should be measured (Spitzer, 1987). Part of this confusion stems from the fact that quality of life is not a single concept. It has
multiple meanings. When social scientists study quality of life they are interested in the broad societal and environmental aspects of life which embrace a multitude of factors beyond health such as education, employment, family life, standard of living, community safety, air quality, water quality, population density and cultural opportunities. To others, quality of life is viewed as an existential or spiritual concept where meaningful life and purposeful existence are the dimensions of interest. The health care system and its providers generally restrict evaluation of quality of life to a consideration of only those aspects of personal functioning and well-being that are most likely to be directly affected by disease and clinical interventions.

The recurrent themes from the health literature distinguish three primary attributes or indicators of quality of life. These include: physical health, in terms of both functional capabilities and symptoms due to disease or treatment, psychological health, both the cognitive and emotional aspects, and social health, in terms of interpersonal relationships and role functioning. This conceptualization of quality of life is consistent with the World Health Organization's definition of health as a state of "physical, mental and social well-being, and not merely the absence of disease and infirmity" (Feeny, Guyatt & Patrick, 1991; Kaplan & Anderson, 1990; Mosteller & Falotico-Taylor, 1989; Wood-Dauphinee & Kuchler, 1992).

The health literature uses the words health, health status, functional status quality of life and more recently health-related quality of life, interchangeably. The 1989 International Conference on the Measurement of Quality of Life as an Outcome in Clinical Trials recommended that the term health-related quality of life (HRQL) be employed when referring to health outcomes beyond the traditional outcomes of death and physiologic symptomatology (Feeny et al., 1991). Health
status, a measure of functioning in terms of physical, social and mental well-being, was judged to be too narrow in scope. It omitted the necessary element of subjective valuation by the patient. Functional status was also too narrow in scope, limited to a description of selected activities of daily living. On the other hand, quality of life as discussed earlier, was too broad and embraced a multitude of factors which reside in the basic social conditions of our larger world that are unlikely to be influenced by health-care interventions, and therefore are less useful for their valuation (Feeny et al., 1991, p. 266S). Health-related quality of life is the term preferred in this study. When this term is shortened to health or quality of life, it is done with the understanding that the definition still encompasses the person's level of physical, psychological and social functioning and perception of well-being.

Methodological and Measurement Issues

Inferences made regarding quality of life outcomes are constrained by the methodology and the measurement tool(s) selected in the evaluation process, so it is incumbent on the investigator to make these choices carefully. Methodological and measurement decisions should be determined after balanced consideration of the nature of the research question, the strengths and weaknesses of the alternate quality of life measures, and the availability of resources to address the question (Aaronson, 1988; McDowell & Newell, 1987; Read, Quinn & Haefer, 1987). The important methodological and measurement considerations are discussed below.

Viewpoint

There is a growing body of research that shows very little agreement between patient-assessed and provider- or public-assessed quality of life. Providers tend to equate quality of life with severity of illness. They believe that reduction of illness will result in improvement of quality of life. From the patients'
perspective, this analysis does not hold. In a study by Parkerson, Broadhead and Tse (1992), confinement, not severity of illness, was the strongest predictor of patient quality of life when assessed by the patient. The implication being that quality of life, from the patients' viewpoint, remains good as long as they are able to get out of the home and go about their usual activities, regardless of the severity of the illness.

Quality of life evaluations in health care are usually designed to inform and guide treatment by clinicians and therefore the patient's viewpoint is the preferred source. However, in some instances when the research is conducted to inform health planning and policy decisions, it can be argued that the relevant quality of life values are those of the general public (Drummond, 1987). A compromise position, to avoid both the neglect of, and the overreaction to, the needs of patients in health planning and policy decisions, is to complement the general public evaluations with patient evaluations to a degree determined by the prevalence and projected incidence of the target disease (Sackett & Torrance, 1978; Sisk, 1987).

**Quantitative or qualitative methodology.**

When the World Health Organization first introduced a definition of health in terms of physical, mental and social well-being it was criticized as unmeasurable, "but just as language molds the way we think, our health measurements influence (and are influenced by) the way we define and think about health" (McDowell et al., 1987, p. 14). In recent years the construct, quality of life, has been successfully operationalized and a wide variety of standardized health/quality of life measures have emerged. A bibliography of these instruments is available in Volume 28 (supplement 12) of *Medical Care* (Spilker, Molinek, Johnston, Simpson & Tilson, 1990).
Qualitative methods provide contextual understanding of the subjects' responses and qualitative elements are sometimes incorporated into standardized instruments. For example, a questionnaire might ask not only whether or not the subject is able to perform a set of physical activities it also probes the degree of effort and the personal satisfaction associated with the activity (Aaronson, 1988). However, a quantitative methodology is the dominant investigative approach in quality of life studies in health care. The strengths of quantitative methods are they produce factual, reliable outcome data that are usually generalizable to some larger population (Steckler, McLeroy, Goodman, Bird & McCormick, 1992).

**Generic or specific instruments.**

There is, at present, considerable variation in the quality and sophistication of the standardized health measurements available to assess health-related quality of life, which can be bewildering to researchers. Generic measures have been developed to evaluate the entire spectrum of HRQL attributes and, when there is interest in exploring just one attribute, disease or population in more depth, specific measures have been developed (Guyatt, Bombardier & Tugwell, 1986; Guyatt, Van Zanten, Feeny & Patrick, 1989).

Two classes of generic instruments include health profiles and utility measures. Health profiles break down the concept HRQL into a number of important attributes. Some commonly used examples are the Sickness Impact Profile (Bergner, Bobbitt, Carter & Gilson, 1981), the Nottingham Health Profile (Hunt, McKenna, McEwen, Williams & Papp, 1981), the Medical Outcome Study SF-20 (Stewart & Ware, 1992) and SF-36 (Ware & Sherbourne, 1992), and the Index of General Well Being Scale (Kaplan, Bush & Berry, 1976). Health profiles evaluate aspects of health relevant to all ages, races, sexes and socioeconomic backgrounds. They allow comparison between different populations or conditions.
The disadvantage is that they may not be sufficiently sensitive to detect small but important differences in health among subjects. Utility measures are derived from economic and decision theory. They measure quality of life holistically as a single number along a continuum from death (0.0) to full health (1.0). Some examples include the Time Trade-Off (Torrance, 1987), Standard Gamble (Torrance & Feeny, 1989), and Healthy Year Equivalents (Mehrez & Gafni, 1991). An advantage of utility measures is that they are useful for conducting an economic analysis. Some disadvantages are that they represent global quality of life as a single number which is very reductionistic and does not allow an examination of functioning in the different health domains.

Specific instruments are developed for a particular aspect of functioning, disease or population of patients. They potentially increase responsiveness (sensitivity), because they focus on aspects of health relevant to the disease or population under study are included. The Beck Depression Inventory (Beck, Rush, Shaw & Emery, 1979), and the Affect Balance Scale (Bradburn, 1969) are examples of instruments developed to explore emotional functioning in more depth. Some disease-specific instruments include the Kidney Disease Questionnaire (Laupacis, Muirhead, Keown & Wong, 1991) and the Arthritis Impact Measure (Meenan, Gertman & Mason, 1980). Other instruments are developed specific to children or the geriatric population.

Whereas instruments that are specific to a disease or that focus on only one quality of life domain may be a useful addition to a generic measure, on their own, they provide incomplete information on a person’s quality of life and it is misleading to label the results as quality of life outcomes. An example of the abuse potential is provided by Ferrans (1987) who reviewed the literature on the quality of life of hemodialysis patients. Studies that focused on objective indicators of quality of life
such as physical functioning and productivity in the workforce, reported evidence of a fair to poor quality of life for the majority of hemodialysis patients. Results from studies that focused on subjective indicators of quality of life such as happiness and life satisfaction showed evidence of a good quality of life for the majority of patients, comparable to the general population. Interpretation of quality of life data ultimately depends on how quality of life has been defined and operationalized in the study. Incomplete evaluations yield misleading results. Studies that examine both the objective and subjective domains of quality of life give a more accurate account of the quality of life of patients. Following this approach, Evans et al. (1985) found that the quality of life profile of hemodialysis patients was mixed. Dialysis patients have reduced quality of life on objective items (physical functioning), but a near normal quality of life on subjective items (affect, life satisfaction and well-being).

Mode of administration.

The majority of quality of life measures in use today are designed to be self-administered. However, they can usually be adapted for face-to-face or telephone interviews (Aaronson 1988). A limitation of the self-administered questionnaire is that subjects must be literate, and motivated to respond. In their defense, some authors believe that self-administered questionnaires place less pressure on the subject for immediate response and that this is a desirable feature (Selltiz, Wrightsman & Cook, 1976, p. 296). Self-administered questionnaires are also relatively inexpensive to administer and score. Whereas a personal interview approach may increase subject participation rates, they are more expensive in that they require interviewer training and supervision, they impose time and travel costs for both the interviewer and the subject and they necessitate tighter quality control to minimize interviewer bias and error. The major reservation about telephone
interviewing is that those people who have telephones, and are therefore eligible for participation in the study, may not be representative of the target population. Some people have unlisted numbers and some may not have telephones at all.

**Breadth vs. depth**

The breadth-depth phenomena refer to item selection within a quality of life instrument. Disease has a multidimensional impact on life and HRQL is appropriately viewed as a multidimensional concept with both subjective and objective features. Subjective features are the unobservable indicators such as pain and feeling states; objective features are the observable indicators such as ability to function (Evans et al., 1985; Feeny et al., 1991). Similarly, a quality of life instrument is characterized by a multidimensional structure that evaluates the domains of physical function, emotional well-being and social and role functioning. However, trade-offs are inevitable. Generally speaking, a broader selection of items within each domain is traded off against more depth in selected items. Ultimately, the choice around scope of measurement depends on the research question, and the acceptable burden on the respondent and/or interviewer. Instruments that cover a wider selection of items and permit a wider choice of responses will be more sensitive to differences over time and between patient groups but they will also be lengthy and time consuming to complete.

**Data (dis)aggregation.**

Different instruments offer different possibilities in terms of aggregating or disaggregating the data. Quality of life dimensions are conceptually distinct and can be measured and interpreted separately or combined to provide an overall score. A single summary statistic amenable to statistical analysis is useful particularly if there is interest in combining quality of life outcomes with clinical or cost data. However, a lot of valuable information is lost when scores are
aggregated. A global score might be too reductive for the research question. In large samples, the availability of computer scoring is clearly an advantage (Aaronson, 1988; McDowell et al., 1987).

**Scaling method.**

There is little empirical data to guide the choice between the various scaling methods. Response scales vary in complexity. The crudest approach to scaling is to rank order the responses in terms of severity and then to assign a numerical code to each response category. Category scaling can take the form of a dichotomous response (e.g., yes or no) or a Likert-type scale (e.g., never, some of the time, most of the time, always). Because people can only choose between a fixed number of adjectival responses and because people will use the same adjectives in different ways the actual value of the numbers assigned to the responses and the numerical distance between each category, hold no intrinsic meaning (McDowell et al., 1987, p. 20). Mathematically, only a straight count of the frequency of the responses is appropriate.

Scales such as the visual analogue scale use an interval scaling method which has greater mathematical power. Patients are asked to mark the point on the line that most closely corresponds to their experience. The scale is usually 10 cm in length with 0 representing the worst experience possible and 10 representing the best experience possible. One can add, subtract and determine averages with interval data because a change in scale value represents a constant interval change across the range of the scale.

Some measures, such as the Sickness Impact Profile, use an equal-appearing interval scaling method to produce an interval scale (Carter, Bobbitt, Bergner & Gilson, 1976). Numerical weights of severity are attached to the items in the measure by a sample of judges. After a consensus about the scale values is
obtained, data are collected to test scoring based on these scale values. Generally speaking, scaling will increase the discrimination, precision and sensitivity of an instrument.

**Range of measurement.**

A related consideration in selecting a quality of life measure is the range of measurement offered. Many quality of life measures developed for use in health care emphasize only the negative end of the health continuum. As Ware (1987) observes, this situation is analogous to a scale for measuring weight that ends at 100 pounds. The result is a substantial loss of information for those people who weigh more than 100 pounds. Instruments that permit measurement into the positive end of the health continuum are valuable particularly in populations of generally healthy individuals (Bergner et al., 1987).

**Question time frame.**

The time frame in a quality of life measure should be specified. Patients may be asked to reflect on their health during the past 24 hours, during the previous two to three weeks, or over the past year. Choice of time frame will depend on whether the investigator is interested in short- or long-term impact of the disease or treatment. Aaronson (1988) suggests that even in the case of long-term effects, the use of a relatively short question time-frame will minimize problems associated with memory loss and will avoid confounding specific symptom experience with a more generalized tendency to complain.

**Reliability.**

A measure should have established reliability i.e., it should be relatively free of measurement error and yield the same results when repeated in stable subjects. Synonyms for reliability include reproducibility, consistency, dependability, stability, predictability, precision, repeatability and generalizability.
The usual methods for determining reliability are inter-rater reliability (i.e., whether the instrument is consistent and different raters using the measure to assess the same respondent obtain the same result), test-retest reliability (i.e., whether the instrument is stable and the same result is obtained when the measure is applied a second time to the same respondent) and internal consistency analysis (i.e., whether there is homogeneity between items and equivalent forms of the same instrument yield similar results). No instrument is 100% reliable. Reliability coefficients are calculated with values between zero and one. Typical values fall in the range of 0.65 to 0.95 with a value above 0.85 considered satisfactory (McDowell et al., 1987, p. 33).

Validity.

A measure should also be valid i.e., it should accurately measure the concept in question, and the concept should be measured accurately. Validity is thought to be of three types: content validity (face validity), criterion-related validity (convergence validity, predictive validity) and construct validity. There is no rigid distinction between these three types of validity. Evidence of one type often supports evidence of another. Some experts view construct validation as the most comprehensive and complex level in the validation process, encompassing the other two levels (Grinnell, 1988, p. 118; McDowell et al., 1987, pp. 27-31; Stewart & Ware, 1992, pp. 309-317).

Content or face validity is a subjective judgment of the sampling adequacy of the items or questions included in the quality of life measure. Often, content validity is not tested formally. A common procedure is to ask experts to comment on whether the questions are meaningful, clear, relevant, reasonable and acceptable for inclusion in the questionnaire. The second type of validity - criterion-related validity - is based on studies of empirical relationships. It is the degree to which the
measure agrees with other accepted approaches for measuring the same characteristic. Establishing the criterion validity of quality of life measures has been a challenge because there is no absolute gold standard against which the new measurement may be compared. Most authors establish criterion validity by convergence of methods i.e., the new and an established measure are applied to the same sample to see if the responses are concordant. Construct validity is the degree to which an instrument successfully measures the theoretical construct. Construct validation is a very involved procedure using evidence from several validation procedures such as factor analysis, multitrait-multimethod approaches and convergent-discriminant tests to determine whether the quality of life concept is being measured by the instrument in hypothesized ways and that the instrument does not measure what it is not intended to measure. The correlation of health-related quality of life measures with clinical status measures of chronic medical conditions is a type of construct validity because certain measures of HRQL can be hypothesized to be correlated with certain clinical measures of chronic medical conditions.

**Sensitivity.**

Instrument sensitivity or responsiveness refers to the instrument's ability to correctly detect important changes in quality of life. Adequate sensitivity is a key requirement in a HRQL measure. Measures shown to be sensitive in one population or treatment group should not be assumed to be sensitive in differing populations or treatment groups. In comparative studies, the requisite sensitivity is dependent on the expected treatment effect size - the smaller the effect size, the greater the required sensitivity of the measure (and the larger the required sample size). If the sensitivity of an instrument is unproved we do not know whether the
lack of a reported change is because the treatment is ineffective or the instrument is insensitive.

Sensibility.

Feinstein (1987) refers to sensibility as "enlightened common sense" (p. 144). The sensibility of an instrument refers to the match of the instrument with the purpose of the research considering the practical constraints and the resources available to conduct the study. The length of the instrument, the mode of administration and the projected burden on the respondents, the interviewers, and the institution should be estimated. The statistical expertise available for analysis is another important consideration. In many ways research is the art of the possible.

Summary

It is unrealistic to expect one single instrument to provide all the health information required in quality of life outcomes studies. Large population surveys of generally healthy people require a general health measure concentrating on the positive end of the health continuum; a trial investigating a treatment for relatively sick people requires measures concentrating on the negative end of the health continuum; treatments for specific diseases require measures sensitive enough to detect small changes in functioning; studies on resource allocation questions require utility instruments that combine quality with quantity of life. Given the newness of the field it is prudent to apply more than one measurement in order to reinforce the conclusions of the study and to increase understanding of the comparability of the measurements in use. Most authors recommend that existing instruments should be employed wherever possible, thereby facilitating comparison of results and evaluation of significance of the results across different studies (McDowell et al., 1987; Spitzer, 1987). The measure selected should be
reliable, valid, responsive, easy and inexpensive to administer, acceptable to patients, and understandable to the health care professional. When a new measure is required, its design should be based on a careful analysis of the strengths and weaknesses of previous scales.

Role of Employment in Adult Life

A review of the literature on the role of employment in adult life begins with a discussion of the value and importance of work in Western society. Then the factors that contribute to employment activity are explored followed by a discussion of the factors which could be important in moderating the negative psychological effects of unemployment.

The Value and Importance of Work

The work role is a major life role for both men and women in our society. Western society endorses the belief in self-sufficiency through work. In a report for the Canadian Mental Health Association, Kirsh (1983) writes that to be accepted as responsible members of society, adults must complement their home world with a work world and a wage (p. 81). There are a number of benefits associated with employment that lend support to the belief that getting people back to work is a good thing. These include:

1. Improved quality of life for the individual. Employed people generally have better social support networks, higher levels of personal satisfaction, self-esteem and general well-being than non-employed people (Adelmann, Antonucci, Crohan & Coleman, 1990; Kessler, House & Turner, 1987; Young, 1985). Employment has been found to associated with life expectancy. Results from the National Longitudinal Mortality Study for 1979-1985 showed the largest differences in life expectancy were between employment categories (Rogot, Sorlie & Johnson, 1992). At age 25, white men in the labour force lived on average about 12 more
years than those not in the labour force, and white women lived on average about 9 more years. Differences in life expectancy were also associated with amount of education and family income. As schooling increased, life expectancy increased. At age 25, there was an estimated 6 year difference in life expectancy between the highest and the lowest levels of education completed for white men, and about 5 years for white women. For family income, differences between the highest and the lowest income groups were about 10 years for white men and 4.3 years for white women. The sample was comprised of 822,347 white persons who were not institutionalized. Levels of functional health were not analyzed.

Paid employment provides outlets for physical and mental energy; it allows the individual to move between at least two physical worlds (home and work) and two sets of routines and responsibilities; the perceived contrasts between work and domestic activities can enhance the perceived value of both (Warr, 1982). Survey data from a national random sample of 2,264 adult Americans showed that 84% of men and 77% of women would work even if they did not have to (Pottick, 1989).

2. Advantages to the household in terms of increased income and insurance benefits. Joblessness contributes to poverty for many people with chronic health problems and disabilities. Although the direction of the relationships between employment, poverty and chronic disability is not well understood, Vachon (1987) estimates that 70% of poverty among certain groups of Americans is the direct result of disability via loss of a job.


4. Advantages for the public sector. Employed people contribute to the public sector through tax revenues and lower government expenditure on social
programs. Without employment or another alternative for obtaining an income, people with chronic conditions create a strain on income-maintenance programs.

Some people have started to question the accepted wisdom that employment is good for most or all people. Despite the many potential advantages of working, employment is not life enhancing for all individuals nor do unemployed individuals always become an economic burden on society. These observations are discussed below:

1. There is growing recognition of the negative impact on health from some forms of employment. Many jobs are tedious, stressful and some are even life-threatening. Employment may contribute to poor health either directly, as with occupational accidents and occupational diseases, or indirectly, as with occupational stress and environmental pollution (McKenna and KcEwen, 1987).

2. Role conflict is a common problem for working parents. The physical and emotional strain of balancing home and work responsibilities may cancel out any feelings of job satisfaction or personal fulfillment associated with employment. On balance, the human cost when a spouse works outside of the home, in terms of lost companionship and support, may not be worth the economic benefits to the household.

3. Regarding the potential economic cost to society, there is controversy over whether in times of high unemployment it actually benefits the economy to employ people with chronic health problems. These people may have increased absenteeism and reduced productivity. In times of high unemployment, when an individual is absent from work due to illness, there are plenty of people willing to fill the void. From an economic viewpoint it might be more profitable to retain the replacement worker, than to rehire the chronically ill worker. Williams (1992) observes that initially there may be "some small ‘frictional’ losses while the system
readjusts, but at the end of the day each sick person ‘off work’ will have been replaced by some otherwise unemployed person now ‘in work’, and the gross national product will be virtually unchanged” (p. 9).

Factors that Contribute to Employment

As a society we tend to blame people for their unemployment, and people without jobs are perceived as unproductive and less valuable human beings (Kirsh 1983, p. 81). This view, that unemployment is an individual problem, detracts attention from the complexity of the issue and results in ineffective solutions. Like most of human behavior, the decision to enter, reenter or retain one’s position in the workforce has more than one cause and more than one purpose.

Participation in the workforce is influenced by many psychological, social, medical, and environmental factors. Work holds different meanings for different people. For the individual, work may be variously viewed as affliction, addiction, fulfillment or exchange (Kahn, 1991). The personal value and meaning we attach to work will impact on our motivation to work. The existence of a strong social support network is also an important factor (Auslander, 1988). Medical factors, such as disease symptomatology and functional abilities, are clearly linked to employment. People in poor physical and mental health are less likely to seek, obtain, continue in or return to paid employment than their more healthy counterparts (Adelmann et al., 1990). However, we also observe work disruptions in the absence of poor health (Ware, 1984).

Schechter (1981) examined American Census data to identify the main factors contributing to employment behavior in a sample of disabled Americans surveyed in 1972 and 1974. The combined data showed that compared to those not working, employed people were more likely to be male, younger age, needed to provide financial help to relatives, had more years of predisability work
experience, and had a less severe level of health problems. Contrary to public belief, there was no evidence that income-maintenance programs were a disincentive to working among the severely disabled. According to Schechter, the major substantive conclusion that emerged was that previous work experience is central in the work response to disability. The amount of work experience prior to onset of illness, independent of age, predictably affected employment outcome after disability.

Roessler (1989) explained work response of people who experience mid-career disabilities from three perspectives. Based on social learning theory, return to work will occur when people have the necessary work skills and believe in their ability to succeed. According to instrumental theory, action to obtain work will occur when the prospect of work provides people with something they value (steady wage, security, social recognition, identity). Before deciding to seek employment, a consideration of how working will affect existing financial and medical benefits is an important consideration as is the impact of work on physical and mental health. People seek employment based on the probability of a successful outcome and/or the utility of the outcome and/or the costs associated with the outcome. Green and Kreuter (1991) categorize the factors affecting human behavior as predisposing, enabling and reinforcing. To use their model, work activity will likely occur when the individual is predisposed to work, has the necessary resources to work, and receives positive reinforcement for working.

**Factors that Moderate the Negative Effects of Job Loss**

The negative effects of job loss upon physical health and well-being of the individual and family are well documented in the literature review by Murgatroyd and Woolfe (1982, pp. 95-97). Whereas physical resources depreciate with use, human resources depreciate when not in use. Warr (1982) discusses several
moderating factors which may influence the strength of the association between employment status and health. These include length of unemployment, age, work involvement, gender, occupational status, financial position, family unemployment, social support networks, local levels of unemployment, hobbies and personal interests.

The role of work in the context of the person's life is key. Many people report very full and satisfying lives without actively participating in the workforce. Engagement in activities that are personally meaningful seem to be particularly important to well-being whether the activity be work or leisure pursuits (Haworth and Evans, 1987, p. 242).

Although there are justifiable reasons to be concerned about the employment rate of people with kidney transplants, it is not a homogeneous problem. Within the group of employed transplant recipients there will be some individuals who are satisfied and find fulfillment in their work situation and some will be dissatisfied and unhappy. Likewise, within the group of unemployed people some individuals will be satisfied and involved in other meaningful activities and some will be psychologically devastated with their unemployed status. No single theory satisfactorily explains the phenomenon. Theories that explain the health effects do not tend to encompass data on the subjective meaning of employment. Theories concerned with social comparisons do not deal with the phenomena of intra-psychic conflict. Theories about alienation as a consequence of the division of labour are unsuitable for explaining individual differences in attitudes to work (Jahoda, 1982).

**Review of Patient Outcomes in Kidney Transplantion**

Transplantation did not come into its own as the treatment of choice for end-stage renal disease until the introduction of the immunosuppressant, cyclosporine,
in the 1980s. The following review covers North American studies, published after 1980, examining the quality of life and employment outcomes of renal transplant recipients and the main factors or characteristics associated with positive outcomes. Care must be taken in reviewing studies on quality of life because of the different criteria for judging quality of life. Finding differences in quality of life are dependent largely upon how the construct is defined. Until recently, quality of life was poorly conceptualized, and its meaning and measurement varied dramatically from one study to another depending on the investigator's personal values and underlying motivations. Some definitions focussed on subjective criteria of quality of life such as feelings of well-being and life satisfaction; some focussed on objective criteria such as physical functioning; other definitions focussed on dimensions such as employment and other social and role activities. Although the majority of the studies reviewed are quantitative in design and use standardized questionnaires to evaluate quality of life, the results are not directly comparable since a number of different instruments were used. Studies that selected instruments that evaluate the emotional dimensions of quality of life show excellent life quality for the majority of patients - in many studies, similar to that of healthy persons. In contrast, studies that selected instruments to capture lifestyle and major life roles such as employment report only good to fair outcomes for the majority of patients.

In 1985 Evans and his colleagues published a landmark study in the New England Journal of Medicine on the quality of life of ESRD patients from 11 dialysis and transplantation centers throughout the United States (Evans et al., 1985). Data were obtained from 144 transplant recipients and 715 patients receiving maintenance dialysis. Both objective indicators of quality of life and subjective indicators were analyzed. Functional impairment based on the Karnofsky Index
and the perceived ability to work at a job for pay were defined as the objective indicators of quality of life. The subjective indicators included psychological affect, well-being and life satisfaction as measured by the instrument used in the work of Campbell, Converse and Rodgers (1976, pp. 519-564). When treatment modalities were compared, the successful kidney transplant group reported a better quality of life outcome than the dialysis group. In fact, the subjective quality of life of transplant recipients did not differ significantly from that of the general population. Transplant recipients had less functional impairment than any other ESRD treatment modality. An analysis of scores (that were not adjusted for case mix) showed that 74.1% of transplant recipients said they were able to work compared to 59.3% of home hemodialysis patients, 37.2% of in-center hemodialysis patients and 24.7% of continuous ambulatory peritoneal dialysis (CAPD) patients. No comparative general population data were available for the objective variables of functional impairment and ability to work. However, when actual labour force participation rates were compared, the transplant group rate was 53.5% compared to a labour force participation rate of 63.8% for the general population. The authors concluded that kidney transplant recipients were not returning to the work force at the expected rate. Others might question this interpretation of the study findings, i.e. is it realistic to expect equal employment outcomes within a population of people with a chronic disease?

An earlier study by Johnson et al. (1982) combined physiologic with psychological measures to assess the quality of life of 59 patients (20 transplant patients and 39 dialysis patients). Questions were drawn from the Campbell, Converse and Rodgers Index of Well-Being and Life Satisfaction and The Social Readjustment Rating Scale devised by Holmes and Rahe. The psychological functioning of successful transplant patients compared favorably with national
norms. Transplant patients also showed greater physical and occupational rehabilitation than patients on chronic hemodialysis. Since the sample was small and nonrandom, the authors were cautious in making any strong conclusions about their results. However these early findings are in concordance with results from later studies.

In a study by Simmons et al. (1988) of 766 nondiabetic ESRD patients between the ages of 19 and 55, questionnaires were analyzed from 91 kidney transplant recipients at one year post-transplant, 82 long-term transplant recipients, 510 CAPD patients and 83 in-centre hemodialysis patients. Physical, emotional and social well-being was assessed. Successful transplant patients had a higher quality of life than either CAPD or hemodialysis patients. There was almost no difference between the long-term and the one-year transplant groups. The employment rate for the sample of transplant recipients at one-year was 51.6% Among male transplant recipients, 64% were working full-time and among females, 31% were working full-time.

Bremer et al. (1989) studied the quality of life of a representative sample of 187 transplant patients and 302 patients on dialysis from 59 renal centres in a US network. Quality of life questionnaires included subjective measures (Bradburn Affect Balance Scale and the Campbell, Converse and Rodgers Index of Well-Being and Life Satisfaction) and objective indicators included items such as participation in the workforce and hours per week seeking medical care. They found that successful transplant patients reported significantly higher levels of positive affect than the general population norm. Approximately 53% of transplant recipients were working full or part-time compared to between 6 and 46% for dialysis patients. The mean number of hours spent seeking medical care in a week was approximately 2 hours for transplant patients and between 10.5 and 16.8
hours for dialysis patients. The authors concluded that except for diminished employment, successful transplant patients have a nearly normal quality of life.

The Medical Outcome Study Short-form General Health Survey was used in a pilot study by Singer et al. (1992) to measure the comparative health outcomes in 41 hemodialysis patients and 42 transplant recipients. Successful transplant recipients scored better than dialysis patients on all six domains of functioning and well-being. The authors intend to pursue this enquiry using the SF-20 scores as the dependent variable in order to determine which independent variables (sociodemographic variables, co-morbidity, laboratory tests) are predictors of health.

An exploratory/descriptive study to assess the quality of life changes following renal transplantation and to determine if staff or patients more accurately anticipate these changes was conducted by Hauser, Williams, Strong, Ganza and Hathaway (1991). Thirty-nine transplant recipients were interviewed at the time of transplant and again between sixteen and twenty-six months post-transplant. The investigators used the chronic illness and quality of life conceptual framework of Strauss and Glaser to study quality of life. The most significant finding was that over 80% of the patients reported they were able to resume previous activities after transplant. Both patients and staff were accurate in their expectations of the number of negative quality of life changes that would occur after transplantation. The patient, on the other hand, grossly underanticipated positive changes.

Using the Time Trade-Off approach to prospectively measure changes in quality of life in a sample of 27 patients before and after transplantation, Russell Beecroft, Ludwin and Churchill (1992) reported a difference in mean TTO scores of .33 (an increase from .41 to .74). This large, clinically important, and statistically significant improvement in TTO scores was found in 20 of 27 patients emphasizing
the consistency as well as the size of the effect produced by successful transplantation. The small sample size precluded the use of an analysis of covariance to examine whether factors other than type of treatment could account for the observed difference in TTO scores. Employment status was also determined. Employment was defined as full-time work for a pay. The proportion of patients working after transplant was 71% compared to a proportion of 44% pre-transplant. The authors note that the increase of 27% was not statistically significant.

In general, younger, more educated patients score more favourably on both objective and subjective dimensions of quality of life (Evans et al., 1985; Simmons et al., 1988). Duration of treatment is not a significant determinant (Evans et al., 1985; Simmons et al., 1988).

The factors that may contribute to successful employment were reviewed in a historical study of 142 renal transplant recipients by Flores and Callender (1987). Positive outcome was associated with: (a) a satisfactory home environment and work experience at the time of transplant; (b) a high degree of self-motivation; (c) higher education; (d) younger age; and (e) involvement with physical therapy, occupational therapy, social work or vocational rehabilitation counsellor early in the pretransplant stage. They also identified some of the factors that were barriers to employment such as: (a) the constant threat of rejection, and the uncertainty as to long-term prognosis; (b) the unavailability of former jobs; (c) high dependency needs after years of assuming the dependent role as dialysis patient; and (d) structural disincentives of the system.

Erickson (1989) in an unpublished employment study commissioned by the Ontario branch of the Kidney Foundation of Canada, surveyed 686 ESRD patients from the Toronto area. Of this total, only 175 questionnaires were analyzed.
reflecting a poor response rate of 25.5%. Erickson reported that 64.6% of the 97 transplant recipients were working full- or part-time. She found significant associations of employment with younger age, higher education and better health. The issue of structural disincentives in society as a potential barrier to employment was discussed. Erickson noted that due to the eligibility criteria of the Canada Pension Plan Disability benefits, it may be in a transplant person's financial interest to remain on disability payments rather than seek employment. A person's future health status remains uncertain even after a successful transplant. If the transplant were to fail after the person had returned to work, he or she may not have contributed long enough to be eligible for the Canada disability pension for a second time.

Multivariate data analysis techniques were used to examine the contributing factors to employment in 302 transplant recipients from five U.S. centres in a recent analysis of the data from the Battelle Research Institute (Evans et al., 1990). Data were available for 226 patients (a response rate of 74.8%). A multiple regression model was estimated for those patients who had retained their original grafts. Using this model, the variables found to be statistically significant and positively associated with employment were as follows: age less than 60 years (p < .05), male (p < .001), nondiabetic (p < .001), physical health status as measured by the Sickness Impact Profile (p < .05), and a college degree (p < .05). The length of time since transplant did not have a significant effect on employment status, although the relationship between employment and time since transplant was in the expected direction. Patients who had a functioning transplant for more than three years were more likely, although not significantly more likely, to be working than patients who had retained their grafts for less than three years.
Jones and colleagues (1992) studied the impact of renal transplantation in 312 adults from Minneapolis. They reported a trend for more patients to be employed post-transplant but the change in employment status from pre-transplant (53% employed) to post-transplant (58% employed) was not significant. Recipients receiving disability payments pre-transplant were likely to continue to receive payments post-transplant. They concluded that pre-transplant employment status was a major predictor of post-transplant employment status.

Most studies exploring the issue of employment are based on the experience in the United States. The lack of Canadian data is significant in that one might expect the circumstances of people with kidney disease in Canada to differ from those in the United States due to the different medical and social programs that are available. No studies were found on the employment status of people in British Columbia following renal transplantation.

There is need for more systematic study of the degree of disability and the employment status of Canadian transplant recipients as well as an analysis of the variables that are most strongly associated with employment. Based on the literature review, the important variables to consider are sociodemographic variables (age, gender, education, previous work experience), health-related variables (functioning, and the underlying disease of diabetes), psychological variables (personal motivation to work) and environmental variables such as the availability of jobs. It is hypothesized that younger, nondiabetes with some post-secondary education, good health and personal motivation to work will be in the employed group of transplant recipients.

In the following chapter, the method and procedures that were used to guide this study are described and presented.
CHAPTER THREE

Methods

Introduction

In this chapter the research design, sampling procedure, data collection instruments, data collection procedures, limitations, ethical considerations, and the statistical procedures for data analysis are presented and described.

Research Design

A combination of methods was used to answer the research questions in a two-stage process. In stage one, a quantitative cross-sectional survey design was used to (a) describe the perceptions of renal transplant recipients concerning their health-related quality of life, (b) to estimate the proportion of renal transplant recipients who are employed, and (c) to determine the most significant health and sociodemographic factors that distinguish the employed from the not employed. The results from this survey raised questions about other factors that might be important in determining employment status. To explore further the characteristics associated with employment outcomes a phenomenological approach using personal interviews was taken in stage two. This between- or across-method triangulation was done to add breadth and depth to the analysis and increase the validity of the findings (Denzin, 1978, p. 291).

Sampling Procedure

The target population for the study was adult kidney transplant recipients in the province of British Columbia. In order to control for variations in work potential due to geographic location, age, and unstable kidney function, the following inclusion criteria were used:

1. The subjects were adults of working age at the time of the study (i.e., between 18 and 65 years of age).
2. The subjects were residing in the lower mainland of BC.
3. The subjects were at least six months past the date of transplant surgery.
4. The subjects had stable graft functioning as indicated by a serum creatinine of 50-400 umol/L.

These eligibility criteria were readily available from the data base of the British Columbia Transplant Society (BCTS). Of the 566 renal transplant recipients living in BC, the number of eligible transplant recipients for this study was 315.

In stage two, an additional eligibility criterion included literacy in the English language. This criterion was necessary as subjects would be interviewed by an English-speaking interviewer. A purposeful sample of four employed and three unemployed transplant recipients was selected using a maximum variation sampling strategy. Kidney transplant recipients are a heterogeneous population. They come from different socioeconomic and cultural backgrounds and they have diverse personal goals and aspirations. A maximum variation sampling strategy selects cases that are diverse and that reflect the heterogeneity of the population. The purpose was to describe the variation in the sample, and to capture the unique experiences of each case while also exploring the common themes and patterns that emerged (Patton, 1990, p. 174).

**Instrumentation**

**Stage One: Health and Employment Survey**

Two data collection instruments were combined to form the Health and Employment Survey (see Appendix A): (a) the Medical Outcome Study Short-form General Health Survey (MOS SF-20) was used to measure health-related quality of life, and (b) a questionnaire designed by the researcher captured relevant socioedodemographic and employment information.
Medical Outcome Study Short-form General Health Survey (MOS SF-20).

The Medical Outcome Study Short-form General Health Survey is a self-administered multidimensional measure of functional health and well-being (Stewart, Hays & Ware, 1988). The SF-20 is a comprehensive, psychometrically sound, short, simple to use instrument. It asks 20 questions and takes about four to five minutes to complete (Appendix A, questions 1-7). Each respondent receives a score on six dimensions of health: physical functioning, role functioning, social functioning, mental health, health perceptions and pain. The SF-20 contains items on both the positive and the negative end of the health continuum which is useful in surveys of generally healthy people such as stable kidney transplant recipients. All scores are recorded on an interval scale of 0 to 100, with higher scores indicating better health. The definitions and procedures for combining these items are summarized in Table 1 (see Table 1 next page).

Comparison group norms are available for the general population, people with no chronic illness, and several other chronic disease conditions such as hypertension, diabetes, arthritis, and angina. The MOS SF-20 internal-consistency reliability coefficients for the dimensions range from .81 to .88; reliabilities are as good in subgroups of patients with different chronic conditions, as they are in the general population (Stewart et al., 1989). Preliminary tests of validity have been done including product-moment correlations of the short-form MOS with a long-form MOS. All correlations were statistically significant (p< 0.01). The instrument was successful in discriminating between patient and general population groups. Correlations with sociodemographic characteristics were consistent with results using longer form measures. As an example, older people tended to report poorer health and people with more education and income tended to have better health (Stewart et al., 1988).
Table 1

**Definition of Medical Outcome Survey Health Variables**

<table>
<thead>
<tr>
<th>Health Variable</th>
<th>No. of Items</th>
<th>Definition</th>
<th>Survey Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>6</td>
<td>Extent to which health interferes with a variety of activities (e.g., sports, carrying groceries, climbing stairs, and walking)</td>
<td>2a - 2f</td>
</tr>
<tr>
<td>Role functioning</td>
<td>2</td>
<td>Extent to which health interferes with usual daily activity such as work, housework, or school</td>
<td>4, 5</td>
</tr>
<tr>
<td>Social functioning</td>
<td>1</td>
<td>Extent to which health interferes with normal social activities such as visiting with friends during past month</td>
<td>6a</td>
</tr>
<tr>
<td>Mental health</td>
<td>5</td>
<td>General mood or affect, including depression, anxiety, and psychologic well-being during the past month</td>
<td>6b - 6f</td>
</tr>
<tr>
<td>Health perceptions</td>
<td>5</td>
<td>Overall ratings of current health in general</td>
<td>1, 7a - 7d</td>
</tr>
<tr>
<td>Pain (a)</td>
<td>1</td>
<td>Extent of bodily pain in past 4 weeks</td>
<td>3</td>
</tr>
</tbody>
</table>

**Note.** (a) This scale is scored so that a high score indicates better health (i.e., the absence of pain).

**Sociodemographic and Employment Questionnaire**

The sociodemographic and employment items included in the Health and Employment Survey were based on a review of the literature and in consultation with two social work colleagues currently working in the renal transplant programs at Vancouver General Hospital and St. Paul's Hospital. Some items were
borrowed directly from previous employment surveys conducted by Erickson (1989) and Evans et al. (1990). Sociodemographic questions included marital status and level of education. Employment questions included current employment status, type of employment, satisfaction with current job, need for job modifications due to health and type of modification, employment status in year before transplant, main reason for not working, satisfaction with the amount of work being done, source of income, ever-employed status, and years of previous employment. Supplementary information on the respondent’s age, gender, ethnic origin, primary diagnosis of diabetes and length of time since transplant surgery was retrieved from the BCTS data base using the respondent’s personal identification number.

The majority of the response options for the sociodemographic and employment questions were fixed and pre-coded. For some questions, such as the main reason for not working, the response option *other* was available. Branching questions were used where appropriate to allow respondents to avoid irrelevant questions (see Appendix A, questions 4, 6 & 12).

A series of small pretests of the Health and Employment Questionnaire were conducted on five transplant recipients during a regular clinic appointment at Vancouver General Hospital. In order to simulate delivery by mail, no additional explanation of the questionnaire was provided beyond the written information contained in the letter of explanation. Based on the comments from these five patients, the questionnaire appeared to have face validity. The patients showed no reluctance to answer any of the questions. They found the items to be relevant and easy to answer. Minor revisions were made around the ordering and phrasing of some of the questions in the employment section. No changes were made in the health section of the questionnaire (SF-20) since changes would have affected the instrument’s previously established validity and reliability. Patients were asked to
choose between two different formats: printed material on one or both sides of the paper. Four of the five patients surveyed preferred printed material on both sides of the paper for environmental reasons and that format was used in the final version.

**Stage Two: Personal Interview**

A semi-structured interview guide and a patient contact form were developed in order to collect the data from the personal interviews with patients (see Appendix B). The interview questions were developed based on the literature review (chapter two) and the conceptual model illustrated in Figure 1 (Chapter one). As suggested by Brink (1991, p. 169) the questions were written in such a way as to avoid acquiescent response sets or agree-disagree response modes.

The interview guide was pre-tested. Two transplant recipients were asked to comment on the clarity, the relevance and the completeness of the questions. Following the pre-test the opening question was narrowed from “If I were to follow you through a typical week what would I see you doing?” to “Please describe your current work situation”. Although the first version provided some interesting detail on the patient’s lifestyle, it did not focus the interview quickly enough on the specific research question (employment experience), and the interview became too lengthy. In order to improve the content validity of the interview guide and remain sensitive to the time burden on the subjects, a more focussed, direct approach was preferred. The final interview guide included the following questions:

1. Please describe your current work situation.
2. Past experience with work? (ex. years worked prior to illness, type of work)
3. How important is it that you participate in the workforce?
   **probe:** what are the benefits to you? The disadvantages?
4. Has your attitude to work changed since your illness?
5. What makes it possible for you to work / what is going to help you find work?
6. What for you is a barrier to work / in seeking work?
7. What other activities are important in your life?
8. Background questions: age, education, occupation, marital status, years since diagnosis and years with transplant?
9. Is there anything you wish to add?

The questions were written according to the sequencing suggested by Patton (1990, p. 294). The interview began with non threatening questions that describe the subject's current work situation. It then moved to discuss attitudes to working and whether these attitudes are different today than before the diagnosis of renal failure. Background questions concerning the subject's age, education, occupation, marital status, years since diagnosis and years with transplant were asked at the end of the interview if this information did not come out naturally during the interview process.

**Data Collection Procedures**

**Stage One: Mailed Questionnaire**

Participants in this study were obtained through the BCTS provincial data base. Permission was granted by the BCTS director for the data management staff to conduct a computerized data base search to identify adult transplant recipients who lived in the lower mainland, were at least six months past the date of transplant surgery, and had a serum creatinine of 50-400 umol/L. The computer search generated a list of patient names, addresses, and labels for mailing. Based on these criteria, the total number of eligible respondents for stage one of the study was 315.

All eligible respondents were mailed a packet with an enclosed pre-addressed, stamped return envelope. Each packet contained a letter of information explaining the purpose of the study and requesting their participation (see
Appendix C). Patients were informed that a returned questionnaire was a proxy for informed consent. A coded questionnaire was also included in the packet. The BCTS patient registration number was used as the patient code for this study. In order to improve the response rate a follow-up letter was mailed to all potential respondents two weeks after the initial mailing (see Appendix D). As the questionnaires were returned to the study centre, the patient registration numbers were matched to the master list and the nonresponders were identified. Four weeks after the initial mailing a follow-up telephone call was made to urge delayers in responding and to provide any assistance that may be needed in answering the questions (see Appendix E).

Stage Two: Patient Interview

Participants for the second phase of the study were obtained with the assistance of the renal transplant social worker from Vancouver General Hospital. The social worker identified ten potential subjects, from diverse backgrounds, who met the eligibility criteria. Potential study subjects were mailed a letter of information explaining the purpose of phase two of the study (see Appendix F) and a patient consent form (see Appendix G) was included. Patients were informed that the study investigator would be contacting them by telephone to discuss their willingness to participate (see Appendix H). An appointment time for the interview was set up with the first four employed and three unemployed patients who consented to participate. Patients were offered a choice of home or office interview. The office interview was conveniently located in a shopping mall one block from Vancouver General Hospital. Patients found this location to be most convenient. All interviews ended up being done in the BCTS office in City Square.

The interviews lasted between 40 and 60 minutes. They were audio-recorded, and transcripts were made for purposes of analysis (see Appendix I for
example of an interview transcript). Subjects were assured their confidentiality would be respected by using a code to identify them. The subjects were also informed they would have access to the thesis results, upon request, at completion of the study.

Patton (1990) writes of three basic approaches to collecting qualitative data in open-ended interviews: the informal conversation, the general interview guide, and the standardized open-ended interview (p. 280). The interview procedure employed in this study was the general interview guide approach. The interview opened with the first question in the guide and an effort was made to follow the sequencing of questions, but the wording of the questions were not precisely as written and some additional questions were asked if they seemed appropriate or important in the context of the actual interview. The outline of questions served only as a general guide to ensure all relevant aspects were covered. The patient contact summary form was reviewed at the end of the interview. Any demographic items not captured in the actual interview were obtained at the end of the interview.

Assumptions

It was assumed that all subjects were able to identity and comment on their health-related quality of life. Although many transplant recipients do not work, it was assumed that all will have considered the idea of participating in the workforce at some point in their lives and therefore they would be able to communicate their thoughts and opinions about the phenomenon. It was also assumed that the data emerging from the mail survey and the personal interviews were a truthful representation of the subjects' experiences.
Limitations

Many features of this study have potential limitations that may affect the validity, reliability and the generalizability of the findings. A discussion of these limitations follows:

1. A cross-sectional research design was used in stage one of this study. A major limitation of this study design is the difficulty verifying employment outcomes when information is collected at only one point in time.

2. A case-control study approach was used to identify predictor variables that may explain why some subjects were employed and others were not employed. This approach has potential bias in identifying predictor variables. Only those variables selected for inclusion in the survey questionnaire were introduced into the regression model. The data from the personal interviews in stage two was intended to validate and to expand on the set of characteristics that were most strongly associated with employment from the survey data obtained in stage one. However, this validity check was limited. Only one interview was conducted with a total of six subjects. Had time permitted, a larger sample size and subsequent interviews with each subject would have been useful to validate the concepts arising out of the single interview.

3. The cultural dimension of the transplant population may not be adequately represented in this study. The cultural limitations of standardized quality of life questionnaires such as the SF-20 are well documented in the literature. Hunt et al. (1986) notes that the use of questionnaires and surveys is so fully accepted in western countries that it is easy to forget that these methods depend upon several presuppositions: that the majority of people are literate, that the respondents share common values in relation to health and that standardized questions and forced choice answers are understandable and acceptable to them.
Cultural limitations in phase two of the study arise due to the unilingual nature of the interviewer. The personal interviews were conducted with only English-speaking transplant recipients.

4. Self-administered questionnaires introduce sources of error that can bias the results: (a) subjects vary in their interpretation and understanding of questions; (b) the different personality traits of subjects may mean that some patients minimize their problems while others exaggerate them; (c) there is a tendency for some subjects to respond in a socially desirable manner; and (d) some subjects may have a response set that results in their choosing the end position on the response scales, while others may prefer the middle. However, the sample size for this survey was quite large which should help reduce error that stems from the variability between subjects.

5. In the qualitative component of this study, the characteristics, style, influence and skill of the researcher/interviewer plays an integral part in establishing the validity and reliability of the results. The interviewer in this study was relatively inexperienced in qualitative interviews. In an effort to reduce potential bias in the recording of the data from the personal interviews, the actual interview was audiotaped and transcribed. However, due to a lack of time and resources, there was no validity check by the patient or a researcher partner on the descriptive themes that emerged from the data.

6. There are limitations to the generalizability of the results from this study. In stage one, the focus of the mail survey was adults between 18 and 65 years of age with a stable kidney transplant living in the lower mainland of BC and as such, the findings based on the 216 respondents are not generalizable to all 566 kidney transplant recipients in BC. In stage two, the symbolic meaning of the data is intersubjective - specific to the individuals under study and time bound
(Anderson, 1991, p. 29). Although this characteristic does not minimize the usefulness of the personal interview data in broadening our understanding of the phenomenon under study and in making “logical” generalizations, the small sample size and the qualitative methodology does not permit the results to be broadly generalized (Patton, 1990, p. 175).

**Ethical Considerations**

Permission to conduct this study was obtained from the University of British Columbia Behavioral Sciences Screening Committee for Research and other Studies Involving Human Subjects. Permission was also obtained from the Director of the British Columbia Transplant Society and the Vancouver General Hospital Research Committee.

All of the potential study participants received a letter of information outlining the purpose of the study and the nature and extent of their involvement. They were informed in writing that they were under no obligation to participate and that a decision to not participate would have no affect on their future care.

Anonymity and confidentiality were maintained throughout the study. Patient identification numbers were used in place of names on the questionnaires and on the interview transcripts. Any information that might identify the patients was not used.

**Data Analysis**

**Stage One: Quantitative Analysis**

To determine whether there were any systematic differences between responders and nonresponders, data from the BCTS data base was used to compare patients who completed the questionnaire with those who did not based on age, gender, race and primary diagnosis of diabetes.
The data from the mail survey was entered on a Macintosh personal computer using the spreadsheet program Excel. They were manually checked for errors, cleaned and then transported to the statistical program, Systat for preliminary descriptive information and exploratory analysis of associations between variables.

To address the first research question pertaining to the health-related quality of life of kidney transplant recipients and how it compared to the general population, descriptive statistics were used to present the frequency distribution and the mean scores for each of the dimensions of the SF-20. The health profile of the renal transplant group was compared to the health profile of the general population reported in Stewart et al. (1989).

To answer the second question, frequency tables and appropriate measures of central tendency and dispersion were used to describe the employment outcomes of kidney transplant recipients as compared to the employment statistics in the general population reported in the Labour Force Survey (Statistics Canada, 1991).

The third question dealt with the difference between the employed and the unemployed transplant recipients based on (a) selected health and sociodemographic variables from the mail survey and (b) the conceptual themes that emerged from the personal interviews. The two comparative groups were the employed transplant recipients and the not employed transplant recipients.

The survey data were analysed using a case-control study approach as described by Breslow & Day (1980). The Mantel-Haenzel chi-square and the Mantel trend test were used to handle the independent categorical variables. For continuous variables, cases and controls were compared using the Wilcoxin rank sum test. The dependent variables in this analysis were dichotomous (employed
and not employed), and not normally distributed so nonparametric multiple logistic regression analysis techniques were used to determine the factors most strongly associated with employment. Individual variables were introduced in a stepwise fashion, beta-coefficients and odds ratios were calculated, and the statistical significance of each coefficient was determined. Odds ratios (OR), a directly intuitive measure of association, represented the ratio of individuals who were in different categories of one variable but in the same category on another. For example, the odds of being diabetic and employed as compared to being a non-diabetic and employed. The 95% confidence limits (CI) were the test-based limits proposed by Miettinen (Breslow et al., 1980). All p-values were two sided tests. A statistician was consulted for this part of the analysis.

**Stage Two: Qualitative Analysis**

The data from the patient interviews were used to add breadth and depth to the quantitative analysis of the factors most strongly associated with employment following transplantation. The intent of the qualitative analysis was to construct an exhaustive description of the major themes that emerged from the patient interviews. The analysis followed the steps to phenomenological inquiry outlined by Collaizi (1978, pp. 58-62):

1. The first step was to read through the transcript of the taped interviews in order to acquire a feeling for the overall experience of the subject and to check for any typographical errors that would distort the meaning of the data.

2. With a line-by-line analysis the phrases or statements that directly pertained to the research questions were underlined and extracted from the transcript as significant elements. The elements were written (using the subject's language) in the right-hand margin of the transcript.
3. The elements were grouped to form conceptual themes. In other words, each element was examined in terms of what was being said by the subject and an interpretation was made in terms of what was meant, in a more abstract sense. The purpose was to group the pertinent elements into a discrete set of conceptual themes which reduced the number of units to be worked with. Strauss and Corbin (1990, pp. 81-95) outline various techniques that can be used to facilitate this step such as: analysis of a single phrase, or sentence; the flip-flop procedure; the making of comparisons, both close-in and far-out; and waving the red flag. The choice of themes was influenced by my reading of the literature, my previous social work experience with patients on the kidney transplant unit and my personal assumptions about what the important factors might be. Care was taken to stay grounded in the original transcript.

4. Once the coding was complete it was validated by referring the themes back to the original statements in the transcript to ensure they were not proposing anything which was not implied in the transcript. A check was then made to ensure there was nothing contained in the original transcript that was not accounted for in the cluster of themes. As Collaizi (1978) notes, it is important not to ignore data or themes which do not seem to fit into the hypothesized model.

5. After the themes were identified, they were examined and classified as a (a) positive or negative predisposing factor, (b) a positive or negative enabling factor, or (c) a positive or negative reinforcing factor. The three categories of predisposing, enabling and reinforcing factors were broad enough to encompass all the themes that emerged from the data.

6. A synthesis of the conceptual themes was developed from the transcripts of the tape-recorded interviews.
Summary

In this chapter the methods used to describe the health-related quality of life, the employment outcomes and the factors associated with employment were outlined. The study was conducted in two stages using a combination of quantitative and qualitative methods: (a) a mail survey and (b) personal interviews. The sample consisted of kidney transplant recipients who were identified through the BCTS data base and who met the inclusion criteria. The instruments used to collect data included the Medical Outcome Study Short-form General Health Survey (MOS SF-20) to evaluate health-related quality of life and a questionnaire designed by the researcher that captured relevant socioedemographic and employment information. A semi-structured interview guide was developed for the personal interviews. In stage one, descriptive statistics were used to answer the first two research questions and multivariate statistics were used to analyze the factors associated with employment status. In stage two, the qualitative analysis followed the steps to phenomenological inquiry outlined by Collaizi (1978, pp. 58-62). The University Ethics Committee, the BC Transplant Society and the Vancouver General Hospital granted their approval to conduct the study. Confidentiality of responses were maintained - no subjects were mentioned by name and data were reported collectively.

In the chapter to follow, the demographic characteristics of the study sample and the findings related to each of the three research questions are presented and discussed.
CHAPTER FOUR
Presentation and Discussion of Findings

Introduction

The study results in this chapter are organized into three sections. In the first section, a description of the sociodemographic and disease characteristics of the sample from stage one and from stage two of the study are summarized. Next the study findings related to the three research questions are presented followed by a discussion of the findings.

Sociodemographic Characteristics of the Sample

Mail Survey Respondents

The BCTS data base generated the names and addresses of 315 potential respondents for the mail survey in stage one of this study. Questionnaires were mailed to the 315 transplant recipients but 39 questionnaires were returned as undeliverable. Consequently, a total of 276 renal transplant recipients were contacted regarding their participation in the study. After one reminder letter and a telephone prompt, 216 completed questionnaires were returned (a response rate of 78.3%).

To determine whether there were any systematic differences between responders and nonresponders, data from the BCTS data base was used to compare the age, gender, race, and presence of diabetes in subjects who completed the questionnaires and those who did not. The results are displayed in Table 2 (see Table 2). In summary, although only 216 out of a possible 315 renal transplant recipients (68.6%) participated in the study, based on the descriptive characteristics available from the BCTS data base, the sample appeared to be representative of the eligible population in terms of age, gender, race and diabetes as underlying cause of renal failure.
Table 2

Comparison of Study Sample to Eligible Population Based on Age, Gender, Race and Diagnosis of Diabetes

<table>
<thead>
<tr>
<th></th>
<th>Study Sample n = 216</th>
<th>Population N = 315</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>43.5</td>
<td>45</td>
</tr>
<tr>
<td>range</td>
<td>22 - 64</td>
<td>22 - 65</td>
</tr>
<tr>
<td>SD</td>
<td>11.1</td>
<td>11.9</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>141 (65.3 %)</td>
<td>199 (63.2 %)</td>
</tr>
<tr>
<td>female</td>
<td>75 (34.7 %)</td>
<td>116 (36.8 %)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>170 (78.7 %)</td>
<td>229 (72.7 %)</td>
</tr>
<tr>
<td>Asian</td>
<td>30 (13.9 %)</td>
<td>47 (14.8 %)</td>
</tr>
<tr>
<td>East Indian</td>
<td>13 (6.0 %)</td>
<td>20 (6.3 %)</td>
</tr>
<tr>
<td>Negroid</td>
<td>2 (0.9 %)</td>
<td>2 (0.6 %)</td>
</tr>
<tr>
<td>N.A. Indian</td>
<td>1 (0.5 %)</td>
<td>1 (0.3 %)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>16 (5.3 %)</td>
</tr>
<tr>
<td><strong>Primary Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetic</td>
<td>25 (11.6 %)</td>
<td>33 (10.4 %)</td>
</tr>
<tr>
<td>Not Diabetic</td>
<td>191 (88.4 %)</td>
<td>282 (89.6 %)</td>
</tr>
</tbody>
</table>

The mean age of the sample was 43.5 years. There were twice as many males as females in the study. The majority of the sample was Caucasian (78.7%). The marital status of the subjects was as follows: 144 (66.7%) were married, 40 had never married (18.5%), and 32 (14.8%) were separated, divorced or widowed.
Table 3

Main Source of Income for Renal Transplant Recipients

<table>
<thead>
<tr>
<th>Source of Income</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wages and Salary</td>
<td>112</td>
<td>51.9</td>
</tr>
<tr>
<td>Disability Pension (Employer, CPP)</td>
<td>61</td>
<td>28.2</td>
</tr>
<tr>
<td>Spouse, Family Support</td>
<td>47</td>
<td>21.8</td>
</tr>
<tr>
<td>Ministry of Social Services and Housing</td>
<td>22</td>
<td>10.2</td>
</tr>
<tr>
<td>Unemployment Insurance</td>
<td>11</td>
<td>5.1</td>
</tr>
<tr>
<td>Other (personal investments)</td>
<td>19</td>
<td>8.8</td>
</tr>
</tbody>
</table>

Note: These categories are not mutually exclusive.

Over half of the subjects (115) had attained an education at the university or college level, 21% (45) had attained an educational level of grade 12, and 25% (56) had not graduated from high school. These education levels are somewhat better than those found in BC where 29.4% of the general population have not graduated from high school (Statistics Canada, 1991, Table 5, p. B-16).

All but eight of the respondents had been on dialysis prior to their transplant. The median length of time on dialysis was 2.8 years (range: 1 month - 14 years). At the time of the survey 50% of the respondents had been transplanted for 3.1 years (range: 6 months - 27 years). It was the first kidney transplant for 89.4% (193) of the 216 respondents.

The categories for main source of income were not mutually exclusive (see Table 3). Some respondents who received money from wages also reported they
received money from personal investments. Some who received disability insurance payments also received financial support from their spouse. Approximately one in ten of the transplant recipients (10.2%) reported they received financial assistance from the Ministry of Social Service and Housing.

**Interview Subjects**

The characteristics of the seven subjects who gave personal interviews are summarized to provide a context in which to view each participant's experience with employment. The participants were identified by a code (P1 through to P7) to enable identification of their responses:

P1 was a 45 year old male who emigrated from the Philippines as a child. He had a grade 12 education. He was employed full-time as a physiotherapy aide at a rehabilitation hospital. At the time of the interview, he had worked in the same unionized job for approximately 16 years. The subject was married and owned a home where he lived with his wife and their two adult children, aged 20 and 22. His wife worked as a nurse. The couple were financially secure. P1 had been a renal patient for approximately nine years. His underlying diagnosis was chronic glomerulonephritis. He received his transplant approximately six years ago. His overall health was good. Prior to the transplant, P1 was on dialysis for three years during which time he was on paid sick leave from his job. Approximately three months following his transplant he returned to his position as a physiotherapy aide.

P2 was a 50 year old Caucasian female who quit school in grade 10 to help her parents manage the family farm. At the time of the interview she had worked full-time in a turkey processing plant for 23 years. The job was unionized with full dental, health and insurance benefits. P2 was single and lived alone. She was diagnosed with polycystic kidneys at the age of 12. She started dialysis at the age of 43. She was on dialysis for four years during which time her health was good
and she retained her full-time position in the turkey processing plant. She was off work for six months following her transplant surgery. She had her kidney transplant for three years.

P3 was a 41 year old French-Canadian male with a grade 12 education. He worked part-time delivering supplies to a chain of restaurants. His previous job was working as salesman, on commission. He quit this job due to his health. P3 was single. He lived with a male partner who worked as a waiter. P3 was diagnosed with chronic renal failure, aetiology unknown, approximately three years ago. He was on dialysis for six months prior to transplant and he had his kidney transplant surgery two years ago. His overall health was good and he was physically active in sports - swimming and tennis.

P4 was a 29 year old Caucasian male with a degree in religious studies. He was self-employed and worked part-time as a computer programmer developing custom software. The subject was single. He lived in a Christian boarding home. P4 went into renal failure seven years ago. His underlying diagnosis was diabetes. He was on dialysis for one year prior to transplant and he received a kidney transplant six years ago. He was blind and had involuntary hand tremors.

P5 was a 34 year old Caucasian male with a university degree in engineering. He had been active in the workforce for about ten years following graduation, but was unemployed, looking for work, and collecting unemployment insurance at the time of the interview. The subject was married with no children. His wife worked as a teacher. The couple were financially secure. The subject had been a renal patient for approximately twelve years. He was on dialysis for one year during which time he worked full-time and he received his kidney transplant ten years ago. His overall health was good.
P6 was a 30 year old Caucasian female with a grade eight education. She was married with two young children, aged six and seven. Prior to having children P6 worked as a fitness instructor. At the time of the interview she was not employed outside of the home. Her husband supported the family through his job as a store manager. P6 had been aware of her kidney problem (IgA nephropathy) since the age of 12. She never received dialysis. She had a kidney donated from her brother three years ago. Her overall health was good.

P7 was a 45 year old Caucasian female with a grade eight education. She was on social assistance (for 20 years) and received a disability allowance from the Ministry of Social Service and Housing. P7 did volunteer work on a regular weekly basis at the Kidney Foundation. The subject lived in a common-law relationship. Her partner also received a disability allowance through the Ministry of Social Service and Housing. The couple did not have any children. P7 had been a renal patient for approximately 15 years. Her underlying diagnosis was polycystic kidneys. She was on dialysis for four years and received her kidney transplant 11 years ago. Her health was stable although she was overweight and developed diabetes a year ago.

Findings

In the section to follow, the findings of this research will be presented in relation to the three research questions.

Research Question 1: The Health-Related Quality of Life of Kidney Transplant Recipients

To address the transplant recipients' perceived level of functional health and well-being, the results obtained on the MOS SF-20 will be presented using descriptive statistics. The dimensions of the health profile include physical functioning, role functioning, social functioning, mental health, health perceptions
Table 4

Medical Outcome Study SF-20 Mean Scores for Kidney Transplant Recipients and People with no Chronic Conditions

<table>
<thead>
<tr>
<th>SF-20 Health Dimension</th>
<th>Kidney Transplant (n = 216)</th>
<th>No Chronic Condition (n = 2,595)</th>
<th>Score Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Functioning:</strong></td>
<td>69.4</td>
<td>86.0</td>
<td>-16.6</td>
</tr>
<tr>
<td>capacity to perform a variety of physical activities such as carrying groceries, climbing stairs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Role Functioning:</strong></td>
<td>70.1</td>
<td>87.2</td>
<td>-17.1</td>
</tr>
<tr>
<td>extent to which health interferes with usual daily activities such as work, housework or school.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Functioning:</strong></td>
<td>83.4</td>
<td>92.3</td>
<td>-8.9</td>
</tr>
<tr>
<td>extent to which health interferes with normal social activities such as visiting with friends or group activities during past month.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mental Health:</strong></td>
<td>74.8</td>
<td>77.6</td>
<td>-2.8</td>
</tr>
<tr>
<td>general mood or affect, including depression, anxiety, and positive well-being during the past month.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health Perceptions:</strong></td>
<td>59.7</td>
<td>72.6</td>
<td>-12.8</td>
</tr>
<tr>
<td>overall ratings of current health in general.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pain:</strong></td>
<td>64.1</td>
<td>74.2</td>
<td>-10.1</td>
</tr>
<tr>
<td>extent of bodily pain during the past month.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note.** SF 20 scores range from 0 - 100 with 100 being the best score possible.
and bodily pain. The mean scores on each dimension of the SF-20 for the study sample are compared to the scores obtained for people with no chronic health condition and the differences in scores are tabulated (see Table 4 previous page).

The comparison group data for persons with no chronic conditions were obtained from the cross-sectional phase of the Medical Outcomes Study reported in the *Journal of the American Medical Association* (Stewart et al., 1989). The SF-20 scores are based on a random sample of 2,595 English-speaking patients, 18 years and older, who visited their doctor for routine general examinations or acute medical problems such as allergy, urinary tract infection and musculoskeletal pain. Persons with chronic disorders such as hypertension, diabetes, kidney disease, cancer, congestive heart failure, arthritis and angina, were excluded from this sample. The authors of the SF-20 state that acute problems tend to be self-limiting, and should not affect functioning and well-being to the same extent as for patients with chronic conditions (Stewart et al., 1989, p. 908). Although it is not a perfect control group, it offers a useful comparison to facilitate our understanding of the effects of a chronic condition such as End Stage Renal Disease on general functioning and well-being.

The results from the Medical Outcomes Study showed that a difference of 9 scale points in the physical functioning domain of the SF-20 was a clinically meaningful difference equivalent to the effect of having arthritis or back problems and a difference of 3 scale points in the mental health domain was a significant effect equivalent to the impact of being fired or laid off from a job (Stewart et al., 1989). Based on these criteria, the SF-20 scores for the kidney transplant population show that transplant recipients not only report lower levels for all dimensions of health when compared to the general population but that the difference in scores is clinically meaningful for all dimensions except mental health.
Table 5

Proportion of Kidney Transplant Recipients and General Population in Poor Health

<table>
<thead>
<tr>
<th>SF-20 Health Variable</th>
<th>Transplant Patients (n = 216)</th>
<th>General Population (n = 2,008)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>% in Poor Health</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>69.4</td>
<td>40.3</td>
</tr>
<tr>
<td>Role Functioning</td>
<td>70.1</td>
<td>38.9</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>83.4</td>
<td>12.0</td>
</tr>
<tr>
<td>Mental Health</td>
<td>74.8</td>
<td>28.2</td>
</tr>
<tr>
<td>Health Perceptions</td>
<td>59.7</td>
<td>63.2</td>
</tr>
<tr>
<td>Pain</td>
<td>64.1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

Note. * = Data not available

Physical functioning and role functioning are most affected in persons with kidney transplants relative to the general population with a mean score difference of 16.6 and 17.1 respectively. Mental health is least affected with a mean score difference of 2.8.

The transplant survey results were analyzed to show the proportion of transplant recipients who function in the poor health range compared to the proportion of people in the general population who function in the poor health range (see Table 5). The health data for the general population were reported in the article by Stewart et al. (1988). Poor health for physical and role functioning
was defined as one or more limitation (a score of 83.3 or less for physical and 50 or less for role); poor social functioning was a score of 40 or less; poor mental health was a score of 67 or lower; poor health perception was a score of 70 or lower; a score of 25 or less indicated a moderate, severe or very severe amount of pain (Stewart et al., 1988). Based on these criteria, about twice as many transplant recipients compared to people in the general population were functioning in the poor range, physically. Three times as many experienced poor role functioning and had a poor perception of their overall health.

Research Question 2: The Employment Outcomes of Kidney Transplant Recipients Compared to the General Population

The transplant respondents were asked to indicate their current employment status (see Appendix J). The employed respondents, those who were on temporary leave from their jobs and those who were unemployed but looking for work were designated as active in the labour force. The respondents who were retired or unemployed but not looking for work were designated as not active in the labour force. The employment outcomes for the study sample are displayed in Figure 2 (see Figure 2, next page). The majority of the respondents (65.7%) were active in the labour force: 122 of the subjects (56.5%) were employed and twenty of the subjects were unemployed but looking for work. Of the 74 respondents (34.3%) who were not active in the labour force approximately one third (25) described themselves as retired. This category included 22 respondents who retired early due to poor health and 3 respondents who retired at the usual retirement age. The remaining 49 respondents who described themselves as unemployed and not looking for work were asked to identify the main reason for not working (see Appendix K). Poor health was the most prevalent reason given for not working (identified by 23 individuals) followed by lack of suitable training or appropriate
Figure 2. Employment outcomes of renal transplant recipients.

Population 18-65 Years of Age (n=216)

<table>
<thead>
<tr>
<th>Total Labour Force (142)</th>
<th>Not in Labour Force (74)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed (122)</td>
<td>Retired (25)</td>
</tr>
<tr>
<td>Full-Time (90)</td>
<td>Poor Health (23)</td>
</tr>
<tr>
<td>Part-Time (21)</td>
<td>Lack of Suitable Training (10)</td>
</tr>
<tr>
<td>Temporary Leave (11)</td>
<td>Home/Family Responsibilities (7)</td>
</tr>
<tr>
<td>Unemployed (20)</td>
<td>Would Lose Disability Insurance (4)</td>
</tr>
<tr>
<td></td>
<td>Student (3)</td>
</tr>
<tr>
<td></td>
<td>Employer Discrimination (2)</td>
</tr>
</tbody>
</table>
jobs (identified by 10 individuals). Three individuals were in school. Concern over the loss of disability benefits was identified as the main reason for not working by four individuals, and two individuals identified employer discrimination as the main reason. An anecdotal comment was added at the end of the questionnaire by one of the respondents who was concerned about losing disability benefits:

"I would like to work, but the income would have to be enough to support me ($1200 net). On disability I receive just $694 total. If I went back to work, lost my disability pension and then was not able to work, I would not be able to get my disability pension back, then I would be in real trouble. Not able to work at certain jobs and no disability pension, what would I do?"

All but fifteen of the respondents had worked for pay at some point in their life. In the year prior to transplant, 118 (54.6%) stated they were employed, 98 (45.4%) were not employed. Of the 118 people who worked in the year before transplant, 89 were working after transplant at the time of the survey, 29 were not working. Of the 98 people who had not worked in the year before transplant, 33 had entered the workforce following transplant, 65 were still not working.

The distribution of employment by occupation for the 122 employed transplant recipients and the distribution of employment by occupation for the general population in BC is shown in Table 6 (see Table 6, next page). The occupation categories were defined according to the definitions used in the Labor Force Survey. The sales category included people selling real estate, insurance, advertising as well as retail clerks. The service category included police, fire, inn-keepers and child care workers. Primary occupations included farming, mining, fishing. Processing referred to manufacturing and factory work.

The employed respondents were asked whether they were currently satisfied with their jobs. Four respondents did not answer this question. Of the 118
Table 6

Distribution of Employment by Occupation in Renal Transplant Recipients and the General Population of British Columbia

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Renal Transplant Recipients (n = 122)</th>
<th>General Population in BC (n = 1592) a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managerial and other professional</td>
<td>36 (29.5%)</td>
<td>467 (29.4%)</td>
</tr>
<tr>
<td>Clerical</td>
<td>32 (26.2%)</td>
<td>252 (15.8%)</td>
</tr>
<tr>
<td>Sales</td>
<td>13 (10.7%)</td>
<td>170 (10.7%)</td>
</tr>
<tr>
<td>Service</td>
<td>23 (18.9%)</td>
<td>233 (14.6%)</td>
</tr>
<tr>
<td>Primary occupations, processing</td>
<td>7 (05.7%)</td>
<td>231 (14.5%)</td>
</tr>
<tr>
<td>Construction, transport equipment operator</td>
<td>11 (09.0%)</td>
<td>239 (15.0%)</td>
</tr>
</tbody>
</table>


...
### Labour Force Statistics of Renal Transplant Recipients and the General Population in British Columbia

<table>
<thead>
<tr>
<th></th>
<th>Renal Transplant Recipients</th>
<th>General Population (in lower mainland)</th>
<th>General Population (22-64 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>216</td>
<td>1,434</td>
<td>1,876</td>
</tr>
<tr>
<td>Total labour force</td>
<td>142</td>
<td>960</td>
<td>1,462</td>
</tr>
<tr>
<td>Employed</td>
<td>122</td>
<td>869</td>
<td>1,310</td>
</tr>
<tr>
<td>Unemployed</td>
<td>20</td>
<td>91</td>
<td>152</td>
</tr>
<tr>
<td>Not in labour force</td>
<td>74</td>
<td>474</td>
<td>414</td>
</tr>
<tr>
<td>Labour force participation rate</td>
<td>65.7%</td>
<td>66.9%</td>
<td>77.9%</td>
</tr>
<tr>
<td>Rate of unemployment</td>
<td>14.1%</td>
<td>9.4%</td>
<td>9.6%</td>
</tr>
<tr>
<td>Employment/population ratio</td>
<td>56.5%</td>
<td>60.6%</td>
<td>69.8%</td>
</tr>
</tbody>
</table>

**Note.**


All subjects were asked whether or not they were satisfied with the amount of work they did. Of the 142 respondents active in the labour force, 29 (20.4%) were not satisfied with the amount of work they did. Of the 74 respondents not active in the labour force, almost half (45.9%) said they were not satisfied with the amount of work they did.

The labour force statistics of the renal transplant recipients were compared to the labour force statistics of the general population in two ways (see Table 7 previous page). First, since the study sample was drawn from the lower mainland of BC, the study findings were compared to the Labour Force statistics of the general population residing in the lower mainland of BC (i.e., economic region #950) for the same time period. When geographic location was controlled, the difference in the employment rate between the study sample and the lower mainland population was 4.1%. However, the age of the general population sample was 15 years and older. Since the transplant sample included people between the ages of 22 to 64, the findings were compared to estimates of similar aged residents in the general population of BC. When the BC statistics were controlled by age, the difference in the employment rate between the study sample and BC residents was much greater, 13.3%. No statistics were available for the general population of BC matched both for age and geographic location.

**Research Question 3: The Factors that are the Strongest Predictors of Employment Activity in the Kidney Transplant Recipient**

The third research question dealt with the most significant variables associated with employment status. The findings are based on (a) a multivariate analysis of the data obtained from the mail survey and (b) a qualitative analysis of the conceptual themes that emerged from the patient interviews. These results will be presented separately.
Results from the Mail Survey

The two comparative groups for the multivariate analysis were the 122 employed transplant recipients and the 94 transplant recipients who were not employed at the time of the mail survey.

The two groups were compared based on their age, gender, race, education, marital status, whether this was their first or second transplant, whether or not they had ever worked previously, if they had worked in the year prior to transplant, length of time on dialysis prior to transplantation, length of time since transplant surgery, physical functioning in the normal or poor range, social functioning in the normal or poor range, mental health in the normal or poor range, health perception in the normal or poor range, pain in the absent to mild range or moderate to severe range, and the presence of diabetes. The role functioning variable on the SF-20 was not entered into the analysis because the item measured work activity which was redundant information.

There were no statistically significant differences in race, marital status, months on dialysis or months since time of transplant between the employed and the not employed subgroups (see Table 8 next page). The sociodemographic variables that were strongly associated with employment status were younger age, male gender, higher education previous work experience and having worked in the year before transplant (in most cases working in the year before transplant means the person worked while receiving dialysis treatments). All of the health-related variables from the MOS SF-20 were significantly associated with employment outcome. An underlying disease of diabetes was also an important factor in predicting employment outcome. Only 9 (36%) of the 25 diabetic patients were employed compared to 113 (59.2%) of the 191 transplant recipients without diabetes.
Table 8

**Sociodemographic and Health Profile of Kidney Transplant Recipients by Employment Status**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Employed (n = 122), 56.5%</th>
<th>Not Employed (n = 94), 43.5%</th>
<th>Statistical Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>median</td>
<td>39.0</td>
<td>48.0</td>
<td>p &lt; .0001&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>range</td>
<td>23 - 64</td>
<td>22 - 64</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>88 (72.1%)</td>
<td>53 (56.4%)</td>
<td>p &lt; .05&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>female</td>
<td>34 (27.9%)</td>
<td>41 (43.6%)</td>
<td></td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>caucasian</td>
<td>99 (81.1%)</td>
<td>71 (75.5%)</td>
<td>NS</td>
</tr>
<tr>
<td>other</td>
<td>23 (18.9%)</td>
<td>23 (24.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>grade 8 or less</td>
<td>05 (04.0%)</td>
<td>15 (16.0%)</td>
<td>p &lt; .01&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>grade 9 - 11</td>
<td>17 (13.9%)</td>
<td>18 (19.2%)</td>
<td></td>
</tr>
<tr>
<td>grade 12 graduate</td>
<td>26 (21.3%)</td>
<td>19 (20.2%)</td>
<td></td>
</tr>
<tr>
<td>post secondary education</td>
<td>21 (17.2%)</td>
<td>21 (22.3%)</td>
<td></td>
</tr>
<tr>
<td>college diploma</td>
<td>25 (20.5%)</td>
<td>12 (12.8%)</td>
<td></td>
</tr>
<tr>
<td>university degree</td>
<td>28 (23.0%)</td>
<td>08 (08.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>married</td>
<td>78 (63.9%)</td>
<td>66 (70.2%)</td>
<td>NS</td>
</tr>
<tr>
<td>other</td>
<td>44 (36.1%)</td>
<td>28 (29.8%)</td>
<td></td>
</tr>
<tr>
<td><strong>Worked in year before transplant</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>89 (73.0%)</td>
<td>29 (30.9%)</td>
<td>p &lt; .0001&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>no</td>
<td>33 (27.0%)</td>
<td>65 (69.1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Worked anytime previously</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>119 (97.5%)</td>
<td>82 (87.2%)</td>
<td>p &lt; .01&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>no</td>
<td>03 (2.5%)</td>
<td>12 (12.8%)</td>
<td></td>
</tr>
</tbody>
</table>

*Table continues*
<table>
<thead>
<tr>
<th>Variable</th>
<th>Employed (n = 122), 56.5%</th>
<th>Not Employed (n = 94), 43.5%</th>
<th>Statistical Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months on dialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>35.5</td>
<td>37.5</td>
<td>NS</td>
</tr>
<tr>
<td>SD</td>
<td>28.0</td>
<td>29.0</td>
<td></td>
</tr>
<tr>
<td>Months since transplant</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>59.7</td>
<td>49.7</td>
<td>NS</td>
</tr>
<tr>
<td>SD</td>
<td>60.9</td>
<td>48.8</td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>normal range</td>
<td>89 (73.0%)</td>
<td>40 (42.6%)</td>
<td>p &lt; .0001 b</td>
</tr>
<tr>
<td>poor range</td>
<td>33 (27.0%)</td>
<td>54 (57.4%)</td>
<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>normal range</td>
<td>116 (95.1%)</td>
<td>74 (78.7%)</td>
<td>p &lt; .0001 b</td>
</tr>
<tr>
<td>poor range</td>
<td>06 (04.9%)</td>
<td>20 (21.3%)</td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>normal range</td>
<td>96 (78.7%)</td>
<td>59 (62.8%)</td>
<td>p &lt; .01 b</td>
</tr>
<tr>
<td>poor range</td>
<td>26 (21.3%)</td>
<td>35 (37.2%)</td>
<td></td>
</tr>
<tr>
<td>Health perception</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>normal range</td>
<td>70 (57.4%)</td>
<td>31 (33.0%)</td>
<td>p &lt; .0001 b</td>
</tr>
<tr>
<td>poor range</td>
<td>52 (42.6%)</td>
<td>63 (67.0%)</td>
<td></td>
</tr>
<tr>
<td>Amount of pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no or mild pain</td>
<td>116 (95.1%)</td>
<td>82 (87.2%)</td>
<td>p &lt; .05 b</td>
</tr>
<tr>
<td>moderate to severe pain</td>
<td>06 (04.9%)</td>
<td>12 (12.8%)</td>
<td></td>
</tr>
<tr>
<td>Diabetic status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetic</td>
<td>09 (07.4%)</td>
<td>16 (17.0%)</td>
<td>p &lt; .05 b</td>
</tr>
<tr>
<td>Non-diabetic</td>
<td>113 (92.6%)</td>
<td>78 (83.0%)</td>
<td></td>
</tr>
</tbody>
</table>

Note.  

^a Based on the Wilcoxon rank sum  
^b Based on the Mantel-Haenszel test  
^c Based on the Mantel Trend test
Table 9

Multiple Logistic Regression Model of Employment Status

<table>
<thead>
<tr>
<th>Variables</th>
<th>Beta</th>
<th>Odds Ratio</th>
<th>Chi-square</th>
<th>P_value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worked in Year Before Transplant</td>
<td>1.57</td>
<td>4.8</td>
<td>22.9</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>0.99</td>
<td>2.7</td>
<td>8.6</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td>Age</td>
<td>-0.039</td>
<td>0.96</td>
<td>6.5</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td>Education</td>
<td>0.24</td>
<td>1.3</td>
<td>4.9</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>Diabetes</td>
<td>-1.04</td>
<td>0.35</td>
<td>4.1</td>
<td>&lt; 0.05</td>
</tr>
</tbody>
</table>

Note.  
^a The response for this variable is (No, Yes)  
^b The response for this variable is (Poor, Normal)  
^c This is a continuous variable  
^d This response has 6 categories

A multiple logistic regression model was estimated to determine the factors most strongly associated with employment status. The fifteen variables identified in Table 8 were introduced in a stepwise fashion. The results are presented in Table 9 (see Table 9). The five variables found to be the most statistically significant predictors of employment status were employment status during the year prior to transplant (p < .0001, odds ratio: 4.8), physical functioning score obtained on the SF-20 (p < .01, odds ratio: 2.7), age (p < .05, odds ratio: 0.96), education (p < .05, odds ratio: 1.3), and diabetes as an underlying illness (p < .05, odds ratio: 0.35). People employed in the year before transplant were more than four times as likely
Figure 3. The comparative health profiles of employed transplant recipients, unemployed transplant recipients and persons with no chronic health condition.
to be employed following transplant. People who scored in the normal range on
the physical functioning dimension of the SF-20 were more than twice as likely to
be employed. There was a negative correlation with age. The older the patient
was, the less likely they were employed. Education was positively correlated with
employment. Patients with diabetes were not as likely to be working as
nondiabetics.

To demonstrate more convincingly the differences between the health-
related quality of life of the employed group of transplant recipients and the not
employed group, the SF-20 group mean scores across the six health domains are
displayed graphically (see Figure 3). The scores obtained by the employed group
of transplant recipients compare favourably to the scores obtained by people with
no chronic health problems. The scores obtained by the unemployed group of
transplant recipients, when compared to the employed transplant group and
persons with no chronic health problems, are lower across all domains of health.
The numeric values are reported in Appendix L.

Results from the Personal Interviews

After the major themes from the seven patient interviews were identified, the
thematic material was displayed in a matrix format as suggested by Miles and
Huberman (1984). Table 10 displays the thematic material that was categorized as
the major predisposing factors that contribute to employment, Table 11 displays the
thematic material that was categorized as the enabling factors that contribute to
employment and Table 12 displays the thematic material that was categorized as
the reinforcing factors that contribute to employment. Themes that were classified
as negative enabling or negative reinforcing factors were labeled as barriers to
employment. These barriers to employment are displayed in Table 13.
Table 10

Predisposing Factors Associated with Employment

<table>
<thead>
<tr>
<th>Predisposing Factors</th>
<th>Employed Group (n = 4)</th>
<th>Not Employed Group (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belief in the work ethic:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- self-sufficiency</td>
<td>“I guess it’s part of the culture, or it’s part of living anyway, like I don’t want to go through life without doing my part ... don’t want to be a burden on society” (P1)</td>
<td>“There’s no silver spoon ... no one owes you a living ... I’m very career-oriented and want to do a lot” (P5)</td>
</tr>
<tr>
<td>- making own way</td>
<td>“People view people who doesn’t do any work who live from social welfare as 'bums'” (P3)</td>
<td>“If my husband were to leave me or cheat on me or something, heaven forbid, or die or something, the thought of welfare does nothing for me. My independence just screams when I hear welfare. I’d go back to work” (P6)</td>
</tr>
<tr>
<td>- personal achievement</td>
<td>“In my opinion there are two legitimate ways to get your money to live. One is to work for it and the other is to get it through charity. I’m personally opposed to welfare. I feel obligated to work. I don’t think I have the option to collect a pension any more, although I have done it in the past” (P4)</td>
<td></td>
</tr>
<tr>
<td>Altruism:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- repay debt to society for “gift of life”</td>
<td>“It’s kind of like I owe so much, because of the situation that I have. I had the transplant which gives me what I had before ... not 100% but about 90% of what I was doing before”</td>
<td>“I feel with volunteering, I owe the Kidney Foundation a lot. Cause I had a transplant, it’s going on 11 years, and I feel that I owe them everything so I decided to”</td>
</tr>
</tbody>
</table>

Table continues
<table>
<thead>
<tr>
<th>Predisposing Factors</th>
<th>Employed Group (n = 4)</th>
<th>Not Employed Group (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertain Health:</td>
<td>I can do again. And I think I owe it to society to give back what I have got, what they have given to me&quot; (P1)</td>
<td>give them some of my time. That's the way I figure it&quot; (P7)</td>
</tr>
<tr>
<td>- provides the incentive to work</td>
<td>&quot;With my health being so good there is an imperative to take advantage of it. I don't know what my health is going to be next year or five years from now. I don't know if I'm going to get very sick or if it's going to keep going. I'm not 100% sure like a lot of people are&quot; (P5)</td>
<td></td>
</tr>
</tbody>
</table>
Table 11

Enabling Factors Associated with Employment

<table>
<thead>
<tr>
<th>Enabling Factors</th>
<th>Employed Group (n = 4)</th>
<th>Not Employed Group (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Good Health:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;I was really lucky</td>
<td></td>
</tr>
<tr>
<td></td>
<td>because I was never</td>
<td></td>
</tr>
<tr>
<td></td>
<td>really sick with my</td>
<td></td>
</tr>
<tr>
<td></td>
<td>kidney disease. Like</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I was tired, but not</td>
<td></td>
</tr>
<tr>
<td></td>
<td>sick sick, to take</td>
<td></td>
</tr>
<tr>
<td></td>
<td>time off work. When I</td>
<td></td>
</tr>
<tr>
<td></td>
<td>was on dialysis I</td>
<td></td>
</tr>
<tr>
<td></td>
<td>continued to work so</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I was really one of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>the lucky ones as far</td>
<td></td>
</tr>
<tr>
<td></td>
<td>as my health goes. The</td>
<td></td>
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<tr>
<td></td>
<td>only time I took off</td>
<td></td>
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<tr>
<td></td>
<td>from work was when I</td>
<td></td>
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<tr>
<td></td>
<td>had my operations to</td>
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<tr>
<td></td>
<td>unclot by fistula and</td>
<td></td>
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<tr>
<td></td>
<td>when I had my</td>
<td></td>
</tr>
<tr>
<td></td>
<td>transplant&quot; (P2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;I went to the CNIB</td>
<td></td>
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<tr>
<td></td>
<td>job hunt club. It was</td>
<td></td>
</tr>
<tr>
<td></td>
<td>useful to a point</td>
<td></td>
</tr>
<tr>
<td></td>
<td>because they teach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>you how to act and</td>
<td></td>
</tr>
<tr>
<td></td>
<td>how to answer certain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>questions&quot; (P4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;When I want to be</td>
<td></td>
</tr>
<tr>
<td></td>
<td>inspired or encouraged</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I hang around people</td>
<td></td>
</tr>
<tr>
<td></td>
<td>who are doing business</td>
<td></td>
</tr>
<tr>
<td></td>
<td>endeavors, people who</td>
<td></td>
</tr>
<tr>
<td></td>
<td>are doing things for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>themselves. I find</td>
<td></td>
</tr>
<tr>
<td></td>
<td>typically people who</td>
<td></td>
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<tr>
<td></td>
<td>are in the business of</td>
<td></td>
</tr>
<tr>
<td></td>
<td>counseling or supporting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>have probably the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>least to say to the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>issue&quot; (P4)</td>
<td></td>
</tr>
<tr>
<td><strong>Formal and Informal Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- vocational</td>
<td>&quot;the job relocation</td>
<td></td>
</tr>
<tr>
<td>rehabilitation</td>
<td>counseling keeps you</td>
<td></td>
</tr>
<tr>
<td>programs</td>
<td>focussed on what you're</td>
<td></td>
</tr>
<tr>
<td></td>
<td>trying to do and how</td>
<td></td>
</tr>
<tr>
<td></td>
<td>to sell yourself ...</td>
<td></td>
</tr>
<tr>
<td></td>
<td>that really helped&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(P5)</td>
<td></td>
</tr>
<tr>
<td>- other motivating</td>
<td>&quot;I really like to hang</td>
<td></td>
</tr>
<tr>
<td>people</td>
<td>around motivating</td>
<td></td>
</tr>
<tr>
<td></td>
<td>people&quot; (P5)</td>
<td></td>
</tr>
</tbody>
</table>

Table continues
<table>
<thead>
<tr>
<th>Enabling Factors</th>
<th>Employed Group (n = 4)</th>
<th>Not Employed Group (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- job contacts</td>
<td>&quot;I found this work through a friend&quot; (P3)</td>
<td>&quot;I know a lot of people so I don't think finding work will be a problem&quot; (P6)</td>
</tr>
<tr>
<td>- God's providence</td>
<td>&quot;It's quite miraculous to me that I actually have work that I can do. There's people</td>
<td>&quot;It's quite miraculous to me that I actually have work that I can do. There's people</td>
</tr>
<tr>
<td></td>
<td>that are so much more qualified than I am that don't. Ultimately, it's God's providence.</td>
<td>that are so much more qualified than I am that don't. Ultimately, it's God's providence.</td>
</tr>
<tr>
<td></td>
<td>I can't think of any other reason. I'm not particularly persevering. I'm kind of lazy actually&quot; (P4)</td>
<td>I can't think of any other reason. I'm not particularly persevering. I'm kind of lazy actually&quot; (P4)</td>
</tr>
<tr>
<td>Type of Work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- flexible work conditions</td>
<td>&quot;my boss is pretty good. I can get time off to come to clinic&quot; (P2)</td>
<td></td>
</tr>
<tr>
<td>- secure work</td>
<td>&quot;because of the union they held my job for me&quot; (P1)</td>
<td></td>
</tr>
<tr>
<td>- sedentary</td>
<td>&quot;it's easy work ... it's not hard or stressful. I like driving. It's like sitting on the couch&quot; (P3)</td>
<td></td>
</tr>
</tbody>
</table>
Table 12
Reinforcing Factors Associated with Employment

<table>
<thead>
<tr>
<th>Reinforcing Factors</th>
<th>Employed Group (n = 4)</th>
<th>Not Employed Group (n = 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Rewards:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- feel healthy</td>
<td>&quot;it feels healthy to be working&quot; (P4)</td>
<td>&quot;work is good for your psyche ... working gives you that day to day challenge. The desire to get out of bed in the morning&quot; (P5)</td>
</tr>
<tr>
<td>- personal achievement</td>
<td>&quot;You’re doing something with your time&quot; (P3)</td>
<td>&quot;It (volunteer work) gives me a sense of purpose. I don’t like sitting at home&quot; (P7)</td>
</tr>
<tr>
<td>- sense of purpose</td>
<td>&quot;I work as a physiotherapy aide. My work is very interesting, very rewarding. It’s quite nice and pleasant&quot; (P1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&quot;Even though it brings money to people, working is nice too. You’re doing something with your time&quot; (P3)</td>
<td></td>
</tr>
<tr>
<td><strong>Social Rewards:</strong></td>
<td>&quot;if I didn’t have to work I could find fulfillment in other things. But I would still like to work part-time to keep in touch with things that are out there&quot; (P2)</td>
<td>&quot;probably the most important part of working is social, I like to be around people&quot; (P6)</td>
</tr>
<tr>
<td>- sense of affiliation</td>
<td>&quot;working just fits into life better, you know you’ve got your five days working and your two days to party and your five days to work and your two days to party&quot; (P5)</td>
<td></td>
</tr>
<tr>
<td>- “fit in”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Financial rewards</strong></td>
<td>&quot;To be paid for the work that you enjoy doing is another plus&quot; (P1)</td>
<td>&quot;I’m definitely considering going back to work because of the finances. Everything costs so much today&quot; (P6)</td>
</tr>
</tbody>
</table>
Table 13

Barriers to Employment

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Renal Transplant Recipients (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Limitations:</strong></td>
<td>&quot;My sight is a significant barrier, something I have to deal with. I've got to work around it. It's shear overhead. It takes me longer to do things&quot; (P4)</td>
</tr>
<tr>
<td></td>
<td>&quot;it was quite a load on me, trying to keep up that way, the long hours .... and also trying to recover from the transplant&quot; (P5)</td>
</tr>
<tr>
<td></td>
<td>&quot;Since I got this problem with blood pressure and stuff like that, I had to be more careful, so I put aside my work as clothing salesman on commission&quot; (P3)</td>
</tr>
<tr>
<td></td>
<td>&quot;My joints ache and that limits me&quot; (P2)</td>
</tr>
<tr>
<td></td>
<td>&quot;I get tired easily ... I developed diabetes a year ago ... I can't handle stress as well as I used to&quot; (P7)</td>
</tr>
<tr>
<td></td>
<td>&quot;There's always that period of self-blame. Even though my company laid be off for economic factors, you always wonder what you could have done different&quot; (P5)</td>
</tr>
<tr>
<td><strong>Role Conflict:</strong></td>
<td>&quot;I have two children and a husband and I work at home and I work by butt off, and gardens and a dog, and it's fulltime work&quot; (P6)</td>
</tr>
<tr>
<td><strong>Special Needs</strong></td>
<td></td>
</tr>
<tr>
<td>- extra time off for medical appointments</td>
<td>&quot;My employer was not happy with me being away from work for the transplant ... and when I came back there was a lot of monitoring to do and that entailed one or two visits for blood work every week to hospital which meant missing a morning or a couple of hours every morning that happened ... I was laid off shortly after that&quot; (P5)</td>
</tr>
<tr>
<td>Barriers</td>
<td>Renal Transplant Recipients (n = 7)</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>- flexible hours to accommodate family</td>
<td>“I want to be home when my kids get home from school ... I just simply won’t take a job unless they let me leave at a time so that I can be home for my children” (P6)</td>
</tr>
<tr>
<td>responsibilities</td>
<td></td>
</tr>
<tr>
<td>Discrimination by employers</td>
<td>“The human resources people said no, don’t take this guy. He’ll get sick and then we’re going to have this big debt. We’ll have to support this guy who’s not doing anything anymore” (P5)</td>
</tr>
<tr>
<td>Environmental Factors:</td>
<td></td>
</tr>
<tr>
<td>- economic recession</td>
<td>“the recession has meant mines are shutting down .. development is what fueled a lot of job opportunities” (P5)</td>
</tr>
<tr>
<td>- no suitable jobs</td>
<td>“Being an engineer I’ve been overqualified for the jobs I’ve applied for” (P5)</td>
</tr>
<tr>
<td>- structural disincentives</td>
<td>“because of the disability pension I had the option, I’m well provided by the contract between the union and the employer. If I’m on a job that is not as enjoyable as what I’m doing now ... I might not have decided to go back to work” (P1)</td>
</tr>
<tr>
<td>e.g. disability insurance</td>
<td></td>
</tr>
<tr>
<td>e.g. affirmative action programs</td>
<td>“Another barrier was the affirmative action program. I did a 6-month position for the government. And in that job the important thing was that I was a statistic, a disabled person with a job, and what I was accomplishing was not of importance. I've come to that conclusion. And so after that when I went to try and get work in a private sector company everything is going fine until they asked how much I had accomplished in my term with the government and that basically disqualified me. they wanted to know what I had actually done. I had done so little. The government didn’t care about productivity. It was more important that they gave a job to a disabled person” (P4)</td>
</tr>
</tbody>
</table>
The three categories of contributing factors—predisposing, enabling and reinforcing factors—were broad enough to encompass all the themes that emerged from the data. The categories are not fixed and rigid. Depending on one's perspective, conceptual themes such as "social rewards" or "financial rewards" could be viewed as reinforcing factors associated with employment, as they were in this analysis, or they could be viewed as predisposing factors (i.e., people are motivated to work because of their desire to "fit in" and their desire for money). In this sense, today's reinforcing factors are tomorrow's predisposing factors.

**Discussion of Findings**

A discussion related to each of the three research questions will follow. The findings of this research will be discussed in relation to theoretical expectations, other research studies, and methodological issues.

**Health-Related Quality of Life Outcomes**

Quality of life comparisons of renal transplant recipients to the general population of BC show that the health outcomes of people with renal transplants, as perceived subjectively, are worse than the health outcomes of the general population across all health domains. The health domains most affected are physical and role functioning (walking uphill, carrying groceries, running, participating in sports, doing housework, working outside of the home). About twice as many renal transplant recipients function poorly in the physical and role categories compared to the general population. The area of health least affected is mental health. In terms of general mood, affect and well-being there is no clinically meaningful difference between renal transplant recipients and the general population. This finding—poor levels of health in terms of physical functioning but comparatively good levels of health in terms of mood and affect—is consistent with
the findings of other investigators (Bremer et al., 1985; Evans et al., 1985; Johnson et al., 1982; Singer et al., 1992).

One possible explanation for the good levels of psychological health reported by the transplant recipients may be the tendency for people to accommodate or adapt to their situation over time reflected in gradual increases in satisfaction and well-being. The majority of the transplant recipients in this study have lived with end-stage renal disease for approximately six years and have been transplanted for over three years. Although they may have functional limitations due to their disease, their health is stable. In the short-term, deterioration in health may touch off surges of dissatisfaction, but if a person is in a fixed situation for a long enough period of time, aspiration levels will gradually contract and the satisfaction level will increase (Campbell et al., 1976, p. 485).

It is important not to overstate the significance of these quality of life outcomes as a measure of the success or failure of renal transplantation. There is no question that renal disease and transplantation have an impact on perceived functioning and well-being but variations in health outcomes are potentially confounded by many non-renal variables such as the presence of other coexisting diseases, stressful life events, and socio-demographic factors such as age and education. A second consideration is that health-related quality of life is not yet a fully developed construct. There are serious limitations in the interpretation and application of quality of life data. Methodologically, the use of a short, self-administered quality of life measure although efficient and inexpensive to administer is also very reductionistic by nature. Scores obtained on the SF-20 may not accurately reflect the health-related quality of life of the transplant recipients. The SF-20 may not be adequately sensitive to small but clinically important variations in health between patients. There is also evidence that short-form
measures present problems with ceiling and floor effects, whereby substantial numbers of patients achieve the highest or the lowest possible scores (Ware & Sherbourne, 1992). A very simple scoring system is used in the SF-20. The number of items experienced by the patient are tallied, with no weights attached to the item to indicate its relative importance. For example, a patient may view the transplant as successful with only one or two positive changes recorded on the health questionnaire, but those changes happen to be the ones that are most important to the patient. The health care provider may feel that unless there are changes across all six domains, the treatment has not been successful (Hauser et al., 1991). With this type of scoring system, the interpretation of the meaning of the scores is subjective and it is important not to judge the success or failure of renal transplantation solely on the quality of life score.

**Employment Outcomes**

The employment rates (56.5%) of the renal transplant recipients in this study were within the range of employment rates reported in the renal transplantation literature. However, cross-study comparisons of employment are problematic due to the different definitions of work applied by different investigators. For example, in this study people employed full-time, part-time or on temporary leave from their jobs were all considered to be employed, consistent with the definition used by Statistics Canada. In the study by Evans et al. (1985), 53.5% of transplant recipients were working full- or part-time but it is not clear if people on temporary leave were included in this calculation. Similarly, Bremer et al. (1989) reported 53% of transplant recipients were working full or part-time. Other investigators such as Johnson et al. (1982) who reported a very high rate of employment (70%) used a definition of work which was broad and included housewives performing their housework without any help. Any attempt to aggregate study findings is
further complicated by the differences in sample characteristics across studies. Gender is known to be associated with employment. Males are more likely to be working for pay than females (Evans et al., 1990; Simmons et al., 1988). In this study both males and females were represented. In studies where only males were surveyed employment rates for transplant recipients were reported as 79% (Simmons et al., 1988).

Sample size and response rate are important considerations when assessing the representativeness of the sample and determining the significance of the study findings. A large sample size combined with a good response rate improves the validity of the findings. The sample size in this study (216) was large and the response rate (78.3%) was high. When the respondents were compared to the nonrespondents based on age, gender, race and diabetes, the groups appeared to be comparable. However, despite these considerations, the subjects who responded to the mail survey may differ from those whose who did not respond in an important way. It may be that the subjects who responded were more likely to be employed than the subjects who did not respond. Consequently the employment rate may be overreported slightly in the study findings.

The results of this study confirm the findings of others that kidney transplant recipients experience lower rates of employment and higher rates of unemployment compared to the general population (see Table 7). The employment rates of the transplant sample were compared to the general population in two different ways. First, since geographic location is known to affect employment rates, with more employment opportunities available in large urban centres, geographic location was controlled in this study and subjects were drawn from the lower mainland of BC. Based on a comparison of the study findings with the general population from the lower mainland of BC the employment rate was
56.5% for the study sample and 60.6% for the general population (a difference of 4.1%). The literature consistently supports the finding that younger age is positively correlated with employment status in ESRD patients as it is in the general population (Evans et al., 1990; Flores et al., 1985; Simmons et al., 1988, Statistics Canada, 1991). Age was also controlled in this study. The age of the respondents ranged from 22 to 64 years. When the study sample was matched to the general population in BC based on age, the difference in employment rates became much more dramatic (56.5% vs. 69.8%, a difference of 13.3%). The unemployment rate in the study sample was 14.1% which was quite a bit higher than the unemployment rates in the general population (9.4% to 9.6%). Based on these findings, renal transplant recipients are not equally represented in the workforce.

Official statistics on unemployment count only those people who are actively seeking employment. The statistics ignore substantial numbers of people who do not have jobs but who have become discouraged and stopped looking for work. Almost half the subjects (45.9%) who were not active in the labour force said they were not satisfied with the amount of work they did. Adding some of these jobless individuals to the unemployment calculations of the study sample would depict an incidence of unemployment much greater than 14.1%. However, the gap between the employment activity of the renal transplant recipients and the general population may not increase in size since the same tendency to underreport unemployment occurs in the official Labour Force Survey from Statistics Canada.

The proportion of people working in managerial and professional occupations in the renal transplant population (29.5%) was comparable to the general population of BC (29.3%). The categories that showed large discrepancies in distribution were the clerical occupations, the primary and processing occupations and the construction and transport equipment operators.
Renal transplant recipients were much more represented in the clerical occupations and much less represented in the primary, processing and construction occupations. This finding probably reflects the fact that renal transplant recipients are not able to handle the physical demands of jobs in the primary occupations and construction and are more suited to sedentary office work.

Slightly more people were working following their transplant (56.5%) than when they were on dialysis (54.6%) although the difference in the employment rates was not large. People moved between the employed and the not employed groups. A total of 33 respondents who had not worked in the year prior to transplant were working after transplant; 29 respondents who were working while on dialysis had dropped out of the workforce after transplant. A cross-sectional survey captures only a snapshot in time. The study design is limited in what it can say about the flow of people in and out of the workforce. However, based on the findings in this study it would seem that transplantation is slightly more successful than dialysis in returning people to the workforce.

Factors Associated with Employment Status

Participation in the workforce is a complex phenomenon. Employment is dependent on a combination of factors that reside in the individual and in the socio-cultural, economic and political realm. These factors can be classified as predisposing, enabling or reinforcing factors. Generally speaking, for work behavior to occur and persist the individual must be sufficiently motivated to work (a predisposing factor), have the ability to work and the availability of a job (enabling factors) and there must be some monetary or personal reward for the work effort (reinforcing factors). Analysis of the data from the Health and Employment Survey identified the five most statistically significant enabling factors associated with employment following transplantation: employment in the year
prior to transplant, good physical functioning, younger age, higher education and no diagnosis of diabetes. This list was expanded to include some very important predisposing and reinforcing factors that emerged from the analysis of the data from the personal interviews. The combined results add breadth and depth to our understanding of the combination of factors associated with employment outcomes in the renal transplant population.

The data that emerged from the personal interviews showed that both the employed and the not employed group share a common belief in the work ethic. They feel it is important to contribute to society through work activity and they value personal achievement and self-sufficiency. However, due to individual circumstances three of the seven subjects were not working for pay at the time of the interview, although they were involved in other meaningful activities. To subject P5, looking for work was a full-time job: “I spend eight to ten hours a day at this. Working through my phone calls and going for lunch with different people that I know. Keeping in touch with my contacts” (Appendix I, lines 209-211). Subject P6 was a homemaker and in her view this activity was full-time work: “I have two children and a husband and I work at home and I work my butt off, and gardens, and a dog, and it’s full-time work”. Another subject, P7, worked two days a week as a volunteer at the Kidney Foundation office. She tired easily and she felt she would not be able to handle the physical demands of working for pay. She took pride in her volunteer work, and to her it was as important as a job. It became clear that these subjects preferred a broader definition of work that recognizes the various forms of unpaid work that many people perform.

Belief in the societal work ethic motivates some people to work. Other people work for more personal reasons. Two interview subjects were predisposed to work because they were grateful for their good health and it made them feel
good to give something back to society through working: “It’s kind of like I owe so much, because of the situation that I have” (P1); “I feel I owe them everything so I decided to give them some of my time, that’s the way I figure it” (P7). The uncertainty of future health was a motivating force for another subject: “With my health being so good there is an imperative to take advantage of it” (P5).

There are numerous factors that enable people to participate in the labour force. Health is dominant in this list. Health and employment are directly related to each other and the relationship is reciprocal - positive health selects people into the employment role and employment for a variety of reasons can have a beneficial effect on health. Normal physical functioning based on the scores received on the MOS SF-20 health questionnaire was the second strongest predictor of employment (p < .01) in the survey sample. The issue of functional health also emerged from the personal interviews as an important theme. The transplant recipients’ functional health status is extremely variable. In some cases, transplant recipients are able to work an eight hour day and participate in physical activities such as tennis and swimming. In other cases transplant recipients are forced to lead more sedentary lives. They have persistent trouble with hypertension, fatigue, poor muscle strength or shortness of breath on exertion.

Diabetes is the primary renal disease for approximately 18% of the ESRD patients registered in BC (CORR, 1991, Table 43). Based on the survey results, the fifth strongest predictor of employment was diabetes as the primary renal disease (p < .05). There are many long-term complications associated with diabetes such as damage to the nerves, eyes and kidneys that contribute to the inferior health status of transplant recipients who have a primary diagnosis of diabetes and the negative correlation of diabetes with employment. The correlation of diabetes with employment is consistent with the findings of Evans et al. (1985) and Simmons et
al. (1988). The subject P4 had diabetes and he was also blind. He acknowledged that his blindness was a significant barrier to employment: “I've got to work around it. It’s shear overhead. It takes me longer to do things”.

Past work experience and an uninterrupted attachment to the workforce are important enabling factors. Based on the survey results people who were employed in the year before transplant were more than four times as likely to be employed following transplant compared to those who were not employed during that time (odds ratio: 4.8). Evans et al. found the same association: “the patients that work prior to transplant are the same patients that work posttransplant, consistent with the adage that the best predictor of a person’s future behavior is their past behavior” (1990, p. 7-20). Scheckter examined the American Census data and concluded that strong ties to work prior to onset of illness, independent of age, affect employment outcomes following disability (1981, p. 25).

All people with ESRD will inevitably go through periods of time when they are unable to work. Worklife is interrupted when dialysis is initiated and some people are unable to resume work while they are on the dialysis program. For those who choose to have a transplant, the minimum time off work is approximately three months. Prospective employers will want an explanation for these work interruptions. Transplant recipients such as P1 and P2 who have secure unionized jobs with good benefits find they are able to return to their jobs once their transplant stabilizes, even though they may have been off work for several years while on dialysis. Other individuals are not so fortunate. In some cases people with renal transplants never regain the same energy and strength they had prior to the onset of their disease and they need to retrain and look for less strenuous employment. For others, absenteeism from work due to episodes of illness may jeopardize their careers - they may be overlooked for promotions, laid off or even fired from their
jobs. The psychological strain associated with chronic illness is compounded by the strain of forced unemployment. Therefore a key objective of renal social work should be job retention to prevent persons with ESRD from ever leaving the workforce.

Education and training are important factors in securing employment. Higher education was the fourth strongest predictor of employment based on the survey results (p < .05). Many previous studies support the finding that higher education is positively correlated with employment status (Erickson, 1989; Evans et al., 1985, Flores & Callender, 1987; Simmons et al., 1988; Statistics Canada, 1991).

Although education is an important enabling factor, we observe many Canadians, such as P5, who are unemployed despite a university degree and previous work experience. This finding supports the conceptual framework that employment is not strictly an individual issue. It is intricately connected to the economic, social and political environment. New technologies reduce the demand for labour in old industries and minimize the demand in new ones. The economic recession has led to the downsizing and the closure of many industries. P5 is young, healthy, well-educated, and highly motivated to work, but despite his engineering degree and his work experience in the mining industry he is unemployed. P5 is a good example of someone who is not highly employable due to a poor person-environment fit: “The mining industry is shrinking. It’s in the throes of its own little recession here in BC. There’s not a lot of development. What fueled a lot of job opportunities, was the expansion. So you have more miners than you have mines right now. So it’s time to move from that industry” (Appendix I, Lines 131-136).
Vocational counseling was viewed by one of the interview subjects as an important enabling factor:

"The sessions that I have had keep you focused on what you’re trying to do and tell you about the latest things - how to sell yourself. We even videotaped interviews. I’d sit for an interview with one of the counselors or one of the other people. You’d go through different types of interviews - the lousy interview, the stress interview, the professional interview and then we’d read over the job description and put me in a situation like I might face in the actual interview. That worked quite well. It really helped (Appendix I, lines 177-186).

This same individual also emphasized the value of his family and his social contacts to support, inform and motivate him.

Some of the reinforcing factors associated with work are tangible in the form of wages but also intangible in the enhanced feelings of well-being and sense of purpose that accompany paid employment. Enjoyment of the social contact and sense of affiliation were also identified by interview subjects as important reinforcing factors.

Factors that Act as Barriers to Employment

When the 74 renal transplant recipients not active in the labour force were asked to identify their main reason for not working, 23 listed poor health as the primary reason and an additional 22 reported that they had retired early because of poor health for a total of 45 (60.8%). The importance of good health as a positive enabling factor has been discussed earlier. Conversely, poor health emerged as a negative enabling factor (a barrier) to employment. When people have physical limitations or when they feel unwell they are less able to handle the demands of a job: “it was quite a load on me, trying to keep up that way, the long hours” (Table
13, P5). Even when their health is stable, transplant recipients live with the knowledge that they are immunosuppressed and therefore more susceptible to infection and that the transplant itself could reject at any time: "I don't know what my health is going to be next year or five years from now. I don't know if I'm going to get very sick or if it's going to keep going" (P5). Whereas P5 was motivated by his uncertain health situation - "with my health being so good there is an imperative to take advantage of it" (P5) - other people are inhibited by the uncertainty and more protective of their health - "I won't work at just anything, I'll dictate some conditions, because I have to in my position ... it really means everything to me to take good care of my health" (P6). Cautious individuals who are protective of their health are likely to be more selective of the kind of employment they are willing to consider which will lower their return to work rates.

Older age is a well-recognized barrier to employment. Job opportunities diminish for the older worker and re-entering the workforce is hardest for those over 45 years of age (Kirsh, 1983, p. xi). Even vocational rehabilitation programs are geared to assist the younger unemployed clients. Older individuals are viewed as too old for rehabilitation services - their expected careers being too short to justify the investment of dollars in education and job retraining. As the selection criteria for dialysis and transplantation has broadened to include older adults, the mean age of people with end-stage renal disease has increased. Of the 278 people in BC who started treatment for ESRD in 1991, and who potentially will experience some disruption in their work situations, 38.5% (107) were between 45 and 64 years of age compared to 23.4% (65) who were under the age of 45 (Canadian Organ Replacement Register, 1991, Table 28). A large proportion of the transplant sample in this study (44.4%) was over the age of 45. The results from the transplant survey indicate that 25 (33.7%) of the 74 survey respondents not active
in the labour force retired early primarily due to poor health. Given the increased age of the renal transplant population, and the disadvantages older adults face in the job market, it may be that we need to modify our expectations of their participation in the workforce.

Discrimination in the hiring practices of employers is a concern of chronically ill people and it was reported by two respondents from the mail survey as the primary reason for their unemployment. One of the interview subjects recounted a personal experience where he experienced discrimination in applying for a job: “the human resources people said ‘no, don’t take this guy. He’s going to get sick and then we’re going to have this big debt. We’ll have to support this guy who’s not doing anything anymore” (Appendix I, lines 256-260). Discrimination is difficult to prove, but it seems probable that companies would choose to give preference to employees in good health over those who have a chronic disease.

As the results from the survey indicate, working following transplant requires tolerance and flexibility on the part of employers. For 17% (21) of the transplant recipients who were working, extra time off was required to attend medical appointments. Another 10% (12) had their employers make tasks a little more manageable for them. Another subject (P5) interviewed for this study expressed the view that he was laid off in part because of the extra time he required to attend medical appointments.

One of the questions in the interview guide was whether or not attitude to work had changed since diagnosis. The assumption was that people who have faced death might reevaluate the importance of work and give priority to other life roles and activities such as their role within the family or their leisure activities. According to this subject’s experience ties to work did not change post-illness, if anything he became more motivated to work (Appendix I, lines 396-406).
Some investigators have raised the question of whether or not social assistance programs foster dependency and are a structural disincentive to employment (Erickson, 1989; Flores & Callender, 1987). Public assistance programs categorize welfare recipients as either employable or unemployable, and benefits for the unemployable are higher. It is therefore in a client's interest to present him or herself as not able to work and the social worker who wants to help the client get the best support, might be subtly motivated to encourage this practice (Riches, 1989, p. 298). Similarly, due to the eligibility criteria of the Canada Pension Plan Disability benefits, it may be in a transplant person's financial interest to remain on disability payments rather than risk employment which might then disqualify the individual from receiving future benefits. People on social assistance who are categorized as unemployable and disabled receive extended medical and dental benefits - important benefits to people diagnosed with a chronic illness. Recent reports indicate that approximately one in ten British Columbians are receiving social assistance and the largest single group of all welfare recipients is single men (Baldry, 1993). Results from the mail survey show that a comparable number (10.2%) of the survey respondents receive social assistance; 28% (61) receive public or private disability pensions; and 5% (11) receive unemployment insurance benefits (Table 3). Fear of losing disability benefits was reported by four respondents as the main reason they were jobless. The question of whether or not the social programs in our society are a disincentive to working was not specifically addressed in this study and cannot be answered by the data. The decision to work for pay is influenced by many factors. A more positive approach to the concern about the high numbers of people dependent on social programs might be to ask the question whether or not our society provides adequate incentives to working.
In conclusion, there is a complex and reciprocal relationship between the major themes (classified as predisposing, enabling and reinforcing factors) and employment activity. Personal values and beliefs, skills and abilities are directly related to employment (as predisposing, enabling and reinforcing factors) and the relationships are reciprocal. The work ethic predisposes people to work and participation in the workforce reinforces working as part of our personal identity and belief system. Our environment (the political and economic environment, the physical work environment as well as our more interactive social and cultural environment) directly impacts on employment behavior. Health is directly related to employment. and the relationship is also reciprocal - good health selects people into the employment role and employment, for a variety of reasons (valued social role, access to health insurance, social support), can have a beneficial influence on health. Several sociodemographic factors are directly related to employment. Previous research has shown that people with more education are more likely to work, regardless of marital status and age. Education is viewed as directly related to employment. Marital and parental status are directly related to employment (married women may be less financially compelled to work and may even be subject to pressure by family members to stay at home rather than seek employment, parents of small children may be less likely to work). Age is directly related to employment and it may also be indirectly related to employment through health (older people are more likely to have health problems and they are less likely to work).

In the final chapter, the study conclusions, implications for social work practice, and recommendations for further research are presented.
CHAPTER FIVE
Conclusion, Implications and Recommendations

Introduction

This study was designed to investigate patient outcomes following kidney transplantation in terms of health-related quality of life and employment, from the perspective of the renal transplant recipient. In addition, it was designed to identify the main factors or characteristics associated with employment. The study conclusions, implications for social work practice, and recommendations for further research are presented in this final chapter.

Conclusions

The impetus for this study arose from the researcher's clinical observation that the medical team expected individuals, with successful kidney transplants, to return to full employment following surgery. It seemed that many transplant recipients were not meeting this expectation. However, there were no recorded statistics on the actual health and employment outcomes of renal transplant recipients in BC to determine the extent and nature of the problem. Published reports on the employment outcomes of renal transplant recipients were based primarily on centres in the United States. Most reports did not go beyond a simple reporting of the employment statistics. There was no comparative information provided on employment rates in the geographic area from which the study samples were drawn which made it difficult to interpret the results. Few investigators conducted a multivariate analysis to determine the factors or characteristics most strongly associated with employment. It was recognized that a study was needed to provide estimates of the extent of the employment problem within the renal transplant population in BC and to generate baseline knowledge regarding the contributing factors to employment that could
provide new directions for the provision of effective vocational rehabilitation services to the renal transplant population.

This descriptive study was conducted in the lower mainland of British Columbia, in two stages. In stage one a cross-sectional survey design was used to describe the perceptions of renal transplant recipients concerning their health-related quality of life, and to estimate the proportion of renal transplant recipients who were employed and the proportion who were not employed. Then a case-control study approach was used to retrospectively describe the characteristics of the employed and the unemployed subgroups and to estimate the strength of the association between each characteristic and the employment outcome (in the form of the odds ratio). In stage two, personal interviews were conducted to explore further the characteristics associated with employment outcomes and the meaning of work in a purposeful sample of four employed and three unemployed transplant recipients.

Examination of the health-related quality of life outcomes of renal transplant recipients as measured by the MOS SF-20 showed a mixed profile. When compared to the general population, physical functioning and role functioning were the health domains most affected, followed by health perceptions, pain and social functioning. There was no clinically significant difference in the mental health of renal transplant recipients when compared to the general population.

The labour force activity of the renal transplant recipients was less (65.7%) than the labour force activity of the general population in BC when matched for age (77.9%). The unemployment rate was higher in the transplant sample (14.1%) compared to the unemployment rate in the age-matched sample from the general population (9.6%).
A multiple logistic regression model was estimated to determine the factors most strongly associated with employment status. The five variables found to be the most statistically significant predictors of employment status were employment status during the year prior to transplant (p < .0001, odds ratio: 4.8), physical functioning score on the Medical Outcome Survey (p < .01, odds ratio: 2.7), age (p < .05, odds ratio: 0.96), education (p < .05, odds ratio: 1.3), and diabetes as an underlying illness (p < .05, odds ratio: 0.35). These factors were classified as enabling factors according to the PRECEDE-PROCEED model. The employed group were more than four times as likely to have worked in the year before their transplant, 73% of the employed transplant recipients had normal physical functioning compared to 42.5% in the unemployed group, the mean age of the employed group was 39 years compared to 48 years in the unemployed group, 60.6% of the employed group had some post-secondary education compared to 43.6% of the unemployed group, and 7% of the employed transplant recipients were diabetic compared to 17% in the unemployed group.

In conclusion, although kidney transplantation is the optimal treatment for people with end-stage renal disease, many people with renal transplants do not return to full health. Based upon the findings of this research approximately two thirds (63.2%) perceive their health to be impaired. Limitations persist particularly in the area of physical functioning and the ability to perform one’s usual roles at home, school and work. The area least affected is the transplant recipients’ mental health. People with renal transplants generally adjust well to their condition and their mental health approaches the levels found in the general population.

As a society we tend to view unemployment as an individual problem and perceive the unemployed as less productive and therefore less valuable human beings. To take this view detracts attention from the complexity of the issue and
results in ineffective solutions to the unemployment and underemployment of renal transplant recipients. Employment prospects and opportunities are less than optimal for people with kidney transplants as evidenced by the study finding that employment rates for kidney transplant recipients lag behind the rates for the general population. The reasons for this finding are multifactorial and reside in the individual and in the socio-cultural, economic and political reality. When poor functional health is compounded by limited education, increased age, forced separation from the workforce, the conflicting demands of other important and meaningful life roles such as parenting and the unavailability of suitable work, disadvantages in employment increase. Some additional barriers to employment for the renal transplant recipient include an inflexible work environment that does not permit additional time off for medical appointments and discrimination in the hiring practices of employers.

**Implications for Social Work Practice**

The implications for social work training and practice are discussed in the following section beginning with a commentary on the public policies that shape the delivery of health care and create employment opportunities for renal transplant recipients in Canada.

**Public Policy**

Public policy establishes goals, sets priorities and directs the allocation of resources. The clients that require social work intervention are part of an open, dynamic system. The challenge to social work is to connect the personal troubles of the renal transplant population to the broader domestic policies that shape the provision of health care services and the opportunities for employment in Canada.

Canada's health policy under the principles of the **Canada Health Act** of 1984 are fairly well defined with the goal to protect, promote and restore the
physical and mental well-being of residents of Canada through the provision of universal access to high-quality medical and hospital facilities and services. Canadians with end-stage renal disease are offered several alternative treatments, principle among these is renal transplantation. The medical and hospital costs for the transplant surgery and follow-up care are fully covered through the provincial health care plans. In British Columbia, the costs of all immunosuppressant medications are also covered through the provincial Ministry of Health. Transplant surgery is a highly specialized procedure that is currently available in three hospitals in BC - Vancouver General Hospital, St. Paul's Hospital and Children's Hospital. Access to the Vancouver transplant teams may create a financial burden for some people with ESRD who live in the remote areas of the province, but as the province shifts its focus to providing post-transplant care "closer to home", any current financial strain on patients may be reduced.

Canada’s employment policy is less clear. In the post-war years the Canadian white paper entitled Employment and Income described broad agreement that a full employment goal could be reached through government intervention at little cost. The prevailing view was that unemployment was largely involuntary due to frictional or cyclical forces; it represented wasted resources; and it created economic hardship. Unfortunately, the measures to guarantee full employment did not materialize and today, although unemployment has become the country’s leading social issue, a consensus on the nature of the problem and what to do about it is not so easily reached. Today it is recognized that some unemployment is voluntary and, through the financial support of income compensation programs, the unemployment rate is no longer a valid indicator of the financial hardship of unemployment; unemployment is not a signal that companies are inefficient, in fact many companies report increased business
activity and profits after they restructure; government attempts to reduce the
unemployment rates would be expensive and result in an acceleration of the
inflation rate (Ashenfelter, 1983). In 1945 there was zero tolerance for
unemployment, an acceptable level of unemployment in 1964 was 3 percent, by
1985 it had more than doubled to between 6.5 and 8 percent, by 1991 the national
rate of unemployment reached 10 percent and it has continued to rise. Most
economists would agree that, despite public expectations, full employment is no
longer a national goal.

A number of commentators have suggested that Canada is not experiencing
a recession from which there will be a recovery. Canada is facing a restructuring of
the economy. Mass unemployment is here to stay attributed to technological
advances, a declining Canadian economy, a free trade arrangement with the
United States, and foreign competition from industrialized countries where wage
rates and other costs of production are much lower (Guest, 1989). In contrast to the
responsibility of the post-war government to maintain a high and stable level of
economic activity, government in the last ten years has relied on private market
forces to become the driving force of economic renewal. Business does not have a
history of assuming responsibility for the poor or disadvantaged. As chronic
unemployment grows it is likely to disproportionately affect minority groups
including persons with chronic health problems (Riches, 1990).

Clinical Practice, Program Development

Within this national context what is an appropriate employment goal for the
renal transplant population? Do we want to see equal outcomes to ensure that
transplant recipients are fairly represented in the labour force? Do we want to work
towards equal opportunity to apply and be considered for a job? If our goal is a
reduction in the unemployment level to the national average, we first need to
ascertain the number of “employable” persons with work related problems in order to derive an estimate of need for programmatic responses. If equal access to jobs is our goal we might need to improve our advocacy programs, provide more aggressive public education and outreach programs, perhaps create some incentives to employers.

Outcome studies on the health and employment status of renal transplant recipients provide baseline data on current patient outcomes. These study findings allow monitoring of progress toward meeting the goal of full rehabilitation for this population. They also provide estimates of the need for social work services. The health profiles act as a guide enabling social workers to direct intervention in areas where they are most needed. However, there are limitations in the clinical applications of survey findings. Surveys describe the average patient outcome. Social workers do not work with average or "typical" patients. Knowledge of the average effect of disease and treatment on quality of life and employment may be quite different from the specific effect on the individual client. For clinical decision-making this general survey knowledge needs to be supplemented with more specific and detailed information that reflects the richness and complexity of the individual client's circumstances at the time of contact (Holman, 1993).

High levels of unemployment and underemployment of the renal transplant population will create an additional strain on people already under the stress of adjusting to life with a chronic illness and it will affect the context of clinical practice. Unemployment has an impact on the type of personal and social problems experienced by renal transplant recipients. The literature attests to the relationship between unemployment and poverty, the negative consequences on personal health and well-being, and the associated increases in family breakdown, wife battering and child abuse (Ternowetsky, 1989, p. 317).
A study identifying the factors that contribute to or inhibit employment activity is an important first step to developing an understanding of the reciprocal relationship between the individual and the environment. Chronic illness, unemployment and the personal troubles associated with both, exist within a wider socio-cultural, economic and political world. Social work is an applied discipline that empowers people to deal with their problems within the context of their situations. If social workers are to provide effective help, they need to develop a broad knowledge base and a wide range of clinical, programmatic and policy skills that allow them to intervene at many different levels.

The mapping of the correlates of employment into predisposing, enabling and reinforcing categories may be a useful framework to guide social work intervention. Using this model, specific features of the client's situation can be grouped according to the types of social work intervention available. Predisposing factors refer to the individual's motivation to work and individual counselling might be effective in this area to help modify self-defeating attitudes or beliefs that are negatively impacting on motivation to work. However, a strong desire to work is not enough. To be successful in securing a job, the unemployed individual may require assistance to make appropriate occupational choices, to learn specific job search skills, or to access training programs or financial services. Family work might be useful to improve the social support network of the client. If discrimination by employers is viewed as a barrier to employment, the social worker may need to become a patient advocate, do some public education, community organization or social action. Social work has been criticized for not addressing the structural imbalances that perpetuate important social problems such as unemployment (Ternowestsky, 1990). In responding to the increasing unemployment and underemployment of their clients, social workers may need to become politically
active and challenge the economic policies of the government for providing enormous sums of hidden, fiscal welfare for corporations that are creating unemployment while restricting aid to the poor and unemployed (Ternowestsky, 1990, p. 321).

Woods and Vandergoot in The changing nature of work, society and disability write that in periods of economic growth and full employment there was little reason to question the concept of paid employment as the route to a healthy individual and a healthy economy. However, the situation in Western societies has changed. Most economists do not expect Canada to return to a period of full employment. The various forms of unpaid work that many people perform need to be recognized and the right to a guaranteed minimal income must be acknowledged formally (Woods & Vandergoot, 1987). Many renal transplant recipients, despite good kidney function, are not likely to work and the social worker will have to develop strategies to promote the health of these individuals. The time has come to modify our expectations of the return to work rates for people following renal transplantation, to broaden our definition of work, and to assume a community responsibility to support the jobless.

Recommendations for Further Research

Subjects for this study were drawn from one geographic area, the survey material was in English, and the personal interview was conducted in English only. In order to broaden the generalizability and potential implications of the study findings there is a need for replication of this study throughout the entire province of BC. Consideration should be given to identifying the preferred language of the respondents and providing translations of the data collection instruments.

It may also be useful to replicate this study in populations with other chronic conditions in order to determine if the factors that impact on employment in the
renal transplant population are common to persons with other chronic health problems. This information would allow us to develop a broad strategy for improving access and equal opportunity to jobs for all persons who desire them.

Health and employment outcomes in this study were only measured at one point in time. Longitudinal tracking of the health and employment outcomes in the same individuals over time, and across various treatment modalities, would provide additional information on the flow of people in and out of the workforce and the relative strength of the relationships between employment activity and perceived health status.

The findings of this study raise questions about quantifying a realistic employment goal for the renal transplant population. Should we be expecting renal transplant recipients to participate in the labour force at the same rate as the general population? How do we determine the number of “employable” persons with work-related problems who require rehabilitation services in order to ensure adequate resources are in place to meet the need?

As we move into a post-industrial society characterized by high rates of unemployment, it is likely that minorities such as people with chronic health conditions will be disproportionately represented in the workforce. Patient outcomes research has important practical value in monitoring our progress toward meeting the goal of full rehabilitation within these populations, as well as theoretical relevance for developing conceptual models of health promotion and planning.
REFERENCES


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Appendices
Appendix A

Health and Employment Survey
I would like to begin by asking you some questions about your HEALTH. In most cases you will be asked to circle the number that represents the answer you prefer.

1. In general, would you say your health is:

   (circle one)
   Excellent 1
   Very good 2
   Good 3
   Fair 4
   Poor 5

2. In general, does your health limit you in the activities listed? Please circle "1" for YES and "2" for NO.

   YES     NO
   The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports 1 2
   The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling 1 2
   Walking uphill or climbing a few flights of stairs 1 2
   Bending, lifting or stooping 1 2
   Walking one block 1 2
   Eating, dressing, bathing, or using the toilet 1 2

3. How much bodily pain have you had during the past 4 weeks?
   (circle one)
   None 1
   Very mild 2
   Mild 3
   Moderate 4
   Severe 5
   Very severe 6
4. Does your health keep you from working at a job, doing work around the house or going to school?  
   (circle one)  
   Yes 1  
   No 2  

5. In the past four weeks have you been unable to do certain kinds or amounts of work, housework or schoolwork because of your health?  
   (circle one)  
   Yes 1  
   No 2  

6. Please circle the answer that describes how you have been feeling during the past month.

<table>
<thead>
<tr>
<th>How much of the time, during the past month, has your health limited your social activities (like visiting with friends or close relatives)?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
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</tbody>
</table>

<table>
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<tr>
<th>How much of the time, during the past month, have you been a very nervous person?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
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<td>6</td>
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</table>

<table>
<thead>
<tr>
<th>During the past month, how much of the time have you felt calm and peaceful?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
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<tbody>
<tr>
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<tr>
<th>How much of the time, during the past month, have you felt downhearted and blue?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
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<tr>
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<td>4</td>
<td>5</td>
<td>6</td>
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</table>

<table>
<thead>
<tr>
<th>During the past month, how much of the time have you been a happy person?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
</tr>
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<tbody>
<tr>
<td></td>
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<td>4</td>
<td>5</td>
<td>6</td>
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<table>
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<tr>
<th>How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?</th>
<th>All of the time</th>
<th>Most of the time</th>
<th>A Good Bit of the Time</th>
<th>Some of the time</th>
<th>A Little of the Time</th>
<th>None of the time</th>
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<tr>
<td></td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
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</table>
7. Please circle the answer that best describes whether each of the following statements is true or false for you. Circle one answer for each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely true</th>
<th>Mostly true</th>
<th>Not Sure</th>
<th>Mostly False</th>
<th>Definitely False</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am somewhat ill</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am as healthy as anybody I know</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>My health is excellent</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I have been feeling bad lately</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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Now I would like to ask you some questions about YOURSELF and your EMPLOYMENT situation.

1. What is your current marital status?
   (circle one)
   - Now Married 1
   - Separated 2
   - Divorced 3
   - Widowed 4
   - Never married 5

2. What level of education have you completed?
   (circle one)
   - Grade 8 or less 1
   - Grade 9 to 11 2
   - High school graduate 3
   - Some post-secondary 4
   - Post-secondary certificate or diploma 5
   - University Degree 6

3. Is this your first kidney transplant?
   - Yes 1
   - No 2
4. Were you on dialysis before receiving your transplant?
   Yes 1
   No 2
   If Yes, for how long? ________

5. Did you work for pay in the year before your last transplant?
   Yes 1
   No 2

6. Have you ever worked for pay?
   Yes 1
   No 2
   If Yes, how many years have you worked in all? ________

7. Are you satisfied with the amount of work that you do?
   Yes 1
   No 2

8. What is your current source of income? Please circle all that apply.
   Wages and salary 1
   Unemployment insurance 2
   Spouse, family support 3
   Ministry of Social Services and Housing 4
   Employer pension 5
   Old age security pension 6
   Canada disability pension 7
   Other (please specify) 8
9. What is your CURRENT work activity or employment status?

- Employed full-time (30 + hours a week) 1 (continue)
- Employed part-time (less than 30 hours a week) 2 (continue)
- Employed but temporarily on leave 3 (continue)
- Unemployed, looking for work 4 (go to Q. 13)
- Unemployed, NOT looking for work 5 (go to Q. 13)
- Retired prematurely because of health 6 (end of survey)
- Retired at usual retirement age 7 (end of survey)
- Other (specify) ___________________________ 8 (go to Q. 13)

10. What type of work do you do? Please describe: e.g., office clerk, factory worker, typist, school teacher.

________________________________________________________________________

11. How satisfied with your job are you?

- Completely satisfied 1
- Very satisfied 2
- Satisfied 3
- Neutral 4
- Dissatisfied 5
- Very dissatisfied 6
- Completely dissatisfied 7

12. Does your employer do anything special for you because of your health to make it easier for you to work at your job?

- Yes 1 If Yes, what does he or she do? ______

- No 2

<p>| |</p>
<table>
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<tbody>
<tr>
<td>(end of survey, thank you)</td>
</tr>
</tbody>
</table>

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13. There are a number of reasons people have for not working outside of the home. The main reason you are not working for pay at this time is:

- Personal illness or disability 1
- Home or family responsibilities 2
- I am too old to work but not retired 3
- Going to school 4
- Personal choice, do not wish to work 5
- No suitable work available 6
- Laid off, expect to return to work in future 7
- Would lose disability benefits 8
- Lack of job training or education 9
- Employer discrimination 10
- Other (Please describe) 11

THANK YOU FOR YOUR ASSISTANCE WITH THIS STUDY. IF YOU WOULD LIKE TO MAKE ANY ADDITIONAL COMMENTS PLEASE DO SO HERE.
Appendix B

Patient Interview Guide and
Patient Contact Form
Patient Interview Guide

Most of us think about working for pay at some point or another in our lifetime. The decision to work takes into account many factors. The purpose of today's interview is to explore the importance and meaning of employment from your point of view and to learn about the things that you considered in making a decision to work or not.

I want to remind you that this information will be used for my thesis, "the quality of life and employment status of kidney transplant recipients". Although I am taping the interview the information is confidential in so far as you will not be identified by your real name in any reports. As we go through the interview if you have any questions about why I am asking something or if there is anything you don't want to answer just say so.

Do you have any questions before we begin?

1. Please describe your current work situation.
2. Past experience with work? (ex. years worked prior to illness, type of work)
3. How important is it that you participate in the workforce?
   probe: what are the benefits to you? The disadvantages?
4. Has your attitude to work changed since your illness?
5. What makes it possible for you to work / what is going to help you find work?
6. What for you is a barrier to work/seeking work?
7. What other activities are important in your life?
8. Background questions: age, education, occupation, marital status, years since diagnosis and years with transplant
9. Is there anything you wish to add?
Patient Contact Summary Form

Date: ________________________________
Time: ______AM / PM
Length of Interview: ___________ minutes

Patient Name: ____________________________
ID Code: ____________________________
Race: ________________________________
Age: ______________
Education: ________________________________
Marital Status: ________________________________
Household Composition: ________________________________
Employment Status: ________________________________
Previous Work Experience:

Household Income: ______ $25,000 or less
 ______ $25,000 - $45,000
 ______ $45,000 - $60,000
 ______ $60,000 or more

Health:

Importance of Work:

Contributing Factors:

Barriers to Work:
Appendix C

Letter of Information, Stage One
Dear Friend,

I am a graduate student in the UBC School of Social Work and as partial fulfillment of the MSW degree I am conducting a survey entitled, Health and Employment Status After Kidney Transplantation. The survey is sponsored by the British Columbia Transplant Society and it is under the supervision of Dr. Manson-Willms (ph. 228-3251). We hope that you will be able to give us ten minutes of your time.

We know that some people with kidney transplants work outside of the home and others do not. We are interested in learning more about the decisions people make concerning employment. You can help by filling in the enclosed questionnaire and sharing with us your experiences and thoughts about your state of health and your employment situation.

You are under no obligation to participate in this study and failure to participate will not affect your medical care in any way. A returned questionnaire will indicate your consent to participate.

Your response will be anonymous. We use identification numbers only to check on our returns; you will never be indentified by name. In this way we can ensure your complete confidentiality.

If you have any questions about this project or if you need help filling out the questionnaire, please feel free to call me collect, Monday to Friday, during the day at 875-4377.

Please return your completed questionnaire in the enclosed pre-stamped envelope by March 15.

Thank you very much for your assistance.

Yours sincerely,

Beryl Ferguson, B.S.W.,
Student Investigator
Telephone # 875-4377.
Appendix D

Follow-up Letter, Stage One
Dear Friend,

We are pleased with the response we have had so far with our Health and Employment Survey. We appreciate how busy everyone is and how difficult it can be to make time to fit in extra requests of your time.

If you have already returned the questionnaire, we thank you. Your time is much appreciated.

If you have been unable to return the questionnaire we hope you will find 10 minutes in your busy schedule to fit it in. Many have already been returned. We would like to hear from all of you by March 15.

Please remember I am available to provide any assistance you may require in filling out the questionnaire. If you have misplaced the questionnaire I would be more than happy to send you another one. Please feel free to call me collect, Monday to Friday, during the day, at 875-4377.

Thank you for your time and help in this endeavor.

Yours sincerely,

Beryl Ferguson, B.S.W.,
Student Investigator,
Health and Employment Project.
Telephone # 875-4377
Appendix E

Follow-up Telephone Contact, Stage One
Follow-up Telephone Contact, Stage One

Hello _______________________

My name is Beryl Ferguson. I am a graduate student in the MSW program at UBC and I am calling regarding a survey that was recently mailed to you regarding your health and employment status following kidney transplantation.

We have not yet received a reply from you and I wonder if you intend to participate in the study? (WAIT FOR RESPONSE)

If YES: a) do you require another copy of the questionnaire? 
b) would you like to complete the questionnaire by phone with me now?

If NO: Thank you for your consideration of this request. I hope I have not disturbed your evening. Good night.
Appendix F
Letter of Information, Stage Two
Letter of Information

Dear

I am a graduate student in the UBC School of Social Work and as partial fulfillment of my MSW degree I am conducting a research study under the supervision of Dr. P. McNicoll. The purpose of this study is to gather information that will help health care providers understand the importance of the work role to people with a chronic illness such as end-stage renal disease and the things that inhibit or contribute to employment from the patient’s perspective.

As someone who has a good functioning transplant you have been selected to participate in this study. You are in a unique position to describe your current work situation and share your thoughts about the importance of the work role in your life. However, you are under no obligation to participate. If you choose not to participate this will not affect your medical care in any way.

I would like to conduct a personal interview with you. The interview will take about 60 minutes. It can take place in your home or in my office at the BC Transplant Society. You will be asked to provide some information concerning your work experience and the factors that you think inhibit or contribute to employment. You will also be asked to provide some background information on your health, your age, education and marital status.

The information you provide during the interview is regarded as confidential. Only the investigators, Dr. McNicoll and Ms. Ferguson will have access to the information. All data will be coded to protect your confidentiality. No names will be used at any time in referring to the data.

I would like you to read the accompanying document entitled, “Informed Consent” and consider whether or not you would be willing to participate in this study. I will telephone you in approximately one week to discuss this with you further.

Thank you very much for your consideration of this request.

Yours sincerely,

Beryl Ferguson
Study Investigator
Appendix G

Patient Consent, Stage Two
INFORMED CONSENT

Title: Determining the importance of the work role in a sample of kidney transplant recipients

Study Investigators: Dr. P. McNicoll (822-2977)  
Ms. B. Ferguson (877-2100)

I am a graduate student in the UBC School of Social Work and as partial fulfillment of the MSW degree I am conducting a research study under the supervision of Dr. P. McNicoll. You have been selected to provide some additional information concerning your views on the importance of the work role to a person with a chronic health condition. Participation is entirely voluntary. You may decide not to participate or you may withdraw from the study at any time without this affecting your normal medical treatment.

I would like to conduct a personal interview with you. You will be asked to provide some information on your work experience and to discuss the importance of the work role in your life and the factors that you think inhibit or contribute to employment. You will also be asked to provide some background information on your health, your age, education, and marital status. This interview will take about 60 minutes. The interview will be conducted in your home or at the BC Transplant Society at a time that is convenient for you. The interview will be audiorecorded.

The information you provide during the interview is strictly confidential. Only the investigators, Dr. McNicoll and Ms. Ferguson will have access to the information. All data will be coded to protect your confidentiality. No names will be used at any time in referring to the data.

If you have questions or concerns at any time during the study, please contact Beryl Ferguson at 877-2100 weekdays from 9 AM to 5 PM.
PATIENT CONSENT

I have read the above information and I have had an opportunity to ask questions to help me understand what my participation would involve. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form.

_________________________________________  ______________
Signature of Participant                      Date

_________________________________________
Signature of Witness
Appendix H

Follow-up Telephone Contact, Stage Two
Telephone Contact, Stage Two

Hello ____________________________

My name is Beryl Ferguson and I am conducting a research study on the importance of the work role to people with end-stage renal disease who have received a kidney transplant. Did you receive some information in the mail concerning this project?

If no, confirm mailing address and mail the information so person has time to read and consider the content before making a decision to participate or not.
If yes, proceed.

As I mentioned in my letter, as someone who has a good functioning transplant you are in a unique position to describe the impact of the transplant on your work situation and your thoughts about the things that you think inhibit or contribute to employment following transplantation. Have you decided whether or not you would be willing to participate in this study?

If undecided, probe for reason and offer to provide more information if needed or to call back in a few days if more time is required.

If yes, proceed.
What is your decision?

If person chooses not to participate. Accept this. Thank her (him) for taking the time to consider the request.

If person agrees to participate, continue.

I'm pleased you have agreed to participate. Now I would like to set up an interview time. It would be best for me to meet during the week. I could see you in my office at the BC Transplant Society or in your home, whichever you prefer. Also I could arrange an interview during the day or evening.

Proceed with scheduling the interview. Remind person that the interview will be audiotaped and will take about 60 minutes.

I am looking forward to talking with you on _{day} _at _{time} _in _{location}. Bye for now.
Appendix I

Transcript of Patient Interview
Transcript of Patient Interview

A = Interviewer
B = Subject (kidney transplant recipient)

1 A: As I mentioned (to you in the waiting room) I'm going to be talking to you about your employment situation and if it's ok I'll be taping the interview. [B: uh hm] I want to talk to you about the meaning and importance of employment from your own point of view and take a look at some of the things that you think about or took into account when you decided to look for work. There are so many different kinds of people receiving treatment for kidney failure and you each come from different backgrounds with different goals and expectations. In my thesis I want to represent the variety of people and the many different perceptions they each have. As we go through the interview if you have any questions about why I'm asking something or if there is anything you don't want to answer just say so. I think the best thing is for you to hold it (the Dictaphone), there, that's good, so the mike is face up, and if you see me looking down at this sheet of paper from time to time it's in order to check on my list of questions to make sure I cover everything. I think the best way to start is for you to just talk freely about your own situation in terms of work.

2 B: Ok, well right now I'm not currently employed. I'm currently looking for work. And being a mechanical engineer I'm looking at heavy industry, consulting companies that kind of thing. And I think I'm being affected by the state of the economy, moving into new industries, not being well known in the Lower Mainland. So far, I haven't been asked about my health at all. I usually present myself looking, you know, sitting up straight, and just as dynamic as any of the
other candidates. [A: uh hm]. So that hasn’t come into the job hunt at all.

A: You said you aren’t well known in the Lower Mainland, did you move here recently?

B: Three years my wife and I moved down from up north. I worked in the mining industry which gives me a particular slant on having a transplant and working in remote areas. That was interesting and required a lot of travel at first (pause)

A: Maybe you could talk a little bit more about how your health has affected your working.

B: I have to go back about twelve years. Late in university my kidneys started to fail. And I graduated from university and moved west and about a year later I started on dialysis. I was employed at that time. I started on dialysis. I kept working. It didn’t interfere with my work [A: uh hm] There was a fair amount of, I detected a fair amount of (pause) my employer was not happy with me being away from work for the transplant. And when I got back, I was laid off shortly after that.

A: For how long were you off work because of your surgery?

B: About six week.

A: And it was a leave of absence was it?

B: It was sick leave. And when I came back there was a lot of monitoring to do and that entailed one or two visits for blood work every week to hospital which meant missing a morning or a couple of hours every morning that happened. And I had to make up the hours in the week-end or late in the day, that kind of thing, or come in early the next day. It was quite a lot of load on me, trying to keep up that way - the long hours and you know making up the time, and also trying to recover from the transplant. [A: uh hm] So it was quite stressful at first. I left that employer and went to work up north enjoying extremely good health. Check-ups were
only every 3 months so it wasn’t a big interference. There
was a recession. There was a drop in the gold price so I left
that mine and ended up working in a coal mine in north-east
British Columbia and I was there for 6 years. And for the
first 4 years, nobody knew that I had a transplant except
for my 2 bosses. I kept it totally to myself. I did karate and I
swam and went to the Transplant Olympics. I just chose to
do that. I was shy about it and I’d seen the different
treatment of me at other employers because of my health
[A: uh hm] so I said this time I’ll just act like everyone else.
That was kind of a funny situation because after going to
Singapore (site of the Transplant Olympics) I came back
and said ‘no wait a minute, I should be sharing this and
letting people know that transplants work and that you
return to a healthy lifestyle’. That was the time at which I
put a big article in our company newspaper and just came
right out of the closet about my transplant [A: (laughs) did
you really] Everybody at work was absolutely amazed and
said ‘how could you keep something like that secret?’. And I
said ‘did it make any difference?’
A: and what was the message in the article?
B: Um, that transplants work and that you can maintain a
healthy lifestyle [A: uh hm, uh hm] Become productive
again. And I was quite proud of what I saw in Singapore -
800 people flying up and down the pool and so on [A: uh
hm] I thought well this is tremendous. I didn’t realize what I
was really part of [A: I see] I think that transplants tend to
focus on themselves so much because the big message
that they share with everybody.
A: You mean when you’re going through the health crisis
you tend to focus on yourself and feel alone with it?
B: Yep. My wife and I withdrew. We had a group of friends
that were quite supportive, but I think even between the
time that I had my transplant in ’83 and now, society and
employers have become much more accepting. Accepting of
transplants. My last employer said 'if it doesn't affect your
work, why should it affect how we treat you?' [A: uh hm]
Ah, 'you've told us about it, you've been honest about it
and that's all we can expect'. So, you can never forget that
as a, doing what you do in your trade or whatever, you've
still got value, you can still make a contribution to the
company and so on, transplant or no transplant. [A: uh hm] I
have to put myself in the employer's shoes every once in
awhile though and say 'ok if this becomes too distracting
then what is the value to them, why wouldn't they treat me
a little bit different and talk to me about it?'
A: What do you mean by distracting?
B: Well you spend so much time away from work [A: ah]
that kind of thing. I think people have to come to grips with
that and realize that companies have their own set of goals.
You want to get back on your feet. Companies want to
make profit, that kind of thing. You have to keep that in mind
all the time but most places especially with our health care
system and all the insurance systems that these places
have, ah, are very well protected. I've always worked for
big companies which have tremendous programs [A: uh hm]
I think with the smaller companies and the entrepreneurs
and the, you know, 1- or 2-man shops you might have
trouble. they don't have the debt that a lot of the bigger
companies have. You have to be right up front with your
employer. When you're hired you have to be right up front
about your needs.
A: So what has happened then since you moved to the
lower mainland 3 years ago? Have you not worked since
then?
B: No, I was with a company for 2 years.
A: Here, down in the lower mainland?
B: Yea, but it was still mining related. And the mining
industry is shrinking [A: uh hm] It's in the throes of its own
little recession in BC, that there's not a lot of development
which is what fueled a lot of job opportunities, was the expansion. So you have more miners than you have mines right now. [A: uh hm] So it's time to move from that industry. And I've been looking at industries more prevalent in the lower mainland. And its been quite a challenge.

A: You were laid off, were you?

B: That's right. There was a number of people laid off at that time and I was one of the last to go. And I understand what my company is going through. They've got to, you know, pull back and do what they're best at.

A: So what is that like for you? Being unemployed and trying to find work? How does that make you feel?

B: Um. I'm keeping my chin up. Ah, you know month after month it's hard to keep going. But I'm quite excited about some of the areas I'm looking at. And I've had some good success with my search. Some of the thing's I'm doing are working really well. My research, my presentations, my resume, all that stuff is working quite well. Unfortunately with job hunting, close, you really don't get anything for that, you might as well be last as opposed to being second.

[A: uh hm] I always say 'close only counts in hand grenades and dancing' (we both laugh) so I've been working at getting even closer. I'm going to win one of them sooner or later.

A: But it sounds like you get some encouragement from being called in for final interviews? Is that what you're saying, that you're getting to the last step with your resumes and presentations?

B: Oh I'm meeting lots of people. Getting lots of interviews. It's really moving into new industries that's tough because there are a lot of people out there. There is so much competition that often candidate a and b might have the same qualifications but candidate a might have worked in that particular industry a little bit or quite a lot so you have
to tune up your sales skills, your presentation, your
interview skills, that kind of stuff.

A: Have you had any help with that? Did you use any
vocational services or anything like that to help you?

B: Yep, yep. The company that I left provided complete
relocation counseling. An office, a phone, a secretary,
computers, resume services, seminars, the whole works.
Unfortunately it was downtown so it's hard to take
advantage of it from where I live in Maple Ridge. But, ah,
the sessions that I have had keep you focused on what
you're trying to do and tell you about the latest things - how
to sell yourself. We even videotaped interviews. I'd sit for
an interview with one of the counselors or one of the other
people. You'd go through the different types of interviews -
the lousy interviewer, the stress interviewer, the
professional interviewer. And then we'd read over the job
description and put me in a situation like I might face in the
actual interview. [A: uh hm] That worked quite well. Really
helped.

A: So what do you think is going to help you find work?

B: There's a lot of things I've been working on. To present
myself to a potential employer. I try to go in and be myself -
friendly, assertive, tell them what I do and don't know, can
and can't do, you know, honesty, ah, try and demonstrate
adaptability, that you can fit, try and demonstrate that
you've taken on some tough assignments and succeeded,
so there's that level of ambition and ability to learn that kind
of thing. I go in with some sincerity. This package right here,
as a matter of fact, is a complete description of what the
company does that I'm trying to get an interview with. And it
gives me the ability to relate more to what they do.

A: So you do some background research before you apply.

B: Oh, you've got to show some hustle. Exactly. It's not
sufficient anymore just to send in a resume. [A: ah hah] I
had a job interview 2 weeks back where I'd actually got into
the organization's library and read the complete justification
for the potential job. That allowed me to control the interview
and really present myself as being able to do the job. It
worked extremely well. I think I might get that one.

A: Oh, that would be great.

B: The effort pays off. It really does. It keeps you busy.
Um, I spend 8-10 hours a day at this. Working through my
phone calls and going for lunch with different people that I
know. Keeping in touch with my contacts. It's a skill that I
never wanted to get good at but [A: uh hm] Probably
something that I should tell you about is that at the age of
34, 35 with questionable health, with a questionable health
background, I've got to find something that I can get very
good at and keep doing for the next 20 or 30 years. It's
very tough having job hunts at the age of 40, 45, it just gets
tougher and tougher and tougher. So now is the time to
make up my mind about what I want to do. And that really
helps in the interview. If they can tell that you've made up
your mind. Ah, I had one interview where the guy said 'yes,
I can tell you know a lot about this job, yes I can tell you
really want to come here' he said that made a big
impression on him that I'd done a lot of research and talked
to a lot of people. Used my contacts to find out all about the
operation. All the personnel people and what they were like
and that kind of thing. I didn't get that because I think it
blowed them over. I just did too much. They thought 'what's
this guy going to be like when he works here'.

A: a powerhouse eh (laugh)

B: 'He'll take it over'. So that kind of backfired on me. You've
got to find a happy medium.

A: Are there any barriers that you experience?

B: No, not in this job hunt. I've actually had to break down
barriers. Sometimes being an engineer I've been
overqualified for stuff that I've applied for. Especially when
it comes to construction and transportation. A lot of those
people are ex-tradesmen and worked their way up. Very
good managers, very knowledgeable. So I've had to, I've
received letters back saying, we've found other more
applicable candidates. And I'll phone them up and say 'well
what kind of guy were you looking for?' And in fact that
worked once. I started telling the guy about stuff I knew
about his business and the stuff he was trying to do and he
said, 'well you sound pretty good, I'm going to pull your
resume out and we're going to interview you anyway'. [A:
hm] He was looking for a mechanic. He had never met an
engineer that had changed oil on a caterpillar dozer before.
And I said 'well, yea, I used to get my hands dirty and work
as a service man' 'oh really'. And I got the interview. So
you've got to break those barriers down.
A: And maybe be very flexible in the kind of work you'd
consider?
B: Keep your options wide open. Yea. There was one
experience I went through though, that company I worked
for for 6 years. Um, the human resources people said 'no,
don't take this guy. He's going to take us for a ride. He'd get
sick and then we're going to have this big debt or whatever.
We'll have to support this guy who's not doing anything
anymore'. He's no longer with that company I'm kind of
outlasted him. Two or 3 other guys at that interview said 'no
this guy wants to do this. He's interested in this'. So I was
able to talk to all the different suppliers to that company and
find out what their problems were. I had potential solutions
for 3 or 4 of their big problems before I had the interview,
after talking to the suppliers. [A: uh hm] And they could tell
that I was genuine and sincere. And those were 2 big
qualities. So there's a case where the barrier was quite
obvious. I didn't find out about it for 2 years, until my boss
and I were skiing together one day and he said 'you know
you almost didn't get this job'. They had to stand up against
A: So how important is working to you? In terms of your life, your satisfaction with life?
B: I've been through 4 or 5 job hunts and I have to think about that every time. And, being an engineer and spending a lot of time in school and that kind of thing. Working is very important to my psyche. Very important to how I feel about myself and my feelings of self-worth. Ah, this recent job hunt, I have to kind of, dig in a little bit and look for a little more emotional strength from my family, my wife and my friends.
A: Sorry? To sustain you through the job hunt process?
B: Yes. I have to start talking about it more. And not worry about it so much. [A: uh hm] Well, the conclusion we came to was that if I was doing everything that I possibly could and trying very hard then what else could I do.
A: It's not your fault. Do you sometimes blame yourself?
B: When you're laid off you can't take it personally, but you always do. There's that period, I've got to come to grips with that. There's always that period of self-blame. And even though my company laid me off for economic factors, um, you always wonder what you could have done different. So that you were more valuable. [A: uh hm] Not irreplaceable, but just a better part of the team. A bigger part of the team. And that's hard to do if you've only been there a year or two. You know, you get special projects and you do them and you do really well and the customer says 'ah, he's great' but when those projects come to an end, can the company see you in a different role? Well, that's the kind of thing I went through for about a month. So, because I'm very career-oriented and want to do a lot. I see a lot of problems in the industry that I'd like to help solve. I'd like to get back in as soon as possible.
What words would you use to describe how work is good for your psyche?

Firstly, working gives you that day to day challenge. The desire to get out of bed in the morning. Working just fits into life better. Um you know you've got your five days working and your two days to party and your five days to work and your two days to party. You know, routine.

Oh, ok, so there's a sense of a social order out there that you become part of.

Yep. If that's ingrained in you?

Oh yeah. Yeah.

How do you think that gets ingrained?

From your upbringing. From your education. My wife is also very career oriented.

is she?

She's doing really well.

What does she do?

She's a teacher. She's got herself into library now. And it's funny she's so young to be doing what she's doing. She's at one of the province's flagship schools right now. And she's in there because she was very assertive and went after that. [A: ah hah] Came down and gave a conference and handed all the people at the conference her business card and said she'd like to work in the Lower Mainland and she had 3 interviews before she left the conference. Um things like that. And when people walk into the library, they walk right up to her and ask for the librarian. They're looking for somebody older. So I'm quite proud of her. [A: uh hm] We kind of like, you know, we have a lot of goals and things we want to achieve.

What are some of those goals?

We're very interested in retirement and financial stability. Paying off the house. A lot of it has to do with money. And that was my first worry when I was laid off, was money.
How are we going to survive? [A: uh hm] I sat down at the computer and I worked out that we'd do fine. That there was no real financial worry. We just wouldn't get ahead as fast as we thought we would.

A: Now was that because you had some money coming in from UI?

B: We took all those things into account. Our little nest wasn't going to grow as fast as we wanted it to. There were some things that we'd have to postpone. But we're used to cutting back. Most times when we do our budget and think of all the things that we want to do next year. We look at it and say 'well we've probably spent more here than we've got, what are we going to take out?' [A: uh hm] So we're used to doing that anyway. So we have to roll back quite a bit. So my first worry was finances. But going back to this emotional propping up that is necessary. A friend of mine had a nervous breakdown and he was going through some hard times with his business but he didn't tell anybody including his wife. And he was in hospital for a week and part of his therapy was to tell people. To talk about it. [A: really] So I learned something from that. I said 'well wait a minute, you've still got your family, you've still got your house, you're still physically fit. You can ski and do all the things you love to do. What's so bad about that? And I have to do that for myself and say 'well ok, you're doing everything that you can, why worry about it so much?'

A: Ok, so what other things in your life are important to you besides work?

B: Work's always been a dominant factor. But you've got to balance that. There's a lot of things to do around the house, you know basic things that husbands do - vehicles to look after and lawns to mow that kind of thing. And then I've got a fair interest in some of the technical societies that go along with what I do - the engineering society and some of the
maintenance groups that I belong to. I do a lot of work for that, I'm usually involved on the executive. And then recently, especially after coming out of the closet with my transplant, training for the games and helping to organize the games have been come important. This group here has been doing such a fantastic job that there hasn't been a lot of call for help from me except that there's a board of directors and I go and help with some of the decisions and stuff like that, give advise. So I spend most of my time training. Swim every day and that helps the job hunt too because I get up early every morning and go for the swim, come back ready to go and get at it. I try to keep a bit of balance that way.

A: You do sound like you have a very full life.
B: It's fun to keep busy. I always have.
A: So are you basically satisfied with your life right now?
B: Well, always have been. I guess the old saying: if you reach for the stars you won't come up with a handful of sand. So, that to me is, keep your targets and go after them. And keep busy, that's the whole idea. [A: uh hm] The other thing too is, this is really deep and I haven't developed this thought for awhile but with my health being so good there is an imperative to take advantage of it. I don't know what my health is going to be next year or 5 years from now. I don't know if I'm going to get very sick or if it's going to keep going. I'm not 100% sure like a lot of people are. So, we don't tend to live life to the max by any means, we're still very conservative about what we do, but there's always that thought in the back of my mind. Do my traveling. If we're going to have a family, get started and that kind of stuff. [A: uh hm] That's in the back of my mind.

A: Do you think that attitude to work and your motivation gets set early on? Where does it come from?
B: There's motivating people and there's self-motivation. I really like to hang around with people connected to the
games, they're so up, like C., she is just so buoyed and L. he's so enthusiastic about everything. There's another thing that I'm very big on and that's discipline, self-discipline and um it's not something you're given. There's no silver spoon about it. No one owes you a living. It's something you develop and success breeds more. If there's things I've done in my life that I'm really proud of and I'm going to say 'great' and I keep building on those and I've got that confidence and I can keep going. But despite that, I don't know, my wife comes from a, her father is an electrician, and worked all his life and um retired now and just loving it. My dad was a forrester and a landscape architect and worked all his life and he's retired and he's just got a beautiful house and stuff like that. And when my wife and I first got married, we kind of had an aloofness about what we were doing and looking at our parents and saying, 'man did they ever struggle' but 10 years later we're just living the lives of our parents. We look at each other and we laugh. We've got the house and the car. We look at each other and we laugh. We're living our parent's lives. Our parents worried about retirement so now we're worrying about that. We dig in a little bit and realize what our parents have been through with some of the stuff they had to do. I mean they were bringing up a family at the same time. So some of the things we've been through give us some perspective. 'We're not doing too bad. Let's make the most of this'. We're
very careful. We’re very optimistic though and we’re sure something is going to come along soon.

A: Well I would agree with you. I think something is likely to come along very soon for you. I hope so. And I want to thank you very much for talking with me this morning. This has been a very rich interview. I must tell you you’ve really got a lot of very interesting thoughts and personal experiences that are going to help my understanding of things. Do you have anything you’d like to add?

B: No I think that covers it. You should talk to some of the people working in the transplant games. They’re really doing well.

A: Yes, I might just do that. But I also want to talk to some transplant recipients who aren’t doing that well so that I get opinions from a variety of different people (B: oh yea). Thanks again very much for talking with me this morning.
Appendix J

Current Employment Status of Study Sample
## Current Employment Status of Study Sample

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Frequency</th>
<th>Percent</th>
<th>Labour Force</th>
<th>Study Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full-time</td>
<td>90</td>
<td>41.7</td>
<td>Active</td>
<td>Employed</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>21</td>
<td>9.7</td>
<td>Active</td>
<td>Employed</td>
</tr>
<tr>
<td>Employed but temporarily on leave</td>
<td>11</td>
<td>5.1</td>
<td>Active</td>
<td>Employed</td>
</tr>
<tr>
<td>Unemployed, looking for work</td>
<td>20</td>
<td>9.3</td>
<td>Active</td>
<td>Not</td>
</tr>
<tr>
<td>Unemployed, NOT looking for work</td>
<td>31</td>
<td>14.3</td>
<td>Not</td>
<td>Not</td>
</tr>
<tr>
<td>Retired prematurely because of health</td>
<td>22</td>
<td>10.2</td>
<td>Not</td>
<td>Not</td>
</tr>
<tr>
<td>Retired at usual retirement age</td>
<td>3</td>
<td>1.4</td>
<td>Not</td>
<td>Not</td>
</tr>
<tr>
<td>Other a</td>
<td>18</td>
<td>8.3</td>
<td>Not</td>
<td>Not</td>
</tr>
<tr>
<td></td>
<td>216</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Note.** a The 18 respondents who reported "other" as their employment status were not considered to be part of the labour force. They specified unpaid volunteer work, school, parenting or home repair and maintenance as their work activity.
Appendix K

Main Reason for Not Working
## Main Reason for Not Working (Unemployed Respondents)

<table>
<thead>
<tr>
<th>Main Reason</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal illness or disability</td>
<td>23</td>
<td>46.9</td>
</tr>
<tr>
<td>Home or family responsibilities</td>
<td>7</td>
<td>14.3</td>
</tr>
<tr>
<td>Too old but not retired</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Going to school</td>
<td>3</td>
<td>6.1</td>
</tr>
<tr>
<td>Personal choice, do not wish to work</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>No suitable work available</td>
<td>5</td>
<td>10.2</td>
</tr>
<tr>
<td>Laid off, expect to return to work in future</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Would lose disability pension</td>
<td>4</td>
<td>8.2</td>
</tr>
<tr>
<td>Lack of job training</td>
<td>5</td>
<td>10.2</td>
</tr>
<tr>
<td>Employer discrimination</td>
<td>2</td>
<td>4.1</td>
</tr>
<tr>
<td></td>
<td><strong>49</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
Appendix L

Mean Scores Obtained on the MOS SF-20
Mean Scores Obtained on the MOS SF-20

<table>
<thead>
<tr>
<th>SF-20 Health Dimension</th>
<th>No Chronic Condition (n = 2,595)</th>
<th>Employed Transplant Recipient (n = 122)</th>
<th>Not Employed Transplant Recipient (n = 94)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Functioning</td>
<td>86.0</td>
<td>77.3</td>
<td>59.2</td>
</tr>
<tr>
<td>Role Functioning</td>
<td>87.2</td>
<td>88.9</td>
<td>45.7</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>92.3</td>
<td>91.2</td>
<td>73.4</td>
</tr>
<tr>
<td>Mental Health</td>
<td>77.6</td>
<td>77.8</td>
<td>71.0</td>
</tr>
<tr>
<td>Health Perceptions</td>
<td>72.6</td>
<td>70.0</td>
<td>50.3</td>
</tr>
<tr>
<td>Pain</td>
<td>74.2</td>
<td>69.1</td>
<td>57.7</td>
</tr>
</tbody>
</table>

**Note.** SF 20 scores range from 0 - 100 with 100 being the best score possible.