Health Determinants of Persons who are Late-Referred to Chronic Renal Care in British Columbia, Canada

by

Nancy Ellen Blythe
B.A., University of Victoria, 1994

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF ARTS

in the Department of Sociology

Supervisor: Dr. Cecilia Benoit

ABSTRACT

Late nephrology referral, a problem currently identified across many high-income countries, has been associated with reduced opportunities for delaying or halting the progression of chronic kidney disease (CKD), delayed dialysis initiation, reduced choice in treatment modality, increased morbidity and hospitalization, and premature death. Despite a recent finding that the progression of CKD nearly always presents warning signs, and despite the fact that all Canadians are entitled to receive medically necessary health care free at the point of patient entry into the health care system, each year in the province of British Columbia (BC) a substantial number of people with CKD experience late or no referral to nephrology care prior to requiring renal replacement therapy. A subset of these CKD patients experience no referral and experience an acute or emergent start onto dialysis. Existing renal research into late referral has not fully explored the range of potential health determinants that may affect: a) the timing of nephrology referral; and b) the consequences of late referral for patient health status. Using secondary data on BC renal patients who began dialysis between April 2000 and March 2003 (N=2001), this thesis draws on a "determinants of health" perspective to assess the impact of a variety of factors on the timing of renal patients' nephrology referral and, subsequently, their utilization of renal-related hospital and medical services. The factors studied include measures of patients' physical health (cause of renal disease), individual demographics (gender, age, race/ethnicity measures), socioeconomic status (income), social support (marital status, availability of next-of-kin), and geographic and health system characteristics (proximity to care, patient's dialysis centre)

– all of which may be considered to be potential "health determinants" of renal patients' experience regarding initial nephrology referral and ongoing health services utilization.

Using a late referral definition of <3 months before start of dialysis, regression analyses indicated that a number of the physical, demographic, social, geographic and health system characteristics studied had a significant independent effect on the timing of patients' nephrology referral (Phase I of the research) and patients' hospital and/or medical services utilization (Phase II). For Phase I of the research, the physical health characteristic "cause of end stage renal disease" was found to have the greatest impact on the expected probability of whether a renal patient experiences late referral (Wald Chi-Square 117.99, p<.0001) – e.g., diabetics and persons with congenital or polycystic kidney disease had a lower probability of late referral compared to those with renal vascular or other underlying diseases. The next most important predictor of late referral was the health system characteristic "patients' initial dialysis centre" (Wald Chi-Square 51.66, p<.0001); however, social and demographic factors were also found to have significant impact on patients' probability of late referral. The Phase II analysis initially corroborated findings by prior researchers that late referral leads to increased health services utilization for renal patients; however, the subsequent inclusion of additional physical and social factors as potential health determinants resulted in the effect of late referral being largely non-significant. Both phases of research demonstrate the utility of using a broader determinants-of-health framework in an area of study that typically has been examined within a bio-medical framework, and thereby contribute to theory advanced by the sociological population health model.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES AND ILLUSTRATIONS

ACKNOWLEDGEMENTS

This research has been co-sponsored by a 2003/04 research trainee award from the Michael Smith Foundation for Health Research and the British Columbia Medical Services Foundation. Special thanks to my Supervisor, Cecilia Benoit, Professor, Department of Sociology, University of Victoria, for her invaluable guidance and support throughout my work on this thesis. Thanks also to the other members of my supervisory committee: Margaret Penning, Associate Professor, Department of Sociology, University of Victoria, and Anita Molzahn, Professor, School of Nursing, University of Victoria. Additional thanks to Doug Baer, Chair, Department of Sociology, University of Victoria, and Mikael Jansson, Adjunct Professor, Department of Sociology, University of Victoria, for their insightful comments on my data analysis. Access to renal patient data from the Patient Records, Outcome and Management Information System (PROMIS), as well as support in analytical interpretation, was provided by Adeera Levin, Director, British Columbia Provincial Renal Agency (BCPRA), and Ognjenka Djurdjev, Head, Data Management Centre, BCPRA. Access to income quintile and decile data, and hospital and medical services utilization data, was provided by the British Columbia Ministry of Health Services and the Centre for Health Services and Policy Research (CHSPR). The list of ICD-9 and CCP codes required to obtain hospital and medical services data on renal patients was provided by Michele Bamford, Regional Coordinator, Clinical Information Services, Vancouver Island Health Authority.

DEDICATION

I dedicate this thesis to my husband John, for his patience and support throughout my university education, to our daughter Hayley, whose recent arrival has brought new joy and meaning to our lives, and to my mother Judy, whose loving care of Hayley made the completion of this work possible.

CHAPTER 1: INTRODUCTION

The population health or "determinants of health" perspective is a relatively recent way to explain why some people are healthy and others are not. It has emerged in the last few decades as an additional sociological framework to build on and complement the dominant bio-medical model for explaining the health of individuals and populations, by focusing on factors other than those determined by human genetic and biological factors. The health determinants perspective enables us to better understand disparities in health outcomes by pointing to the range of social, economic, environmental, and health service factors that interact in complex ways with personal behaviours and predisposing biological pathways to positively or negatively influence health (Evans et al., 1994; Canadian Population Health Initiative, 2002; Evans, 2002; Raphael, 2004). Research exploring the complex interactions that determine health has practical implications for preventing the onset of illness and improving the health of individuals and groups.

The determinants-of-health framework is particularly valuable for investigating population occurrences of chronic illness and determining why some people fare better than others in regard to timely access to medical treatment. The chronic illness that is focused on in this thesis is kidney disease, a condition prevalent across high-income countries today. I posed the research question of why some people with kidney disease fare better than others, by studying some of the main non-genetic and non-biological predictors of their referral to nephrology care. Late nephrology referral, a problem currently identified among particular populations in many high income countries (see e.g., Cass et al., 2003; Curtis et al., 2002; Jungers et al., 1993; Roderick et al., 2002; Winkelmayer et al., 2001), has been associated with delayed dialysis initiation, reduced opportunities for choosing more ambulatory modes of renal replacement therapy or for delaying or halting disease progression, increased morbidity and hospitalization, and premature death (Iofel, 1998; Jungers, 2002; Levin, 2000). In addition to these health burdens for the patient (in terms of illness and reduced quality of life), there are also substantial financial and resource outlay costs for national health care systems. In fact, it has been estimated that the number of people throughout the world who require renal replacement therapy will reach epidemic proportions by 2015 (El Nahas et al., 2005). Yet, relatively little is known about the determinants of health of persons who are late-referred for nephrology assessment, and what is known is often in the form of conflicting evidence across studies.

My research focuses on the case of people with chronic kidney disease (CKD) in the province of British Columbia (BC), Canada. Despite a recent Canadian finding that the progression of CKD nearly always presents observable warning signs (Curtis et al., 2002), and despite the fact that all Canadians are entitled to receive medically necessary health care, each year in the province of BC a substantial number of persons with CKD experience late or no referral to a nephrologist prior to requiring renal replacement therapy (chronic dialysis or kidney transplant). A subset of these patients acute start[1] onto their initial dialysis treatment – that is, experience an emergent dialysis start. In contrast, early referred patients are able to participate in pre-dialysis programs designed to transition them to treatment and sustain their quality of life by minimizing the effect of their chronic illness on daily living.

---

[1] "Acute start" refers to persons who have chronic kidney disease (CKD), and should not be confused with non-CKD patients who may experience a sudden acute temporary requirement for dialysis that is often able to be reversed when an underlying disease/condition has been treated.

Prior studies on the predictors of late referral to renal treatment and the impact of late referral on health care utilization have not fully explored the range of potential health determinants that may impact both initial access to renal care and the ongoing use of health services (see e.g., Arora et al., 1999; Cass et al., 2003; Curtis et al., 2002; Holland and Lam, 2000; Winkelmayer et al., 2001). This is problematic since it limits both the application and continuing development of relevant population health theory to this area of study, and subsequently restricts the level of information available to health system providers as they search for best-practice solutions related to patients' access to care and overall health status. Therefore, the main purpose of my study was to broaden the scope of research by including into the analysis available physical health data as well as potential demographic, economic, social, geographic and health system predictors made available to me through existing BC provincial health datasets. Such factors may be considered to be potential "health determinants" of renal patients' experience regarding nephrology referral and ongoing use of renal related health services, according to the following definition from Health Canada (found in Raphael, 2004, p.4):

> "There is strong evidence indicating that factors outside the health care system significantly affect health. These "determinants of health" include income and social status, social support networks, education, employment and working conditions, physical environments, social environments, biology and genetic endowment, personal health practices and coping skills, healthy child development, health services, gender and culture (Health Canada, 1998, p.1)."

For Phase I of my research I obtained access to and analyzed socio-demographic and clinical data on the total number of British Columbians with CKD who initiated dialysis during the period April 2000 to March 2003, to test the impact of the following health determinants on the timing of patients' referral to the renal care system: patients' physical health condition (cause of renal disease), individual demographics (gender, age, race/ethnicity measures), socioeconomic status (income), social support (marital status, availability of next-of-kin), and geographic and health system characteristics (proximity to care, patient's dialysis centre). Type of referral was defined as: 1) early referral (≥ 3 months referral time - from date of nephrology referral to date of dialysis initiation); and, 2) late referral (< 3 months referral time). To enable comparison with prior studies by other researchers, I also defined and tested late referral a number of alternate ways to coincide with the various definitions used in those studies (i.e., <1, <4, <6 and <12 months referral) and in consideration of the 12 month referral period proposed by the Canadian Society of Nephrology (Levin, A., 2000). The population under study included CKD patients only; i.e., those who experienced sudden temporary acute renal failure (ARF) due to an underlying disease/condition were not included[2]. I hypothesized that persons with CKD who face certain social structural barriers in society are constrained in their ability to seek treatment before their chronic illness advances to an acute stage and they experience late referral to nephrology care and possibly an acute start onto dialysis - both of which scenarios have been associated with negative consequences regarding patients' specific illness and their general quality of life (Iofel 1998; Jungers, 2002; Levin, 2000).

Phase II of my research was conducted to verify claims made by prior researchers that a late nephrology referral experience translates into greater renal patient morbidity in terms of health services utilization. I had an opportunity to test this hypothesis using BC renal patient data, including data on renal related hospital and medical services

---

[2] Persons with sudden acute renal failure due to some other disease/condition than chronic kidney disease were not included in this study, since the research problem involved comparing the health determinants of persons who had chronic kidney disease yet experienced either early or late referral to nephrology care.

utilization, while controlling for other potential health determinants that may also have a significant direct effect on patient morbidity and health service utilization (i.e., those physical, social and health system factors analyzed in Phase I of my research). I hypothesized that a late referral experience leads to an increased total number of renal related hospital visits, hospital days stay, medical services utilized and total costs associated with medical services, but that the some of the effect of late referral may be explained by other factors included in my analysis.

Phase I of the research attempted to fill a void in the literature regarding the impact of health determinants on renal patients' initial access to renal care services, in a health care system where such services are free at the point of delivery. Phase II of the research provided an opportunity to verify past research claims regarding the negative impact of a late nephrology experience on indicators of patient morbidity, when other potential health determinants are included in the analysis. Both phases of the research demonstrate the value of including physical health characteristics and a variety of social and health system factors to estimate the impact of health determinants on access to and utilization of health care services. The research contributes to the population health model by applying a sociological lens to an area of study that previously was conducted within a medical framework. In terms of sociological contribution, my findings build on the social determinants of health research reported on by Raphael (2004) and others, by including other determinants (physical health and health system factors as well as potential social factors) in my analysis of which variables have the greatest explanatory power regarding health care access and health outcome in a large population sub-group of BC residents. Therefore, the research is a step forward, encouraging sociologists to think broadly when seeking to explain inequality in health and health care access. Further, the findings provide practical information to BC renal patients, their health care providers, and the regional and provincial authorities responsible for effective planning of renal services, and may assist the BC Provincial Renal Agency in developing strategies to reach more renal patients early on in their chronic disease. The project was co-funded by a Michael Smith Foundation for Health Research and British Columbia Medical Services Foundation Research Trainee Award – Population Health category (ST-MAS-279(02-1).

CHAPTER 2: BACKGROUND

Prior to a review of the theoretical background on the determinants of health perspective, as well as relevant literature on the predictors and consequences of late nephrology referral, I present an overview of renal disease, its forms of treatment, and international and Canadian growth patterns in renal disease and treatment.

2.1 Renal Disease

Sudden acute kidney failure is often able to be "reversed if the underlying disease [causing temporary kidney failure] is treated" (CMA website, 11/02/2003). In contrast, chronic kidney disease (CKD) is the progressive failure of the kidneys to "filter waste products and excess salt and water out of the blood" (ibid.). The kidneys' ability to "make hormones that control blood pressure and the production of red blood cells" are also affected (ibid.). The excess poisons that build up in the body can cause various system complications, and dialysis or a kidney transplant is required to maintain life once kidney function has depleted to less than 10% (ibid.). At this point the patient is said to be in "end-stage renal failure".

According to the Canadian Medical Association "[t]he most common causes of kidney disease include diabetes, high blood pressure [hypertension], and atherosclerotic vascular disease" (ibid.). Other causes are related to kidney inflammation, anatomic problems with size/shape of the kidney (polycystic kidney disease and renal glycosuria), and more rare metabolic problems related to "the working of the kidney" (ibid.). Besides the common existence of co-morbid conditions, signs of renal failure are dependent upon the cause of the disease, and can include: passing of blood and/or protein in the urine, and (more rarely) a high fever from bacterial infection or passing more than 2 ½ quarts of urine a day (ibid.). Although renal disease is not considered painful unless associated with the passing of kidney stones (ibid.), a 1998/99 cross-Canada prospective study of renal patients' clinical status at point of dialysis initiation found that only 10% of new patients were asymptomatic, 90% had at least one symptom, and the majority (50%) had the following three symptoms: fatigue, anorexia and nausea (Curtis et al., 2002, p.287). Therefore, it would be unusual for a person with progressive renal failure to have no forewarning of their disease and no impetus to seek treatment prior to reaching end stage renal failure. It is possible that the 10% of new patients in BC who acute start onto dialysis are asymptomatic; however, some may experience mild symptoms that are neglected, perhaps due to social circumstances (i.e. due to a lack of social support, low income, etc.). Unfortunately, due to inconsistency in the collection of symptom data in BC, it was not possible in this study to investigate the impact of patient symptoms on the timing of their referral/access to nephrology care.

2.2 Forms of Treatment

There are three forms of renal replacement therapy (RRT) available to the person who has end-stage kidney failure: hemodialysis, peritoneal dialysis, and kidney transplant. With **hemodialysis**, the patient is hooked up to a dialysis machine or "artificial kidney" that performs the function of the kidneys by removing the patient's blood to filter out wastes and impurities, and restoring the cleaned blood to the patient. In BC, hemodialysis is usually performed in approximately 4-hour sessions 3 times a week, in one of the following possible settings: a hospital outpatient renal clinic, a satellite community renal clinic, or the patient's own home (requires the appropriate equipment set-up, patient ability, and social support). Hemodialysis requires that the patient has an access to their bloodstream created via either a fistula (artery directly connected to a vein) or graft (synthetic tube grafts the artery and vein together) (NIDDK website, 14/04/2003). Hemodialysis is more restrictive to lifestyle than peritoneal dialysis (see below); however, is often used on frailer patients since staff are available to provide the treatment and monitor the individual for possible complications.

There are two forms of **peritoneal dialysis** – continuous ambulatory peritoneal dialysis (CAPD) and continuous cycler peritoneal dialysis (CCPD). Both use the patient's own peritoneal membrane (abdomen lining) to filter water, wastes and chemicals from the blood, via a permanent tube in the abdomen (ibid.). CAPD does not require a machine and is therefore considered more "ambulatory" for the patient. The CAPD patient fills their abdomen with dialysate solution 4 or more times a day for periods of 4 to 6 hours each session, drains the solution at the end of the session and refills with more dialysate. In contrast, with CCPD, a cycler machine automatically does the filling and excreting of the dialysate solution for the patient, usually during the night while the patient sleeps, although sometimes daily sessions are also required, or a combination of CCPD and CAPD is used (ibid.). Both CAPD and CCPD users are subject to risk of infection of the peritoneum, which can, over time, erode the patient's ability to continue with peritoneal dialysis and lead to the requirement for hemodialysis or transplant.

Given the relative shortage of deceased donor organs in BC and across Canada (largely due to inroads made in the reduction of automobile and other accidents) or the need to find a willing living kidney donor (can include a family member or close friend deemed to be a viable match), **kidney transplantation** is not necessarily available to those who may wish to pursue it. Moreover, not everyone is eligible for transplant since they may not meet the medical suitability criteria, which leaves dialysis as their treatment option.

2.3 Cross-National and Cross-Canada Comparisons

Treatment using any of the above renal replacement therapies can only be performed once persons with chronic kidney failure are identified as having their chronic disease and are referred to a nephrologist's care. Although the true prevalence of CKD in a population is difficult to ascertain, it is interesting as background information to this thesis to consider where Canada is placed internationally in terms of CKD identification and treatment, and similarly where BC is placed provincially regarding the identification and treatment of persons with CKD.

2.3.1 Cross-national Comparison of ESRD and Dialysis Treatment

The secondary data used to construct Table 1 and Figures 1 and 2 were accessed through the Organization for Economic and Cultural Development (OECD) Health Data 2004. Cross-national comparisons of the following are presented: the number of persons with end stage renal failure (ESRF) per 100,000 population; the number and percentage of persons with ESRF who are on dialysis per 100,000 population; and, average rates of growth for ESRF and dialysis. The most recent year of data available by nation for ESRF ranges from 1994 to 2000, and for dialysis ranges from 1991 to 2000. Average percentage growth rates for ESRF and dialysis were calculated based on the years of data available for each country (ranges from 2-year to 11-year growth rates). Differences in years of data availability and data completeness mean that comparisons are at best approximate. It should be noted that the OECD data on ESRF includes all patients receiving some form of renal replacement therapy (RRT) as of December 31st each year, including those with a functioning transplant. Therefore, a lower percentage of persons dialyzed simply reflects a country's relative success rate at transplantation, and thus the data on number of ESRF patients per 100,000 population may be the more telling indicator of cross-national disparity in the identification and treatment of renal disease.

Table 1 - Number of Persons with ESRF and on Dialysis, Percent Dialyzed, and Average Growth Rates – OECD Countries, most recent data

OECD Country	ESRF and Dialysis, per 100,000 Pop.					Average % Growth in ESRF and Dialysis			
	ESRF		Dialysis		%	ESRF		Dialysis	
	#	Year*	#	Year*	Dialyzed	% Growth	Years**	% Growth	Years**
United States	117	1998	86.5	1998	73.9	6.6	1990-1998	6.7	1990-98
Germany	87	2000	64.0	2000	73.6	11.5	1990-2000	11.8	1990-00
Greece	82	2000	66.6	2000	81.2	7.7	1990-2000	8.1	1990-00
Spain	80	1999	43.7	1997	54.6	8.8	1990-1999	7.9	1990-97
Canada	**77**	**1999**	**45.7**	**1999**	**59.4**	**6.7**	**1990-1999**	**8.5**	**1990-99**
Austria	71	2000	37.1	2000	52.3	4.9	1990-2000	4.1	1990-00
Australia	61	2000	33.2	2000	54.4	5.1	1990-2000	6.7	1990-00
Denmark	61	1999	36.3	1999	59.5	8.9	1990-1999	7.3	1990-99
Finland	58	2000	22.9	2000	39.5	5.8	1990-2000	6.4	1990-00
Belgium	57	1994	32.9	1994	57.7	6.7	1990-1994	6.0	1990-94
Luxembourg	54	1995	60.1	1999	111.3	8.5	1990-1995	13.4	1990-99
Sweden	54	1995	25.4	1994	47.0	28.6	1990-1995	17.4	1990-94
United Kingdom	54	1999	27.0	1999	50.0	10.3	1990-96 & '99	9.5	1990-96 & '99
Netherlands	51	1995	28.2	1996	55.3	12.8	1990-1995	4.5	1990-96
Switzerland	50	1995	26.5	1994	53.0	1.0	1990-1995	2.7	1990-94
Norway	45	1995	6.1	1994	13.6	5.2	1990-1995	1.7	1990-94
Italy	42	1995	31.6	1994	75.2	7.9	1990-1995	6.5	1990-94
France	41	1995	37.0	1994	90.2	9.3	1990-1995	12.5	1990-94
Slovak Republic	41	2000	39.8	2000	97.1	11.6	1995-2000	12.2	1995-00
Czech Republic	40	1995	38.6	1994	96.5	13.4	1990-1995	24.2	1990-94
Portugal	40	1995	30.3	1994	75.8	3.6	1990-1995	3.2	1990-94
Iceland	37	2000	13.9	2000	37.6	5.7	1990-2000	6.1	1990-00
Mexico	35	2000	32.5	2000	92.9	11.3	1995-2000	20.6	1995-00
Turkey	25	1999	23.4	1999	93.6	18.6	1996-1999	11.8	1996-99
Hungary	18	1994	12.5	1994	69.4	5.3	1990-1994	22.5	1990 & 1994
Ireland	15	1995	9.9	1994	66.0	8.8	1990-1994	4.4	1990-94
Poland	14	1995	128.9	2000	920.7	14.7	1990-1995	7.7	1999-00
Japan	N/A		162.4	2000	N/A	N/A		6.8	1990-00
New Zealand	N/A		27.7	1991	N/A	N/A		9.9	1990-91
Korea	N/A		N/A		N/A	N/A		N/A	

Data Source: OECD Health Data 2002, 4th edition.

* Year = most recent year of data available.

2001 data available for Iceland however was not used, to maximize comparability between nations.

** Years = years available to calculate average percentage growth rate over time.

ESRF Patients = number of patients alive as of December 31st each calendar year who are receiving some form of renal replacement therapy including a functioning transplant.

Note: Shaded cells for "% dialyzed" for Luxemburg and Poland indicate inappropriate percentages due to the fact that their dialysis data are much more recent than ESRF data. For all other countries reporting on ESRF and dialysis, the years of data for both are either the same or no more than 1-2 years apart.

Fig. 1 - Persons with ESRF per 100K Pop. (Series 2), Persons on Dialysis per 100K Pop. (Series 1), and % Dialyzed (Series 3), OECD Countries, 2000 (or most recent data)

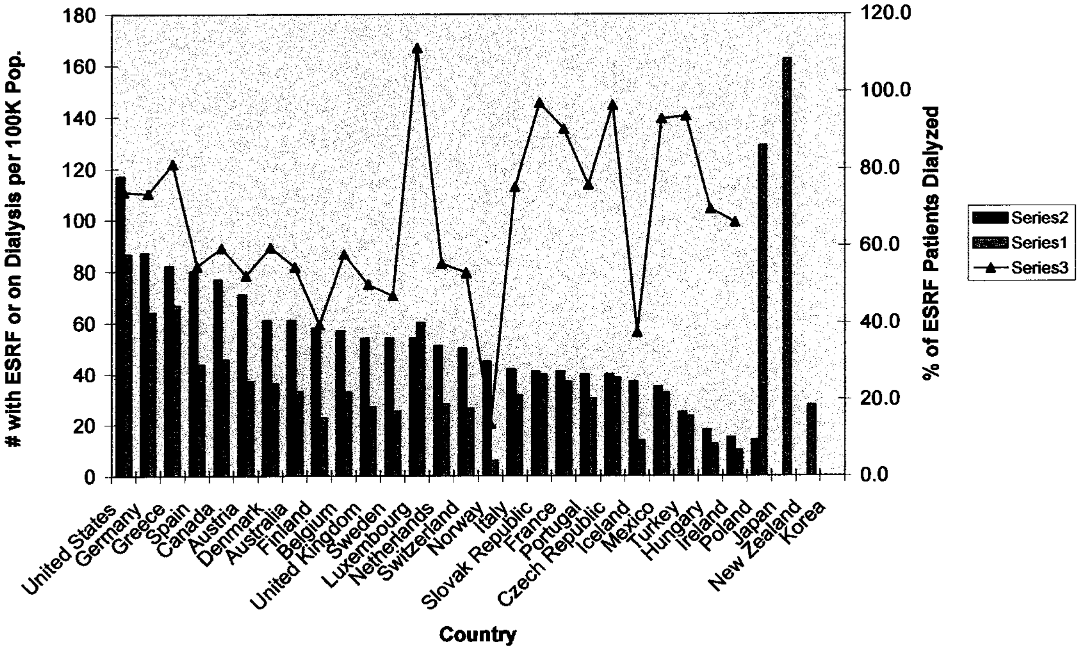
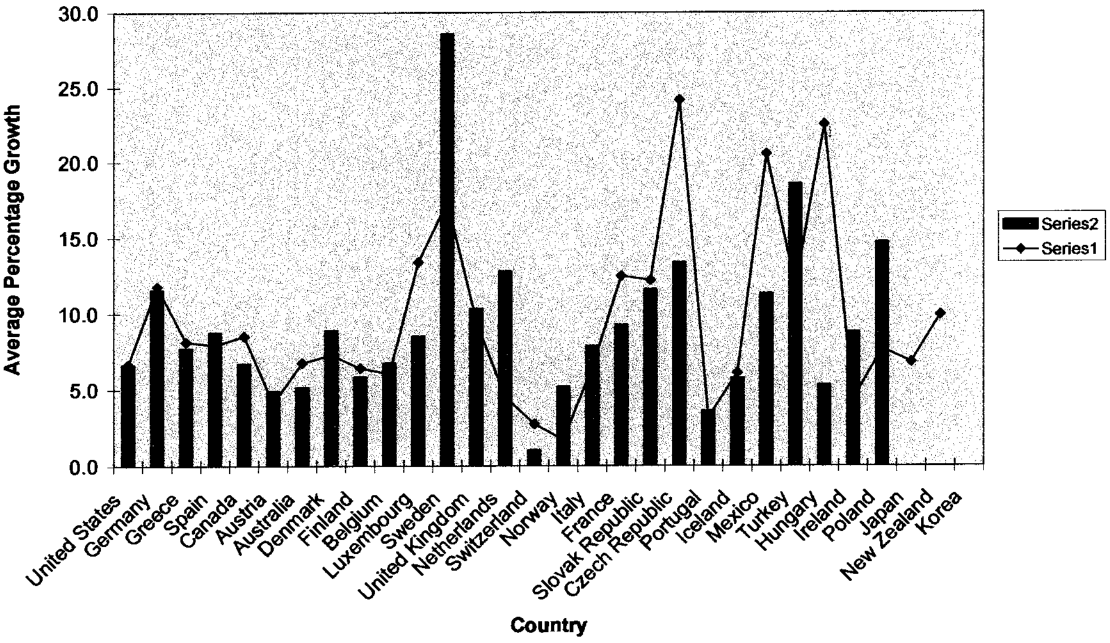


Fig. 2 - Comparison of Average % Growth Rates for ESRF (Series 2) and Dialysis (Series 1), OECD Countries, 1990-00 (or most recent years of data)



A couple of interesting findings emerge from the cross-national comparison on ESRF and its treatment. First, there is quite a discrepancy amongst nations regarding the standardized number of persons identified as having ESRF and provided with some form of RRT. For example, despite a lack of recent ESRF data for Japan and Poland, these countries are providing dialysis to more persons than are identified as ESRF in other countries – i.e., in 2000, Japan was dialyzing 162.4 persons per 100,000, and Poland 128.9. The next highest RRT providers are the United States (117 ESRF patients per 100,000 population), Germany (87), Greece (82), Spain (80), and Canada (in 7th place with 77 ESRF patients per 100,000 population). Those countries with a proportionately lower number of identified ESRF patients include the United Kingdom, the Nordic countries, Italy, France, and middle and low-income countries (e.g., Mexico and Turkey). The second interesting finding is that in a number of countries (most notably France, the Czech Republic, Mexico and Hungary) the dialysis rate of growth far outstrips the rate of growth of ESRF. This may be a function of playing catch-up to meet actual dialysis requirements (in the absence of ability to provide increased transplantation); however, since the data for some of these countries is not recent (e.g. 1994/95), it is not known whether higher rate-of-growth trends have persisted to more recent years. The rates for Canada, which are based on more recent data, indicate a dialysis rate of growth that is slightly higher than the ESRF identification rate – again perhaps this is a function of playing catch-up to meet actual dialysis need, particularly given the lack of available kidney transplants.

In summary, Canada sits in 7th place internationally (OECD countries) in terms of the standardized number of persons identified with ESRF and treated with some form of renal replacement therapy, and similarly is in about 7th place in terms of the standardized number of persons receiving dialysis as their form of renal replacement therapy.

2.3.2 Cross-Canada Comparison of ESRD and Dialysis Treatment

Similar to data available from the OECD, the Canadian Organ Replacement Register (CORR) maintains a national database of provincial data on end stage renal disease (ESRD) patients and their treatment by dialysis or transplant. Table 2 and Figures 3 and 4 are based on CORR data and present the provincial number of persons per million population who are diagnosed with ESRD (treated with some form of RRT, including a functioning transplant) and dialyzed, as well as growth patterns in ESRD and dialysis.

Table 2 – # with ESRD and on Dialysis, % Dialyzed, and Avg Growth Rates, Canada and Provinces

Province	ESRD and Dialysis per Million Pop., 2000			Average % Growth (1990-00)	
	ESRD	Dialysis	% Dialyzed	ESRD	Dialysis
Manitoba	1049.8	712.6	67.9	6.8	10.3
Newfoundland	1046.7	556.8	53.2	6.4	8.6
Nova Scotia/PEI	1019.5	458.4	45.0	8.0	8.2
New Brunswick	902.7	586.8	65.0	7.5	9.8
Ontario	865.7	537.0	62.0	6.4	8.5
Alberta	790.1	396.4	50.2	6.6	7.0
British Columbia	**766.5**	**430.4**	**56.1**	**7.4**	**8.4**
Saskatchewan	741.5	429.8	58.0	7.3	10.4
Quebec**	681.5	388.7	57.0	5.9	6.7
CANADA	810.4	473.7	58.5	6.5	8.1

Data Source: CORR Preliminary Report for Dialysis and Transplantation 2002.
* ESRD includes all patients alive as of December 31st each year who received some form of RRT (including a functioning transplant)
** 2000 data for 3 Quebec dialysis centres not included (an estimated 421 patients).

Fig. 3 - Persons with ESRD per Million Pop. (Series 2), Persons on Dialysis per Million Pop. (Series 1), and % Dialyzed (Series 3), Canada and Provinces, 2000

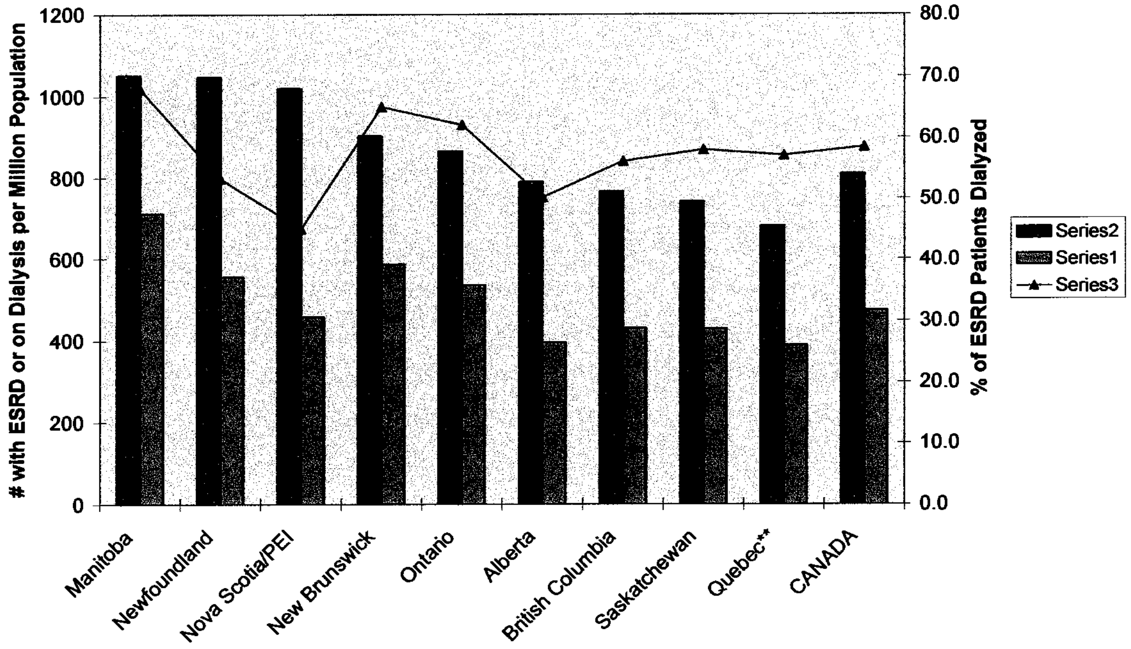
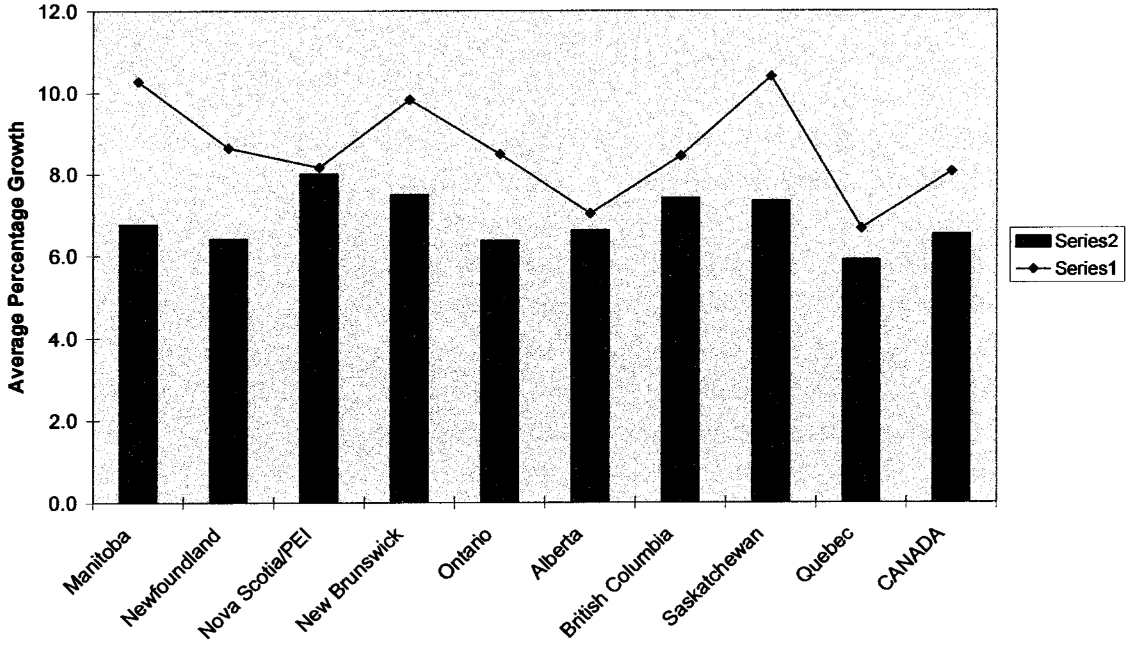


Fig. 4 - Comparison of Average % Growth Rates for ESRD (Series 2) and Dialysis (Series 1), Canada and Provinces, 1990-2000



Similar to the cross-national comparison, a couple of interesting findings emerge from the cross-Canada comparison of ESRD and its treatment. First, there is variation between Canada's provinces in the standardized number of persons identified as having ESRD and receiving some form of RRT. In 2000, Manitoba and Newfoundland had the highest proportion of ESRD patients at 1049.8 and 1046.7 patients per million population respectively. BC was in 7th place overall at 766.5 ESRD patients per million population, which was lower than the Canadian average of 810.4 (i.e., was treating approximately one-quarter less ESRD patients than the highest provincial providers). However, BC had the highest overall rate of growth for ESRD and dialysis in 1999-00 (BC's growth rates for ESRD and dialysis were 8.5% and 11.1%, compared to the Canadian mean rates of 3.7% and 3.4%), perhaps indicating recent efforts to increase the identification of ESRD patients and dialysis treatment capacity in BC. The second point of interest is that in each province, the average rate of growth of dialysis from 1990-2000 has outstripped the rate of growth of ESRD patients (Canadian mean = 6.5% growth for ESRD and 8.1% for dialysis). Higher rates of dialysis growth likely reflect the inability of transplantation to keep up with current demand/need, which puts pressure on the provinces to substantially increase their dialysis capacity.

2.3.3 Summary of Cross-National and Cross-Canada Comparisons

In the absence of further investigation and data on the true prevalence of chronic renal disease in populations, it is difficult to ascertain whether differing cross-national or within-Canada rates of ESRD can be attributed to one or more of the following: greater or lesser burden of disease (for any number of possible social, cultural, biological and genetic reasons); differences in efforts to identify, treat and prevent the progression of renal disease; over-treatment of persons who may receive questionable benefit from care (Gill et al., 1991); or, data availability/reporting differences. Reporting differences are unlikely to explain the degree of national and regional variation noted above. It is, however, possible that differences in the way that health care is structured and delivered may explain a portion of the cross-national or cross-Canada variation. Canada's system of universal health care coverage should theoretically pose no disincentive for identifying and treating all those who would benefit from treatment. Yet across Canada there are known disparities in the timeliness of renal patients' initial access to nephrology care. We must therefore look to other explanations to explain these observed differences. Focusing attention on other factors, such as patients' determinants of health, may offer some insight into this complex problem.

CHAPTER 3: THEORETICAL BACKGROUND

This thesis adopts a population health perspective to investigate the impact of the determinants of health of persons who seek access to chronic renal care services. The population health or "determinants of health" perspective theorizes that "a range of factors interacting in complex ways determine health" (Canadian Population Health Initative, CIHI, 2002, p.1). This perspective is linked to the "sociology of health" paradigm, which itself has evolved from an earlier focus on "medical sociology". The development of theory related to the sociology of health, and the determinants of health, is discussed below.

3.1 Medical Sociology

Medical sociology as an intellectual stance developed in the mid-1900s as a result of developments in both medicine and sociology that conspired to make the two disciplines of interest to each other (for a detailed discussion on this subject see Twaddle, 1982). Medicine's early reliance on the importance of germ theory to the control and reduction of disease resulted in a perceived requirement to change the social organization of medicine to a more specialized and institutionalized structure that altered physician-patient interaction and resulted in a degree of patient alienation. This change in the organization and delivery of medicine, and developments in sociological theory (such as Durkheim's concept of alienation, and Parsons' conceptualization of sickness as deviance) as well as epidemiological challenges to the importance of germ theory (i.e., studies showing that mortality rates declined prior to immunization efforts, and a resurgence in awareness of the importance of sanitation and public health measures to prevent disease – Twaddle, 1982) lead to medicine being embraced as an area of sociological enquiry. At the same time, sociology's tradition of conducting demographic mortality and subsequently morbidity studies, as well as sociology's increasing sophistication regarding research measurement techniques, made sociology of use to medicine in its efforts to study and affect the progression of disease. At one point "medical sociology" formed "the largest specialty group in the American Sociological Association" (Twaddle, 1982, p.334). At mid-twentieth century, Robert Strauss had identified two distinct approaches within the sub-area of the discipline (Twaddle, 1982):

1. Sociology <u>in</u> Medicine - this approach has been distinguished by its applied focus, with sociology treated as more of "an adjunct of medical practice, a supporting discipline to medicine" (Twaddle, 1982, p.331). Problems studied have tended to be defined by the concerns of the medical profession itself, including understanding patient compliance issues, disease distribution and issues related to the doctor-patient relationship. Although sociology in medicine was criticized for its seeming divorce from general sociological theory and for searching for "ways to rationalize sickness behaviour and to bring it into line with physician expectations" (ibid., p.332), Twaddle indicated that it nevertheless made important contributions in the areas of "medical education, social epidemiology, and our knowledge of utilization and compliance". He also pointed out that the sociology in medicine perspective was endorsed widely in many parts of the world (Twaddle, 1982).
2. Sociology <u>of</u> Medicine – this approach focuses on "medicine as a social institution worthy of study in its own right" (Twaddle, 1982, p.332). Twaddle states that this perspective seeks to understand "the role of the physician, the

socialization of physicians, hospital organization, physician-other interactions, and the social psychology of sickness and illness" (ibid., p.333), and was characteristic of early work in medical sociology performed in the United States. The sociology of medicine approach was responsible for inroads made in identifying the medical profession's medicalization of what were once considered normal conditions in the population (e.g., aging, childbirth, homosexuality). Sociology's fascination with medicalization or "medical imperialism" was criticized by Strong in 1979, who argued that medical sociology was itself acting imperialistic in its grandstanding and portrayal of a medical profession gone bad, and was failing to recognize the contributions that medicine had made in treating disease and improving overall quality of life in the population. However, Strong was himself criticized for what was seen as his oversimplification of the issues and confusion of medical imperialism with medicalization – i.e., sociology recognized that only a small portion of the medical profession/system might have imperialist tendencies, and that the medicalization of conditions in the population did not necessarily stem from motive/intent (Williams, 2001). Others such as Conrad (1992) point out that medical sociology's fascination with medicalization has led to contributions in a number of areas: knowledge that women's life processes are more likely to be medicalized than men's, that the aged are highly subjected to medicalized decisions, that conditions can be medicalized yet remain untreated (e.g., mental health conditions), and that there may be international differences or similarities in the way that we conceptualize and/or treat behaviours or conditions in the population. In short, activity under the sociology of medicine is related to the discipline's concern that a strictly medical model may decontextualize social problems by putting them under medical control and individualizing what could otherwise be seen or addressed as a collective social problem (Conrad, 1992).

3.2 Sociology of Health

Despite the gains made by the sub-discipline of medical sociology, a number of events transpired that set the stage for the emergence of the "sociology of health" approach. Dissolution of public confidence in a purely medical model of care, and studies linking disease and mortality patterns to socio-environmental concerns and preventive health practices led to a resurgence of interest in examination of the social factors that impact health. The "crisis of positivism" (Twaddle, 1982, p.349) within Sociology and other social science disciplines led to a concern for alternate ways of conceptualizing factors shaping experiences of health and illness (i.e., social, environmental, political and personal practice determinants). According to Twaddle, there was a clear "change of emphasis... from a positivist emphasis on the organism and its physiological foibles (sociology in medicine) and on the human personality, social roles and deviance (sociology of medicine) toward an emphasis on social structures in which human beings are enmeshed and the problems we all have in coping with those structures" (Twaddle, 1982, p.349). The units of analysis similarly changed from individuals to organizations to societies/social structures (ibid., p.349). By 1982, Twaddle notes the sociology of health was "taking a broadened perspective on all kinds of events, structures, etc. that limit freedom of choice and/or reduce personal effectiveness." (Twaddle, 1982, p.349).

In Canada specifically, Coburn and Eakin, among others, pointed to a noticeable shift in Canadian sociology of health from more of a "social psychological and voluntaristic viewpoint" influenced by American sociology, "to a more 'Canadian' political economy or power perspective" (Coburn and Eakin, 1993, p.85). The authors identified a clustering of research efforts in the areas of health status, health and illness behaviour, and the health care system, while at the same time noting that these areas were not separate. In fact, sociologists working from a sociology of health perspective recognized that all levels of sociological enquiry (micro level social psychological influences to macro level social structural determinants) were indeed important for a full understanding of the social factors that shape health and illness.

3.3 Population Health Framework

The evolution of sociology of health theory to encompass the broad range of social determinants that impact health (i.e., social structural determinants as well as more micro level socio-psychological factors that shape individual health and quality of life) is reflected in the population health perspective advanced by Canada's premier health data collection agency, the Canadian Institute for Health Information (CIHI). The determinants of health are broadly categorized by CIHI as: social, economic, environmental, equity of access to health services, personal health practices and biological predisposition. The determinants of health have been similarly reflected in a variety of Canadian health policy statements, from the federal "Lalonde report" in 1974, to statements later drafted by Health Canada, the Canadian Public Health Association, CIHI, and perhaps most recently in 2002 the Toronto Charter for a Healthy Canada (Raphael, 2004). Such statements have consistently redefined our notion of "health" to encompass a definition that is broader than merely the absence of disease and presence of health care services, to include the adequacy of social, environmental and economic resources required for a full and healthy quality of life (Raphael, 2004). The importance of the determinants of health have been repeatedly corroborated in sociological and other health-related research (see for example Evans et al., 1994; Williams, 2003; Raphael, 2004); however, Canadian research and knowledge concerning the impact of the more social determinants of health has not necessarily translated into the changes in social policy required to support a broad definition of population health (Raphael, 2004). In fact, shifting social, economic and political conditions have instead largely conspired against the construction of healthy social policy (Raphael, 2004), the type of policy that could be beneficial in preventing disparities in health care access and health outcome for persons with chronic illness such as renal insufficiency.

The determinants of health approach is particularly relevant for research that investigates the impact of health determinants on chronic disease/illness, since such studies have shown that whether a disease manifests itself has as much to do with the right socio-environmental conditions being present as with individuals' biological predisposition to disease (Evans, 1994, Raphael, 2004). Given that the social determinants of health "determine the extent to which a person possesses the physical, social, and personal resources to identify and achieve personal aspirations, satisfy needs, and cope with the environment" (Raphael, 2004, p.1), the approach is thus appropriate for my own thesis research into the determinants of disparities in persons' timely access to chronic renal care. This is because the social determinants of health exert their influence over time, having a cumulative effect on the health of individuals and populations

(Raphael, 2004). As Raphael (2004) has explained, social welfare advancements (i.e., improving the quality of the social determinants of health) were responsible for the greatest advances in the overall health of the Canadian population in the past 100 years; however, continuing inequities in the social determinants of health (disparities in income distribution, education, social inclusion, access to appropriate care, etc.) are responsible for continued inequalities in the health of different population groups in Canada (i.e., between aboriginal and non-aboriginal populations, low to high income groups, etc.). The cumulative effect of social determinants of health therefore results in differences in the incidence of disease across population groups, and may similarly affect the ability of various population groups – such as persons with chronic kidney disease in Canada - to access appropriate health care services in a timely manner. Therefore, although access to (or availability of) health services is identified as one of the determinants of health status, the research problem required that I treat access – i.e., disparities in timing of nephrology referral - as the dependent variable of interest upon which other health determinants act.

In order to make sense of what on the surface appears to be a surprising discrepancy in Canadian health care access in the area of referral to renal care, it is important to understand the strengths and weaknesses of the Canadian public health care system. The underlying assumption of the system is that individual need, not ability to pay, drives the utilization of publicly-funded health care services; therefore, all medically-necessary services are covered through the social insurance system at the point of patient entry. The evidence suggests that this is indeed the case: lower income groups have greater health care needs and use comparatively more services in the Canadian health care system (Evans et al., 1994). Yet, the question remains whether those with poorer health status actually access health services *at the rate* that one would expect, given their level of morbidity. Predisposing factors related to demographic, socio-structural and attitude-belief variables, as well as conditions that facilitate the access and use of services (e.g., social support and transportation) may mediate the relationship between sickness and seeking of health services. In short, although sickness determines health care need, the point at which someone identifies with the sick role and becomes motivated to seek treatment is likely to be influenced by their income, other social determinants, and geographical location. To the extent that data are available on these social determinants for BC renal patients they have been included in my thesis research (i.e., measures of social support and income). In consideration of the broad range of potential determinants of population health I also included available measures of patients' physical health; however, due to a lack of pre-existing secondary data, I was unfortunately unable to study the wide range of social determinants that may impact on renal patient access to care and morbidity (e.g., the early childhood influences, education, adequacy of food and housing, employment and work conditions which are reflected in The Toronto Charter for a Healthy Canada – see Raphael, 2004), nor other explanations that would stem from the more medical dominance perspective of medical sociology (i.e., the social psychological impact of physician attitudes/practices or patient compliance). As well, although the determinants of health theoretical framework suggests that social, economic, environmental and health service factors interact in complex ways with personal behaviours and predisposing biological factors to influence population health, a limitation of the theory is its lack of direction for the development of hypotheses related to potential interaction and indirect effects between the variables. Therefore, my research design and hypotheses reflect predictions regarding only the direct effects of patients' determinants of health on their timing of nephrology referral and health status (hospital and medical services utilization). Any effort to discover the indirect effects of renal patients' determinants of health would require longitudinal and multi-level study using primary data, which would enable the measurement of more true indicators of renal patient health status than were possible to study for my Phase II analysis. Nevertheless, I believe that my research forms a necessary first step in looking at the health determinants of renal patients in BC, and will thus inform both sociology of health theory and the population health perspective through its primary focus on identifying the impact of renal patients' social health determinants on initial access to renal care and ongoing patient health status (morbidity).

CHAPTER 4: LITERATURE REVIEWS AND RESEARCH HYPOTHESES

4.1 Phase I Literature Review

As will become clear below, it is probably useful to state upfront that researchers who have studied access to nephrology referral and/or dialysis have paid little attention to patients' health determinants, instead focusing largely on micro issues, such as the impact of physician attitudes/practices on whether persons with CKD are likely to be referred for nephrology assessment (see e.g., Mendelssohn et al., 1995; Sekkarie et al., 2001; Wilson et al., 2001) and, once referred, offered the opportunity of dialysis (see e.g., Kjellstrand and Moody, 1994; Hirsch et al., 1994; McKenzie et al., 1998; Wenger et al., 2000). This focus is consistent with how sociologists would approach the problem if they were taking a medical dominance perspective to the research problem (i.e., the sociology in and of medicine). These studies, as well as a growing number of others that deal specifically with the predictors of late referral (see e.g., Arora et al., 1999; Cass et al., 2003; Curtis et al., 2002; Holland and Lam, 2000; Letourneau et al, 2003; Steel and Ellis, 2002; Winkelmayer et al., 2001) are important but nevertheless only partially answer the overarching question regarding the health determinants of persons who experience late or no referral to nephrology care prior to requiring treatment. In contrast, the determinants of health have been more thoroughly studied in research examining the predictors of developing renal disease (see e.g., Cass et al., 2001; Fored et al., 2003; Kutner and Brogan, 2000; Nzerue et al., 2002; Perneger et al., 1995; Young et al., 1994), renal patient health status (see e.g., Garg et al., 2001; Kriegsman et al., 1995; Kutner, 1987; Turner-Musa et al., 1999), and access as it relates to differences in dialysis treatment or kidney transplantation (see e.g., Garg et al., 2001; Gordon, 2001; Kasiske et al., 2002;

Kutner and Gray, 1981; McCauley et al., 1997; Salvalaggio et al., 2003). Knowledge regarding the predictors of timing of access to this chronic care treatment remains largely untapped, despite the fact that renal patients represent one of the fastest growing groups utilizing health care services in Canada, at a cost that is rising exponentially (e.g., the total number of renal patients in BC has been growing at a rate of approximately 10% a year, with an estimated annual cost per patient of $50,000-$60,000 Cdn).

In preparation for the development of hypotheses regarding the impact of renal patients' health determinants on their type of referral/access, I reviewed the relevant literature on the predictors of late referral to nephrology care, late initiation to dialysis and suboptimal pre-dialysis care. Literature on whether a person with CKD is ever likely to be referred to a nephrologist was largely excluded from this review, since it was beyond the scope of this thesis to ascertain the proportion and determinants of unmet need in the BC population.

The majority of late-referral studies are relatively recent, conducted during the late or early 1990s, presumably due to mounting interest in ways to stem the human costs and health system outlays associated with poor health outcomes for this growing chronic care population. The definition of late referral varies amongst studies, with the majority using a definition of <3 months referral before dialysis (Cass et al., 2003; Curtis et al., 2002; Letourneau et al., 2003; Winkelmayer et al., 2001) or <1 month of referral before dialysis (Jungers et al., 1993; Ratcliffe et al., 1984; Roderick et al., 2002; Schmidt et al., 1998). However, the following definitions have also been used: <4 months referral (Arora et al., 1999; Kinchen et al., 2002), <12 months referral (Ifudu et al., 1999); and, the clinical marker "serum creatinine" (Holland and Lam, 2000; Ifudu et al., 1999). I located two studies on the predictors of late dialysis initiation and one on the predictors of suboptimal pre-dialysis care, and included these in the review due to an established link between delayed nephrology referral and late dialysis initiation (Arora et al., 1999; Iofel et al., 1998). These studies used the following definitions of decreased renal function or anemia as measures of late initiation or suboptimal pre-dialysis care: hematocrit of <22% (Iofel et al., 1998) glomerular filtration rate of <5ml/min per $1.73m^2$ (Kausz et al., 2000), hematocrit of <28%, hypoalbuminemia and erythropoietin usage (Obrador et al., 1999).

The studies reviewed were located in five countries, each with different national health care systems: three studies were conducted in Canada, eight in the United States (US), three in the United Kingdom (UK), two in France and one in Australia. The studies also varied in size of patient sample or population studied (ranging from n=55 to N=155,076) and the number and type of potential determinants analyzed. The determinants most frequently studied were demographic (age, gender and race/ethnicity), followed by socioeconomic status, comorbidities and predisposing disease, and geographical and health service characteristics (proximity to care, and renal centre/network). I located only one prior study that considered the potential impact of patients' social support (i.e., marital status - Kinchen et al., 2002).

The literature summary begins with findings related to the predictive effect of renal patients' health conditions (comorbidities and predisposing disease). These are followed by a discussion of findings related to demographic, socioeconomic and social support indicators and, finally, geographic/health services characteristics (proximity to treatment, and renal centre or network).

4.1.1 Prior Health Conditions

A diagnosis of diabetes has often been found to have a protective effect against late referral (Holland and Lam, 2000; Schmidt et al., 1998; Winkelmayer et al., 2001), presumably due to the close physician monitoring that diabetics are likely to receive. In contrast, a number of studies have not found diabetics to be protected against late referral (Arora et al., 1999; Curtis et al., 2002; Ratcliffe et al., 1984). Obrador et al. (1999) found diabetes to be associated with sub-optimal pre-dialysis care when testing the effect of diabetes on hypoalbuminemia, but found no such association when testing the effect of diabetes on suboptimal care defined by a hematocrit level of <28%. However, Obrador et al. (1999) did find diabetes to be protective against suboptimal pre-dialysis care when testing the effect of diabetes on erythropoietin usage.

There is similar conflicting information regarding the impact of patients' comorbid conditions – i.e., a similar number of late-referral studies found a relationship between comorbidity (type or severity of) and late referral (Holland and Lam, 2000; Kinchen et al., 2002; Roubicek et al., 2000) as did not (Arora et al., 1999; Roderick et al. 2002). In addition, an association between comorbidity and early referral has been reported by Winkelmayer et al. (2001), and Kausz et al. (2000) who found an association between comorbidity and early dialysis initiation.

The findings related to cause of end-stage renal disease (ESRD) are equally contradictory: two studies found an association between cause of ESRD and late referral (Jungers et al, 1993; Ratcliffe et al., 1984) and four studies did not (Arora et al., 1999; Holland and Lam, 2000; Ifudu et al., 1999; Roderick et al., 2002). Schmidt et al. (1998) found an association between diabetic renal failure and early referral; however, Kausz et al. (2000) found an association between cause of ESRD (diabetes) and late dialysis initiation.

4.1.2 Demographics, SES and Social Support

Relevant studies on a variety of demographic and social determinants also reported inconsistent findings. Where age was found to be a factor in type of referral, the majority of studies found increasing age to be associated with greater risk of late referral (Curtis et al., 2002; Holland and Lam, 2000; Letourneau et al., 2003; Roderick et al., 2002; Winkelmayer et al., 2001); however, Steel and Ellis (2002) found persons of younger age to be more likely to be late referred. A number of studies did not find an association between age and late referral (Arora et al., 1999; Jungers et al., 1993; Kinchen et al., 2002; Roubicek et al., 2000; Schmidt et al., 1998), and Ifudu and colleagues (1999) found conflicting results depending on how late referral was defined (i.e., they found increased age to be associated with a poor serum creatinine level, but not with <12 months of referral). On the other hand, Kausz et al. (2000) reported younger age to be associated with late dialysis initiation, but Iofel et al. (1998) did not find age to be related to late dialysis initiation, and Obrador et al. (1999) did not find an association between increased age and suboptimal pre-dialysis care.

The overwhelming majority of late referral studies that included gender as part of the analysis did not find an association between patient gender and late referral (Arora et al., 1999; Curtis et al., 2002; Ifudu et al., 1999; Jungers et al., 1993; Kinchen et al., 2002; Roderick et al., 2002; Roubicek et al., 2000; Schmidt et al., 1998; Steel and Ellis, 2002). However, a few studies found female gender to be associated with late referral (Holland and Lam, 2000), delayed dialysis initiation (Kausz et al., 2000) and suboptimal pre-dialysis care (Obrador et al., 1999). Only one study (Winkelmayer et al., 2001) found male gender to be a factor in late referral (i.e., for males <65 years of age).

Nearly all of the studies that included race/ethnicity as a predictor found non-whites and/or blacks to have a greater probability of late referral, delayed dialysis initiation or sub-optimal pre-dialysis care (Ifudu et al., 1999; Kinchen et al., 2002; Winkelmayer et al., 2001; Iofel et al., 1998; Kausz et al., 2000; Obrador et al. 1999). Two studies did not find an association between race/ethnicity and late referral (Arora et al., 1999; Schmidt et al., 1998), and Ifudu et al. (1999) found conflicting results depending on how late referral was defined (non-whites were found to have a greater probability of late referral measured by serum creatinine concentration; however, race/ethnicity was not a factor in <12 months referral).

Socioeconomic status was variously defined as level of health insurance (US studies), education, urban areas of disadvantage/advantage, and a measure of high/middle/low income. Two studies found a relationship between lower SES and late referral (Cass et al., 2003; Kinchen et al., 2002); however, two other studies did not (Jungers et al., 1993; Winkelmayer et al. 2001), and Arora et al. (1999) found that HMO US patients had a greater chance of late referral than Medicare patients. Low SES was, however, found to be linked to late dialysis initiation (Kausz et al., 2000) and sub-optimal pre-dialysis care (Obrador et al., 1999).

Marital status as a measure of social support was included in only one study (Kinchen et al., 2002) and was not found to be related to late referral. No additional measures of social support were located within the literature reviewed.

4.1.3 Geographic and Health System Characteristics

A number of late referral studies included measures of proximity to, or availability of, renal care services; however, none were found to be associated with late referral (Cass et al., 2003; Holland and Lam, 2000; Schmidt et al., 1998). Two studies did, however, find a patient's renal network (i.e. renal services provider) to be associated with late dialysis initiation (Kausz et al., 2000) and suboptimal pre-dialysis care (Obrador et al., 1999).

In summary, the research findings on impact of prior health conditions are mixed. The majority of studies found increasing age, non-white or Black race/ethnicity, and lower SES to be associated with late referral, late dialysis initiation or suboptimal pre-dialysis care; however, the same was not true of gender. Although social support (as measured by marital status) was not found to be associated with late referral, this finding is based on the strength of one study only. Proximity to care was not found to be predictive of late referral; however, other studies on the likelihood of whether a patient would ever be referred to nephrology care have reported a relationship between proximity to care and nephrology referral (Boyle et al., 1996; Mendelssohn et al., 1995). Patients' renal care network/service was predictive of late dialysis initiation or suboptimal pre-dialysis care; however, was not studied in relation to late referral.

In short, the majority of existing studies on late nephrology referral lack complexity by overlooking important variables that should be included from a determinants-of-health perspective. This lack of complexity and inconsistency in reported findings necessitates further research that is robust in its inclusion of potential variables and involves analysis of statistically generalizable data. The research conducted for this thesis is intended to be a modest step in this direction.

4.2 Phase I Research Hypotheses

Hypotheses derived from my review of the relevant literature and related to those determinants available for study based on my utilization of existing data on BC renal patients are presented in Table 3. Hypotheses regarding the predictive effect of patients' age, race/ethnicity, and SES were straightforward, given the prior research findings discussed above. Although the findings on prior health conditions were contradictory, I hypothesized that cause of ESRD would impact the timing of patient referral, and that a diagnosis of diabetes would be found to have a protective effect against late referral. Similarly, although previous findings regarding gender were contradictory, where a significant association was found it was consistently associated with female gender; therefore, I constructed a hypothesis to this effect. Because social support has been generally ignored in prior studies, I decided to include it in my model, hypothesizing a relationship between reduced social support and late referral. Despite contradictory prior findings about proximity to care, given the size and geography of BC[3], I hypothesized that reduced proximity to care is associated with late referral. In consultation with the BCPRA, I defined reduced proximity as >1 hour's drive, which coincides with the definition used by Schmidt et al. (1998)[4].

---

[3] British Columbia is the western-most province of Canada. Large areas of the central and northern parts of the province are sparsely settled. In fact, nearly three fourths of the population resides in the southwest coastal tip which includes the largest city and chief port of Vancouver and the provincial capital, Victoria, located on Vancouver Island.

[4] It is recognized that a dichotomized definition for proximity to care (≤1 hour or >1 hour drive) is probably a weaker indicator of distance than the continuous measure employed by geographers.

Finally, given prior research findings regarding the impact of a patient's renal network or dialysis centre, I surmised there may be differences in the type of referral experienced by patients accessing different renal care centres in BC.

Table 3 – Phase I Research Hypotheses

Determinant	Research Hypotheses #	Description
Prior Health Condition	1	ESRD cause is directly related to late nephrology referral
	2	Diabetes is protective against late referral.
Age	3	Increasing age is directly related to late referral.
Gender	4	Female gender is directly related to late referral.
Race/Ethnicity	5	Ethnic minority status is directly related to late referral.
SES	6	Low SES is directly related to late referral.
Social Support	7	Presence of spouse/partner or next-of-kin is directly related to early referral.
Proximity to Care	8	>1 hour drive to regional renal centre is directly related to late referral.
Renal Centre	9	Regional renal centre is directly related to late referral.

4.3 Phase II Literature Review

The Phase II literature review encompasses prior studies by researchers into the consequences of late referral, as well as prior research on the impact of late referral and other factors on indicators of morbidity and health system costs.

4.3.1 Consequences of Late Referral

Nephrologists point to repeated findings that indicate late referral of the patient to nephrology care (including access to pre-dialysis education, and counseling on nutrition, types of renal replacement therapy and how to deal with the disease) impairs the ability of the nephrology team to stem or completely halt the progression of kidney disease (BC Renal Review, 2002; Jungers, 2002; Levin, 2000; Levin, 2001). In fact, Junger's team in Paris, France, has estimated that close to 5% of their end stage renal failure cases over a 12-year period could have been completely reversed or halted in disease progression had those patients been referred early enough for aggressive treatment of renal related disease and infection (Jungers, 2002). This represents significant cost to both the patient and the health care system (in terms of reduced opportunities to delay or halt disease progression, increased hospitalization at dialysis start, etc.); therefore, earlier identification and treatment of renal conditions is recommended, accompanied by aggressive treatment of co-morbid conditions (Jungers, 2002; Levin, 2000). In fact, a 1994 consensus statement issued by the National Institute of Health (NIH), the premier federal health research institute in the United States, advised that patients be referred to nephrology care "at least 4 months before initiation of dialysis", and the Canadian Society of Nephrology in 1999 advocated referral "at least 12 months prior to dialysis initiation" for adequate preparation of the patient and family (Levin, 2000, p.9). Despite the variation in the definition of late referral, the consequences of late referral are considered to be serious on a number of counts (see e.g., Jungers, 2002; Levin, 2000):

- increased hospital-stay at dialysis initiation and during ongoing treatment (often due to vascular access failure due to insufficient time to create the more stable fistula instead of graft access);
- reduced ability for patients to pursue a transplant early in their disease onset or to choose more ambulatory forms of dialysis treatment that may represent better quality of life and use less system resources;
- detrimental socio-economic effect to patient (out of pocket expenses in terms of transportation to and from treatment, and potential employment impact due to inability to work regular hours) and health care system;

- Increased risk of morbidity and mortality.

Similar to literature on the predictors of type of patient referral reviewed for Phase I above, prior studies on the consequences of type of nephrology referral on measures of patient morbidity, hospitalization, and survival do not appear to have fully considered the potential impact of other health determinants (i.e., patients' prior health conditions, demographics, SES, social support and geographical and health system characteristics). To augment the existing research, Phase II of my thesis research focused on the impact of patients' type of referral and other potential health determinants on the following indicators of patient morbidity: hospital visits (admissions), total hospital days stay, medical services utilization, and total cost associated with medical services utilization. In the absence of more direct measures of renal patient morbidity, it has been noted that hospitalization data has commonly been used as an indicator of morbidity assessment (Eadington, 1995; Murphy et al., 2000). I have expanded on prior studies by including an assessment of MSP insured services and related costs. In the following section I review prior research on the impact of patients' type of nephrology referral and, if studied, other health determinants, on indicators of renal patient health system utilization and costs.

4.3.2 Morbidity Studies

I located ten articles on studies that addressed the effect of timing of nephrology referral on measures of renal patient hospitalization: two studies were conducted in Canada, three in the United States, two in Britain, two in France and one in Norway. The studies varied in size of patient sample or population studied (ranged from 55 to 1000 patients) and in the definition of late referral used (ranged from <1 to <4 months referral, and one study that defined as late referred those patients who were uremic and required immediate renal replacement therapy). Only one study (Arora et al., 2000) conducted in the United States on 128 CKD patients during the period 1992 to 1997 considered the impact of late referral as well as a range of other potential health determinants (cause of ESRD, comorbidity, clinical conditions, age, gender, race, SES, dialysis treatment modality and type of vascular access) on indicators of patient hospitalization. The Norwegian study (Goransson and Gergrem, 2001) addressed the impact of late referral and patient age on duration of hospitalization; however, the remainder of studies addressed solely the impact of type of nephrology referral on indicators of renal patient hospitalization. One of the Canadian studies (Muirhead and Blyndal, 1995) did not specifically assess the impact of type of nephrology referral; however, their comparison of the impact of attending a pre-dialysis clinic on patient hospitalization could arguably be related to the difference in impact between late and early referral, since early referral would be required for someone with CKD to participate in a pre-dialysis clinic designed to monitor and prepare clients for eventual renal replacement therapy. Similarly, one of the United States studies (Ifudu et al., 1996) assessed the impact on hospitalization of being under a nephrologist's care (i.e., could assume these patients were early referred) compared to non-nephrologist care or no care whatsoever (late/non-referred patients).

All of the above studies reported an association between late nephrology referral and increased hospitalization (measured as number of hospital visits and/or hospital days stay). The majority of studies defined patient hospitalization as the total number of hospital days stay for a renal patient's hospital admission at the time of their dialysis initiation (Gorannson and Gergrem, 2001; Ifudu et al., 1996; Jungers et al., 1993;

Muirhead and Blyndal, 1995; Ratcliffe et al., 1984; Roderick et al., 2002; Roubicek et al, 2000). In contrast, Arora et al. (2000) omitted hospitalization at initial dialysis and focused instead on hospital days in the 3 months following a patient's dialysis initiation, as well as a second measure that looked at hospital days beyond the initial 3 month period. Coyne et al. (1998) looked at three separate measures of hospitalization: hospital visits and days for an unspecified period following initial dialysis; hospital visits and days in the year prior to dialysis; and, the median time to next admission following initial hospitalization. McLaughlin et al. (2001), in a complex study comparing differences in healthy outcome for 1000 simulated renal patients, compared total hospital inpatient days for an unspecified period of time using data from published sources and the Southern Alberta Renal Program.

As mentioned above, only two studies specifically assessed the potential impact of factors in addition to type of nephrology referral on indicators of renal patient hospitalization. Arora et al.'s US based study (2000) found that, in addition to late referral being associated with increased relative risk of longer hospitalization (hospital days stay) in the first 3 months following initial dialysis, a number of other factors were found to affect patients' length of hospitalization in the first 3 months and/or in the period following the first 3 months. Diabetes as cause of ESRD, increased patient age, insurance by a health maintenance organization (HMO) and temporary vascular access (often a result of late referral) were associated with a greater relative risk of hospitalization both within and following the initial 3 month period. In addition, it was found that females had a reduced relative risk of hospitalization compared to males in the initial 3 month period, and an increased relative risk in the period after 3 months. Arora et al. (ibid.) did not find patient race (Caucasian compared to non-Caucasian) nor initial treatment type (hemodialysis versus peritoneal dialysis) to impact the duration of patient hospitalization. Similar to Arora et al. (ibid.), Goransson and Gergrem (2001) found that increased patient age, in addition to late referral, translated into an increased number of hospital days stay at patients' dialysis initiation. Finally, I located one additional cross-Canada study by Murphy et al. (2000) that did not include an assessment of the impact of type of nephrology referral on hospitalization, but instead assessed the impact of type of dialysis treatment (hemodialysis or peritoneal dialysis) and other variables (type of renal failure [acute, acute-on-chronic, or chronic], age, gender, diabetes and other comorbidities) on hospitalization both within the 3 month period following dialysis initiation and in the period following that initial 3 months (i.e., similar to the assessment periods used by Arora et al.). Using poisson regression analysis, Murphy et al. found an increased relative risk of hospitalization (days stay) for those with acute or acute-on-chronic renal failure (RR=1.06, P=<0.003) at time 1 (in the initial 3 months following dialysis initiation), but no difference at time 2 (in the period following that 3 months). They also found an increased relative risk of hospitalization for patients who were older than the median age at time 1 (RR=1.33, P=>0.001) and time 2 (RR=1.25, P=<0.001), a reduced relative risk for males compared to females at time 1 (RR=0.80, P=<.0001) and time 2 (RR=0.75, P=<0.001), and an increased relative risk for persons with diabetes at time 1 (RR=2.02, P=<0.001) and time 2 (RR=2.16, P=<0.001).

4.3.3 Cost-Benefit Studies

Lameire et al. (2002), in their article reviewing the epidemiology of, reasons behind, and consequences of late referral, indicate that there is a lack of recent studies into the cost implications of late versus early nephrology referral. I located information on six studies that addressed the costs associated with type of referral or the cost benefit of attending a pre-dialysis clinic. Three of these were conducted in Canada (Levin, 2001; McLaughlin et al., 2001; Muirhead and Blyndal, 1995), one in the United States (Schmidt et al., 1998), one in Spain (Gorriz et al., as identified in Lameire et al., 2002) and one in Norway (Goransson and Gergrem, 2001).

Costs were measured differently across the various studies. The BC study reported by Levin (2001) looked at the length of time to renal replacement therapy for patients who were late referred (<3 months) compared to those who were early referred and participated in a multidisciplinary pre-dialysis clinic or those who were early referred and received standard nephrologist care. That study found that early referral and pre-dialysis clinic participation resulted in delayed renal replacement therapy (39 months to therapy) compared to those who were early referred with nephrologist care (31 months to therapy) and those who were late referred (only 1 month to therapy) – from which one could infer that delayed time to therapy translates into health system cost savings (i.e., one year off dialysis translates into a cost saving of between $50,000 to $75,000 – see Bernstein, 2003). Muirhead and Blyndal (1995) similarly report on an Ontario, Canada, study that assessed the cost difference between attending versus not attending a pre-dialysis or CRF clinic, finding a difference in cost of $5,926 Cdn for clinic patients compared to $10,718 Cdn for non-clinic patients (costs include hospital stay and temporary vascular access), and stating that the cost savings outweigh the costs of running CRF clinics. McLaughlin et al. (2001) calculated a difference in mean outpatient care cost per patient over a five year period between late referred patients ($164,262 Cdn) and early referred patients ($130,912 Cdn). The McLaughlin et al. results were based on a simulated sample of 1000 patients who were either defined as all early referred or all late referred; however, since that is never the case, they also looked at the cost impact of increasing the percentage of early referred patients from a starting point of 50% (the approximate percentage of early referred patients in BC based on my own study's late referral definition of <3 months) to 75%. This resulted in a cost saving of $8,272 per patient over a 5 year period (as well as a life year gain of 0.04 years, life years off renal replacement therapy of 0.11 years, and 4 fewer inpatient hospitalization days). Gorriz et al. (referenced in Lameire et al., 2002) compared the cost of planned to unplanned dialysis initiation, estimating a cost savings of $675,987 US dollars for planned dialysis based on the number of new renal patients in Spain each year. Schmidt et al. (1998) in the United States looked at the cost implications of emergent dialysis which was more prevalent in their late referred compared to early referred patients (90% of patients referred within 30 days of requiring dialysis experienced emergent dialysis, compared to 22% of early referred patients), calculating a cost overage of $1,992 per late referred patient per hospital day based on a 1-3 day hospital stay, or a total of $204,116 to $332,540 for the 104 patients who experienced emergent hemodialysis. Finally, Goransson and Gergrem (2001) point out that the cost implications of higher median hospital stay in their late referred patients, when applied to their entire population of new Norwegian renal patients for a single year, would be over 6.3 million NOK.

4.4 Phase II Research Hypotheses

Based on the prior research findings reviewed above on the effects of late referral and other variables on morbidity and related costs, I derived two additional hypotheses regarding the impact of late referral and other health determinants on hospital and medical services utilization for BC renal patients (see Table 4).

Table 4 – Phase II Research Hypotheses

Determinant	Research Hypotheses	
	#	**Description**
Late Referral	1	Late referral is directly related to increased morbidity and system costs (i.e. the total number of hospital visits, hospital days stay, MSP services utilized and cost of MSP services utilized), over the period one year prior to and one year following patients' dialysis initiation.
Other Health Determinants	5	Other health determinants (i.e., prior health condition, demographics, SES, social support, geographic and health system characteristics) are directly related to increased morbidity and system costs (the total number of hospital visits, hospital days, MSP services and cost of MSP services utilized) in the period one year prior to and one year following dialysis initiation, and likely mediate the impact of a late referral experience on renal patients' health system utilization.

Since prior studies by other researchers have tended to focus on the impact of late referral on hospitalization at dialysis initiation only (when the effects of late referral might arguably be strongest), I recognized that the effects of late referral on hospital and medical services utilization in my own study (i.e., utilization of services one year prior to and one year following patients' dialysis initiation) might not prove to be as strong as those reported in prior studies.

CHAPTER 5: RESEARCH DESIGN

5.1 Ethics Committee Approval

Since the BCPRA has the written consent of BC renal patients to utilize their data in research efforts, the BCPRA deemed it unnecessary to seek additional patient consent for this project. A copy of the BCPRA patient consent form (see Appendix A) was attached to my Request for Approval of Waiver from the University of Victoria Human Research Ethics Committee. This approval was granted on August 26, 2003 (see Appendix B).

5.2 Data Access Agreements

Data access agreements were drafted and signed with: 1) the BCPRA – to obtain access to patient-specific data contained in the Patient Records, Outcome and Management Information System (PROMIS) on the indicators of interest for this project (personal health numbers were stripped from the dataset and replaced with non-identifiable study identification codes); and, 2) the BC Ministry of Health Services – to access hospital and Medical Services Plan data, as well as income quintile and decile data maintained by the Centre for Health Services and Policy Research (CHSPR) at the University of British Columbia. In order to retrieve the CHSPR data, the BCPRA provided the Ministry of Health Services with patient-specific personal health numbers, which were then scrambled by the Ministry and forwarded to CHSPR. The datasets that I received from the BCPRA and the CHSPR contained a consistent study identification number for each patient included in the population sample, to enable me to link the datasets for purposes of data analysis. Data recovery costs for the datasets provided by

CHSPR were covered by the research and travel grant portion of my Research Trainee Award through the Michael Smith Foundation for Health Research and the British Columbia Medical Services Foundation. There was no cost associated with the BCPRA data.

5.3 Phase I Research Design

This section comprises information on the Phase I research: the data and population sample, the design of the research in terms of the independent and dependent variables studied, and the logistic regression analytical technique.

5.3.1 Phase I Data and Population Sample

The Phase I research hypotheses were tested using existing patient referral and socio-demographic data for BC renal patients provided by the BCPRA, on the total number of new renal patients who initiated dialysis during the period April 1, 2000 to March 31, 2003 (N=2001 patients). Only persons known to have chronic kidney disease (CKD) at the time of their nephrology referral or acute start onto dialysis were included in the population sample; those classified as having acute renal failure (ARF) were not included. Data on CKD patients' socioeconomic status (i.e., income quintile and decile data originally from Statistics Canada, and MSP subsidy status data) were also used for the Phase I analysis and were obtained from the British Columbia Linked Health Database (BCLHD) maintained by the CHSPR at the University of British Columbia. Income data for the year 2001 were used for the majority of patients; however, in instances where patient postal codes had been retired, 1996 income data were substituted where possible (n = 44 cases).

The determinants of health included in the Phase I analysis, based on the availability of existing provincial data in the areas of interest (i.e., prior health condition, demographics, socioeconomic status, social support and geographic/health system characteristics), are presented in Table 5. The use of existing data restricted the research design to data elements currently recorded (e.g., the approximate measure of patient socio-economic status is based on aggregate-level income quintile/decile[5] data derived from the Canada Census). Despite such shortcomings, I believe that the research findings provide an important first step in identifying the potential impact of multiple health determinants on renal patients' initial access to nephrology care.

---

[5] Income quintiles/deciles are relative measures based on census summary data at the Enumeration Area (1996) or Dissemination Area (2001) level. BC quintiles/deciles are calculated to be area-specific (i.e., by Census Metropolitan Area, Census Agglomeration, or provincial residual area not in any CMA or CA), "to minimize the effect on household welfare of large differences in housing costs" (Statistics Canada, 2001). The 2001 quintile/decile data may be affected by a problem identified with the postal code conversion to DA; therefore, data may not always reconcile with data produced in future releases/reports (CHSPR, personal communication, April 7, 2004).

Table 5 – Phase I Measures Operationalized

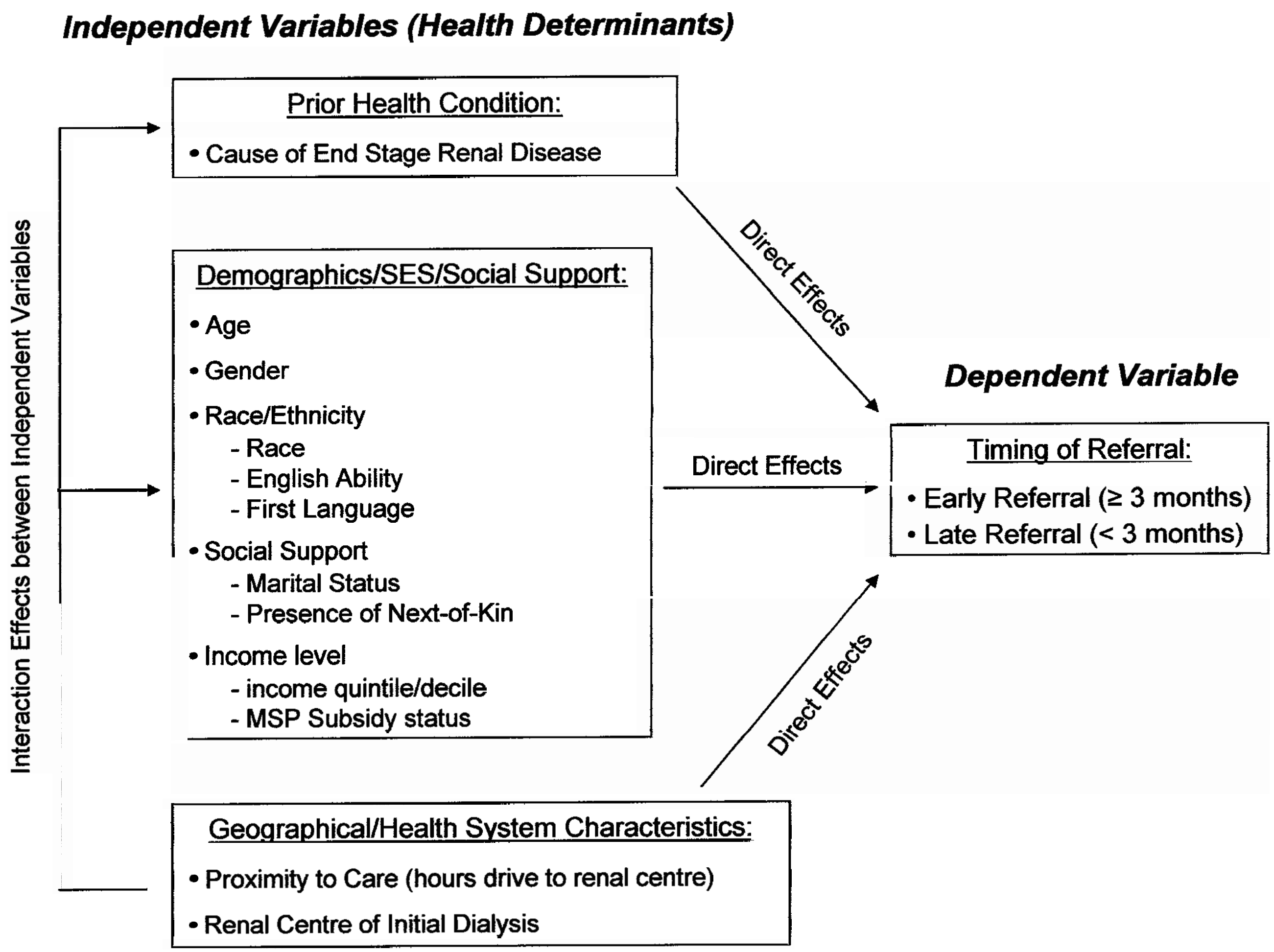
Determinant	Operationalized Measure	Type of Variable IV	DV
Type of Referral	- early referral; late referral		X
Prior Health Condition	- cause of ESRD (primary diagnosis, e.g. diabetes, renal vascular disease, etc.)	X	
Age	- age at dialysis initiation	X	
Gender	- male, female	X	
Race/Ethnicity	- race/ethnicity	X	
	- English ability	X	
	- first language	X	
SES	- income quintile/decile (Census data)	X	
	- MSP Subsidy status	X	
Social Support	- marital status	X	
	- presence of next-of-kin	X	
Proximity to care	- hours drive to regional renal centre	X	
Renal Centre	- regional renal centre (where patient is referred and initially dialyzed)	X	

IV=independent variable, DV=dependent variable

5.3.2 Phase I Research Design

The relationship between the independent variables and dependent variable, including potential interaction effects between independent variables, is represented in Illustration 1.

Illustration 1- Phase I Research Design



5.3.3 Phase I Analytical Technique

Phase I of the research employs a retrospective cross-sectional design. Initially, multinomial logistic regression analysis was performed using the program SAS (Statistical Analysis for the Social Sciences) to study the direct and interactive effects of the independent variables on the following three-category dependent variable for patient referral: early referral, late or no referral, and no referral accompanied by an acute start onto dialysis. For a discussion of these earlier results please see Blythe and Benoit (2004). Subsequent discussions with the BCPRA resulted in collapsing the dependent variable into the following two categories: early referral, and late referral (where late referral includes all those who experienced late or no referral, with or without an accompanying acute start onto dialysis). This was done to ascertain whether analyzing all late referred patients together would produce different results from the earlier analysis that separated out persons who acute started onto dialysis from the other late referred patients. There was no substantive difference in the significance of health determinants found to impact patients' referral experience; therefore, since the two-category dependent variable conforms to methodology used in prior late referral research, the binomial logistic regression analysis based on the two-category dependent variable is reported on here. The binomial logistic regression analysis incorporated a "backwards elimination" statement that had the function of including all variables in the analysis but throwing out those that were not significant in the final model (a sub-statement ensured that the variables gender, age, race/ethnicity and cause of ESRD were maintained in the final results regardless of whether they were found to be significant or not).

Data recodes were performed to deal with small N cell issues within various categories of the independent variables, and to handle missing values within patient records. Missing values were recoded to an "unknown" category for each variable and maintained in the analysis; no attempt was made to attribute values for missing ones. Although there are more complex statistical methods for dealing with missing values, coding them to a separate category was preferable to deleting these cases altogether. The categories of some variables were further collapsed for analytical purposes – e.g., since an earlier analysis of the thesis data indicated that persons who were single had the lowest expected probability of late referral followed by those who were married or common-law (see Blythe and Benoit, 2004), persons who were single were grouped with those who were married or in a common-law relationship when comparing to those who had lost a potential source of prior social support (i.e., the divorced, separated or widowed). I employed a late referral definition of <3 months for the analysis, since it was one of the most often used definitions and has been used in two prior Canadian late referral studies (Curtis et al., 2002; Letourneau et al., 2003). In addition, I re-ran the analysis using alternate late referral cut-offs (i.e., <1, <4, <6 and <12 months referral) to report on potential differences in the significance of health determinant effects on patients' referral type. When testing the impact of patient age, I tested for a possible curvilinear effect, and retained the original one-year age increments for greater statistical sensitivity. Geographic proximity to care was measured using MapQuest (www.mapquest.com), which enabled me to calculate the driving distance between a patient's city of residence and postal code to the street address of their regional renal centre. In calculating a patient's MSP subsidy code, I selected the code closest to the patient's nephrology referral date, which involved using 2000/01 MSP subsidy data for 2000/01 patients, and 2001/02 data for 2001/02 and 2002/03 patients (i.e., the latest year of MSP data available was 2001/02). Subsidy codes ranged from 100% subsidized to 20% subsidized, or no subsidy. In consultation with the BCPRA, a decision was made to include all categories of MSP subsidy together into one "subsidized" category. Finally, two-way interactions between the independent variables (e.g., gender by marital status) were included in the binomial regression model to test for potential interaction effects.

5.4 Phase II Research Design

This section comprises information on the following components of the Phase II research: the data and population sample, the design of the research in terms of the independent and dependent variables studied, and the logistic regression and ordinary least squares (OLS) regression analytical techniques.

5.4.1 Phase II Data and Population Sample

The Phase II research hypotheses were tested using the same BCPRA patient data, income data and MSP subsidy status data used in the Phase I analysis, as well as data on renal patients' hospital and MSP services utilization obtained from the BC Linked Health Dataset maintained by CHSPR at the University of British Columbia (i.e., the total number of hospital visits, total number of days stay in hospital, total number of MSP services, and total cost associated with MSP services). Two additional indicators were included from the BCPRA data file since it was felt they could impact patient hospital and MSP services utilization: 1) patient's clinical condition at time of initial dialysis (i.e., hemoglobin, calcium, phosphate, IPTH, albumin and creatinine levels); and, 2) patient's initial type of dialysis (hemodialysis or peritoneal dialysis). In order to assess the impact of patients' referral experience (based on a late referral definition of <3 months referral) and other health determinants on their hospital and medical services utilization, a decision was made in consultation with the BCPRA to assess patients' use of hospital and MSP services both one year prior to and one year following their initial dialysis treatment. This necessitated using a subset of the renal patients that were used in the Phase I analysis (i.e., n=572 patients, compared to N=2001 patients in Phase I), in order to accommodate the two-year period of service utilization and the fact that the hospital and MSP services data is not as recent as the BCPRA and income data used in the Phase I analysis (i.e., the latest year of data available for hospital and MSP services utilization was 2001/02; therefore, only records for renal patients who initiated dialysis during fiscal year 2000/01 were used in the Phase II analysis).

The dependent and independent variables included in the Phase II analysis are presented in Table 6. Again, the use of existing data restricted the research design to data elements currently recorded; however, the analysis and research findings provide a first step in identifying not only the impact of a late referral experience on BC renal patients' hospital and medical services utilization, but also the potential impact of multiple health determinants on these measures of renal patient morbidity and service utilization.

Table 7 presents the list of renal-related ICD-9 codes (International Classification of Diseases, Version 9) and CCP codes (Canadian Classification of Procedures) provided by the Vancouver Island Health Authority on the request of the BC Ministry of Health Services. The list was confirmed with the BCPRA and used by CHSPR to retrieve hospital/MSP services data on the 572 renal patients who initiated dialysis in 2000/01.

Table 6 – Phase II Measures Operationalized

Determinant	Operationalized Measure	Type of Variable IV	Type of Variable DV
Hospital Utilization	- total number of hospital visits		X
	- total number of hospital days used		X
MSP Service Utilization	- total number of MSP services used		X
	- total cost of MSP services used		X
Type of Referral *	- early referral; late referral	X	
Prior Health Condition	- cause of ESRD (primary diagnosis)	X	
Clinical Condition	- Hemoglobin, Calcium, Phosphate, IPTH, Albumin and Creatinine levels at time of initial dialysis	X	
Age	- age at dialysis initiation	X	
Gender	- male, female	X	
Race/Ethnicity	- race/ethnicity	X	
	- English ability	X	
	- first language	X	
SES	- income quintile/decile (Census data)	X	
	- MSP Subsidy status	X	
Social Support	- marital status	X	
	- presence of next-of-kin	X	
Proximity to care	- hours drive to regional renal centre	X	
Renal Centre	- regional renal centre (where patient is referred and initially dialyzed)	X	
Type of Initial Dialysis	- hemodialysis, peritoneal dialysis	X	

* Late Referral defined as <3 months referral, Early Referral defined as ≥3 months referral.
IV=independent variable, DV=dependent variable

Table 7 – Renal Related ICD-9 and CCP Codes (used for selection of Hospital and MSP Services Data)

ICD-9 Code	DESCRIPTION
250.30	Diabetes with renal manifestations, adult-onset type
250.31	Diabetes with renal manifestations, juvenile type
250.39	Diabetes with renal manifestations, unspecified whether adult-onset or juvenile type
403.0	Hypertensive renal disease, specified as malignant
403.1	Hypertensive renal disease, specified as benign
403.9	Hypertensive renal disease, unspecified
404.0	Hypertensive heart and renal disease, specified as malignant
404.1	Hypertensive heart and renal disease, specified as benign
404.9	Hypertensive heart and renal disease, unspecified
567.0	Peritonitis in infectious diseases classified elsewhere
567.1	Pneumococcal peritonitis
567.2	Other supurative peritonitis
567.8	Other peritonitis
567.9	Peritonitis, unspecified
585	Chronic renal failure
586	Renal failure, unspecified
642.10	Hypertension secondary to renal disease, complicating pregnancy, childbirth and puerperium, unspecified episode of care
642.11	Hypertension secondary to renal disease, complicating pregnancy, childbirth and puerperium, delivered episode of care
642.12	Hypertension secondary to renal disease, complicating pregnancy, childbirth and puerperium, delivered episode of care, post-partum condition
642.13	Hypertension secondary to renal disease, complicating pregnancy, childbirth and puerperium, antepartum episode of care
642.14	Hypertension secondary to renal disease, complicating pregnancy, childbirth and puerperium, post-partum episode of care
642.20	Other pre-existing hypertension complicating pregnancy, childbirth and puerperium, unspecified episode of care
642.21	Other pre-existing hypertension complicating pregnancy, childbirth and puerperium, delivered episode of care
642.22	Other pre-existing hypertension complicating pregnancy, childbirth and puerperium, delivered episode of care, post-partum condition
642.23	Other pre-existing hypertension complicating pregnancy, childbirth and puerperium, antepartum episode of care
642.24	Other pre-existing hypertension complicating pregnancy, childbirth and puerperium, post-partum episode of care
996.1	Mechanical complication of other vascular device, implant and graft
996.6	Infection and inflammatory reaction due to internal prosthetic device, implant & graft
996.7	Other complications of internal prosthetic device, implant and graft
V56.0	Extracorporeal dialysis
V56.8	Other dialysis
V65.4	Other counselling, not elsewhere classified

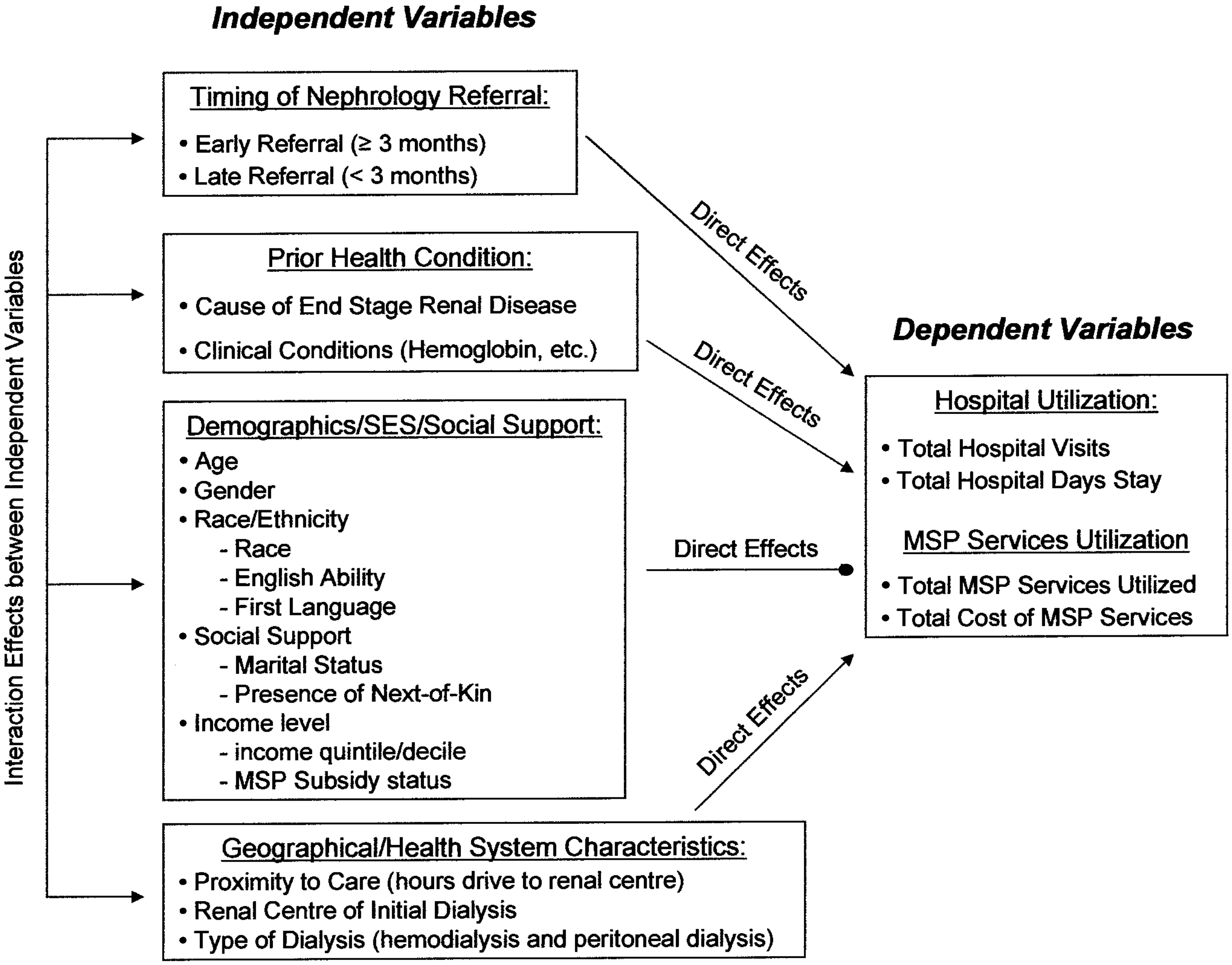
Table 7 (Cont'd.)

CCP Code	DESCRIPTION
51.27	Arteriovenostomy for renal dialysis
51.42	Revision of arteriovenous shunt for renal dialysis
51.43	Removal of arteriovenous shunt for renal dialysis
51.53	Repair of arteriovenous fistula
51.93	Insertion of vessel to vessel cannula
51.94	Replacement of vessel to vessel cannula
51.95	Hemodialysis
66.98	Peritoneal dialysis
67.51	Renal autotransplantation
67.59	Other kidney transplantation
98.06	Insertion of totally implantable vascular access device

5.4.2 Phase II Research Design

The relationship between the independent variables and dependent variable, including potential interaction effects between independent variables, is represented in Illustration 2.

Illustration 2 – Phase II Research Design



5.4.3 Phase II Analytical Technique

Phase II of the research involves the use of SAS statistical analysis models appropriate to deal with dependent variables that involve continuous data (i.e., the total number of hospital visits, the total number of hospital days, the total number of MSP services utilized, and the total cost associated with MSP services utilization). Initially, I attempted Poisson logistic regression to analyze the impact of the various determinants on patients' number of hospital visits; however, the dispersion estimate was greater than 1.0 which pointed to the need to move to a Negative Binomial logistic regression model. Negative Binomial regression is appropriate for use with a dependent variable that has a mean value of no larger than about 8.0, and therefore was appropriate for the analysis on patients' hospital visits (the mean number of hospital visits per patient was 1.63). Since the mean number of hospital days and MSP services were both larger than 8.0 (13.83 and 115.83 respectively) it was necessary to move to Ordinary Least Squares (OLS) regression for these two analyses. The OLS regression model was also appropriate for use with the continuous data on cost of MSP services utilized (e.g., the mean cost of MSP services was $4,305.24).

Due to the smaller sample size used in the Phase II analysis (n=572 patients) a few additional recodes for several health determinant variables were necessary to ensure that there were no small N cell issues. For example, for the "MSP subsidy" and "proximity to care" variables, the few patients for whom MSP subsidy status and proximity to care were unknown were rolled into the "not subsidized" and "≤1 hr drive" categories respectively. For the "cause of ESRD" variable the few cases identified as "nephropathy" were combined with cases identified as "congenital" or "polycystic" disease. Similarly, due to small N cells for some of the regional renal centres, and since an urban versus rural impact had been noted in the Phase I findings, regional renal centres were collapsed into a two-category urban and rural "regional renal centre" variable. Lastly, patients who died less than one year following their initial dialysis date were removed from the data sample and analysis.

In preparation for the regression analyses, it was necessary for me to use SAS to link several different years of hospital and subsequently MSP data (for years 1999/00, 2000/01, and 2001/02), to apply SAS code that tallied each patient's hospital visits and hospital days (i.e., hospital discharges and total days stay based on a care level selection of acute and rehab), as well as MSP services and MSP costs for the period one year prior to and one year following a patient's initial dialysis, and finally to link these files to the BCPRA and income data files. The records of patients who initiated dialysis in a year other than 2000/01 were removed from the two final datasets (one incorporating hospital utilization data, the other MSP services utilization data). Lastly, for each of the four separate analyses I included possible two-way interactions between the independent variables (e.g., age by gender) to test for potential interaction effects.

CHAPTER 6: FINDINGS

6.1 Phase I Findings

The Phase I findings comprise both descriptive and regression analysis statistics.

6.1.1 Phase I Descriptive Statistics

Descriptive statistics regarding the relationship between patient characteristics and type of nephrology referral are presented in Table 8. Of the 2001 persons with CKD who began dialysis in British Columbia during the period April 1, 2000, to March 31, 2003, fully 1,032 patients or 52% experienced late referral to nephrology care. Of those 1032 patients who experienced late referral, 229 (11.4% of the total patient sample) experienced no referral time at all (0 days referral) and had an acute start onto dialysis. A further 473 patients (23.6% of the total patient sample) experienced no referral time but did not acute start onto dialysis, making for a total of 702 patients (35.1%) who had no prior exposure to a nephrologist prior to their dialysis initiation. This is in line with Canadian referral estimates provided by Levin (2000) who reported that 20-50% of new renal patients start dialysis without a period of previous exposure to a nephrologist.

The finding that 52% of new BC renal patients were referred to a nephrologist less than 3 months before requiring dialysis is higher than the 35% reported in a previous Canadian study that involved 15 renal centres across 7 provinces and also defined late referral as <3 months (Curtis et al., 2002). When I re-ran the analysis using alternate definitions of late referral (i.e., from <1 month to <12 months) I found that between 42-73% of new renal patients experienced late referral to nephrology assessment prior to initiating dialysis. The above descriptive data hint at a major problem in regard to timely access to care for persons with CKD, seriously affecting their chronic illness pathways and reducing their overall quality of health.

Table 8 – Phase I Descriptive Statistics: Determinants of Patient Referral

	Type of Patient Referral – Frequency Distribution					
Variable	**Early Referral**		**Late Referral**		**Total Patients**	
	N	**%**	**N**	**%**	**N**	**%**
Type of Referral	***969***	***48.4%***	***1032***	***51.6%***	***2001***	***100%***
Cause of ESRD						
Diabetes	279	65.3%	148	36.7%	427	100%
Glom/AID.	162	58.5%	115	41.5%	277	100%
Nephropath.	12	54.6%	10	45.5%	22	100%
Renal Vascular	98	53.3%	86	46.7%	184	100%
Congenital or Polycystic	83	73.5%	30	26.6%	113	100%
Other	53	34.0%	103	66.0%	156	100%
Unknown	282	34.3%	540	63.7%	822	100%
Gender						
Male	580	49.4%	595	50.6%	1175	100%
Female	389	47.1%	437	52.9%	826	100%
Age	969	48.4%	1032	51.6%	2001	100%
Race/Ethnicity						
Race/Ethnicity						
Caucasian	426	56.9%	323	43.1%	749	100%
Other than Caucasian	265	52.1%	244	47.9%	509	100%
Unknown	278	37.4%	465	62.6%	743	100%
English Ability						
Proficient	619	54.7%	513	45.3%	1132	100%
Less than proficient	138	49.8%	139	50.2%	277	100%
Unknown	212	35.8%	380	64.2%	592	100%
First Language						
English	304	56.3%	236	43.7%	540	100%
Other than English	125	50.4%	123	49.6%	248	100%
Unknown	540	44.5%	673	55.5%	1213	100%

Table 8 (Cont'd.)

Variable	Type of Patient Referral – Frequency Distribution					
	Early Referral		Late Referral		Total Patients	
	N	%	N	%	N	%
SES						
Income Quintile						
1 (lowest)	243	50.0%	243	50.0%	486	100%
2	228	51.7%	213	48.3%	441	100%
3	176	45.1%	214	54.9%	390	100%
4	148	48.1%	160	52.0%	308	100%
5	134	48.6%	142	51.5%	276	100%
Unknown	40	40.0%	60	60.0%	100	100%
Income Decile						
1 (lowest)	125	46.1%	146	53.9%	271	100%
2	118	54.9%	97	45.1%	215	100%
3	127	52.3%	116	47.7%	243	100%
4	101	51.0%	97	49.0%	198	100%
5	86	41.4%	122	58.7%	208	100%
6	90	49.5%	92	50.6%	182	100%
7	79	50.0%	79	50.0%	158	100%
8	69	46.0%	81	54.0%	150	100%
9	71	46.1%	83	53.9%	154	100%
10	63	51.6%	59	48.4%	122	100%
Unknown	40	40%	60	60.0%	100	100%
MSP Subsidy Status						
Subsized	398	47.6%	438	52.4%	836	100%
Not subsidized	563	50.3%	557	49.7%	1120	100%
Unknown	8	17.8%	37	82.2%	45	100%
Social Support						
Marital Status						
Married/Common-Law/Single	411	58.6%	290	41.4%	701	100%
Divorced/Separated/Widowed	68	51.5%	64	48.5%	132	100%
Unknown	490	42.0%	678	58.1%	1168	100%
Presence of Next-of-Kin						
No	15	44.1%	19	55.9%	34	100%
Yes	380	54.9%	312	45.1%	692	100%
Unknown	574	45.0%	701	55.0%	1275	100%
Proximity to Care						
≤1 hour drive	787	49.9%	789	50.1%	1576	100%
>1 hour drive	176	44.0%	224	56.0%	400	100%
Unknown	6	24.0%	19	76.0%	25	100%
Regional Renal Centre						
Dialysis Centre A	161	54.6%	134	45.4%	295	100%
Dialysis Centre B	213	50.5%	209	49.5%	422	100%
Dialysis Centre C	11	57.9%	8	42.1%	19	100%
Dialysis Centre D	185	48.6%	196	51.4%	381	100%
Dialysis Centre E	50	30.9%	112	69.1%	162	100%
Dialysis Centre F	154	50.8%	149	49.2%5	303	100%
Dialysis Centre G	49	46.7%	56	3.3%	105	100%
Dialysis Centre H	29	43.9%	37	56.1%	66	100%
Dialysis Centre I	34	44.2%	43	55.8%	77	100%
Dialysis Centre J	58	47.2%	65	52.9%	123	100%
Dialysis Centre K	25	52.1%	23	47.9%	48	100%

Data sources for Table 8 are the BC Centre for Health Services and Policy Research (for MSP Subsidy data and income quintile/decile data), and the BCPRA Patient Records, Outcome and Management Information System (PROMIS).

6.1.2 Phase I Logistic Regression Results

The binomial logistic regression results indicate that a number of the health determinants studied have a statistically significant effect on the timing of renal patient referral (see Table 9). The overall likelihood ratio test of significance for the model was: Chi-Square=318.5947, DF=30, Pr > Chi-Square=<.0001, allowing me to reject the null hypothesis that none of the independent variables exerted significant effect on the dependent variable "timing of nephrology referral". A statistical significance level of $p \leq 0.05$ indicated that the following determinants have independent effect on the timing of patients' referral: cause of ESRD ($p < .0001$), age (linear effect, $p = 0.0001$), race/ethnicity ($p = 0.0041$), English ability ($p = 0.0032$), SES (MSP subsidy status, $p = 0.0029$), social support (marital status, $p = 0.0023$), proximity to care (hours drive to dialysis centre, $p = 0.0018$), patient's regional renal centre (initial dialysis centre, $p < .0001$), and the interaction "gender by English ability" ($p = 0.0251$). In contrast, the following variables were found to have no significant effect on patient referral: gender, first language, income quintile or decile, and availability of next-of-kin. When I re-ran the analysis using the alternate late referral definitions, I found the following differences in statistical significance of the determinants: 1) a definition of <1 month referral generated the same results as the <3 months definition, except that the variable race/ethnicity was no longer individually significant and the interaction "gender by race" was significant instead of "gender by English ability"; 2) a definition of <4 months referral generated the same results as the <3 months definition; 3) a definition of <6 months resulted in race/ethnicity now not being individually significant; however, the interactions "gender by race/ethnicity" and "gender by English ability" were; and, 4) a definition of <12 months referral resulted in the variables age, English ability and marital status no longer having significant effect; however, race/ethnicity regained significance and the interaction "gender by English ability" remained significant.

Table 9 – Analysis of Effects on Patient Referral
(SAS Type III sum of squares results; Late Referral defined as < 3 months)

Determinant	**Significance of Effect on Referral**		
(Independent Variable)	**DF**	**Wald Chi-Square**	**Pr > Chi-Square**
Cause of ESRD	6	117.9924	<.0001
Age	1	14.7403	0.0001
Gender	1	0.3144	0.5750
Race/Ethnicity	2	10.9917	0.0041
English Ability	2	11.4920	0.0032
MSP Subsidy	2	11.6552	0.0029
Marital Status	2	12.1892	0.0023
Hours Drive to Care	2	12.6241	0.0018
Regional Renal Centre	10	51.6564	<.0001
Gender by English Ability	2	7.3697	0.0251

A "Pr > Chi-Square" of ≤0.05 is considered significant.

Parameter estimates for statistically significant determinants from the binomial regression analysis (late referral defined as <3 months) were converted to odds ratios and then expected probabilities (e.g., the expected probability of experiencing late referral if a renal patient is either married, in a common-law relationship or single, compared to if a patient is either divorced, separated or widowed.) and are presented in Table 10. The expected probability findings for each statistically significant health determinant are subsequently discussed.

Table 10 – Expected Probabilities for Impact of Determinants on Patient Referral

Determinant (Independent Variable)	Odds and Expected Probability of Late Referral Odds Ratio	 Expected Probability
Cause of ESRD		
Diabetes	1.38	0.579 (57.9%)
Glom/AID.	1.78	0.641
Nephropath.	1.82	0.646
Renal Vascular	2.45	0.710
Congenital or Polycystic	0.91	0.477
Other	4.81	0.828
Unknown	4.70	0.825
Age		
10	4.31	0.812
20	3.78	0.791
30	3.31	0.768
40	2.90	0.744
50	2.55	0.718
60	2.23	0.690
70	1.96	0.662
80	1.71	0.631
90	1.50	0.600
Race/Ethnicity		
Race/Ethnicity		
Caucasian	1.93	0.659
Other than Caucasian	1.89	0.654
Unknown	2.80	0.737
English Ability		
Proficient	1.71	0.632
Less than proficient	2.22	0.690
Unknown	2.68	0.728
Interaction: Gender by English Ability		
Male		
Proficient	1.47	0.595
Less than proficient	2.66	0.727
Unknown	2.89	0.743
Female		
Proficient	2.00	0.667
Less than proficient	1.86	0.650
Unknown	2.49	0.714
MSP Subsidy Status		
Subsidized	1.34	0.573
Not subsidized	1.37	0.578
Unknown	5.57	0.848
Marital Status		
Married/Common-Law/Single	1.80	0.643
Divorced/Separated/Widowed	2.06	0.674
Unknown	2.75	0.733
Proximity to Care		
≤1 hour drive	1.34	0.573
>1 hour drive	2.03	0.670
Unknown	3.74	0.789

Table 10 (Cont'd.)

Determinant (Independent Variable)	Odds and Expected Probability of Late Referral Odds Ratio	 Expected Probability
Regional Renal Centre		
Dialysis Centre A	1.18	0.541
Dialysis Centre B	2.14	0.681
Dialysis Centre C	1.23	0.552
Dialysis Centre D	2.27	0.695
Dialysis Centre E	3.84	0.794
Dialysis Centre F	1.18	0.540
Dialysis Centre G	2.26	0.693
Dialysis Centre H	2.77	0.735
Dialysis Centre I	2.84	0.740
Dialysis Centre J	3.15	0.759
Dialysis Centre K	2.81	0.737

Prior Health Conditions

Individuals' genetic endowment and biological processes are primary determinants of health (CPHI, 2002; Raphael, 2004). The data were limited to the extent that I had no information on genetic and most biological determinants of the study population; however, I did have information on certain physical health characteristics (i.e., cause of ESRD) that gave some indication of the association between other disease occurrences, chronic kidney disease and referral to specialized nephrology care.

The expected probability of a patient experiencing late referral varied from a low of 47.7% for persons with congenital or polycystic disease to 82.8% for persons with some "other" unnamed cause. Next to the "other" disease category, persons for whom the cause of ESRD was unknown or unrecorded had the highest expected probability of late referral (82.5%), followed by those with renal vascular disease (71.0%). As expected, being diabetic was found to have a somewhat protective effect against late referral, since diabetics had the second lowest expected probability of late referral (57.9%).

Demographics

a) Age

The expected probability calculations indicated the opposite relationship to what I predicted with my age hypothesis - i.e., a person's expected probability of late referral substantially decreased with increasing age (from 81.2% at age 10, to 60.0% at age 90).

b) Race/Ethnicity

Similar to the findings on age, the expected probability calculations for race/ethnicity indicated the opposite relationship to what I predicted – i.e., Caucasians were found to have a slightly higher expected probability of late referral compared to persons of other known racial background (65.9% compared to 65.4%). However, since there were a substantial number of missing values for this variable (743 out of 2001 patients), it is not known whether these cases would shift the balance of our results - i.e., patients in the "unknown" category had the highest expected probability of late referral at 73.7%.

The expected probability findings for English ability qualify the above race/ethnicity findings somewhat – i.e., those who were less than English proficient had a higher expected probability of late referral than those who were English proficient (69.0% compared to 63.2%). However, again persons in the unknown category (n=592 out of 2001 patients) had the highest probability of late referral at 72.8%.

c) Gender by English Ability (*Interaction Effect*)

The expected probabilities for the "gender by English ability" interaction provided more in-depth information than what was found by looking solely at the results for the individual variables “race/ethnicity” or “English ability” above. The expected probabilities for the “gender by English ability” interaction indicated that the probability of late referral was higher for males than females for those patients who were less than English proficient; however, was higher for females than males in the English proficient group. Again, the highest expected probability of late referral for males and females was in the English ability “unknown” category. Those whose English ability is listed as unknown may in fact be less than proficient in English; however, in the absence of further data gathering it is not possible to confirm this supposition.

Socioeconomic Status

Although income and other measures of persons’ SES have repeatedly been found to have significant effect on persons’ health status in social research (Evans, 1994; Williams, 2003, Auger et al., 2004), neither of the two income measures analyzed here (income quintile and income decile) were found to have a significant independent effect on the timing of renal patients’ referral. However, another proxy measure of income, whether a person is on subsidy for their MSP health care premiums, was found to have a significant effect. Somewhat surprisingly, renal patients who are not subsidized were found to have a slightly higher expected probability of being late referred compared to those who are on MSP subsidy (57.8% compared to 57.3%). Perhaps patients who are MSP subsidized are connected enough to the health care system that their reduced income status does not negatively impact their access to early nephrology referral (when compared to non-MSP-subsidized patients). Again, those for whom MSP subsidy status is unknown have a substantially higher expected probability of late referral (84.8%) compared to the other categories of patients; however, since this group represents only 45 out of a total of 2001 patients, their distribution across the subsidized and unsubsidized categories should not substantially alter the above results.

Social Support

The availability and extent of a person's social support network is also a primary determinant of health (CPHI, 2002; Evans, 1994, Raphael, 2004). Although I had access to data on patients' marital status and the presence of next-of-kin (Y/N), additional data were not available to quantify the extent and quality of other supportive networks likely experienced by some/most patients (e.g., the supportive networks of adult children, other relatives, neighbours and/or community support groups). However, the available measures provided some indication of the association between social support and renal patients' referral experience.

As expected, the presence of a spouse or common-law partner was found to have a protective effect against late referral – i.e., those patients who are married, in a common-law relationship or single (never married and not currently in a common-law relationship) have a 64.3% expected probability of late referral, compared to 67.4% for those who are divorced, separated or widowed. Since a prior analysis of the thesis data indicated that those who are single had the lowest expected probability of late referral, followed by those who were married or in a common-law relationship, single and married/common-law patients were grouped together for the present analysis. Those for whom marital status is unknown have the highest expected probability of late referral (73.3%).

Geographical and Health Service Characteristics

The physical environment and geographical location of populations is a key social determinant of health. Poor environments include exposure to polluted air, water and/or soil. Physical environments can also be inadequate or dangerous because of a lack of affordable housing, over-crowding, poor indoor air quality, exposure to harmful substances in the workplace, inordinate noise and lack of basic amenities, including access to primary and specialized health care services (CIHI, 2004; Bryant, 2004; Jackson, 2004). My data included measures of geographic proximity and a limited measure of health care service - the regional renal centre to which a patient was referred for nephrology care and initial dialysis treatment (i.e., ongoing dialysis may be accessed at a community dialysis centre rather than the hospital-based outpatient dialysis centre, depending on a patient's health condition and location of residence).

a) Geographic Proximity

As expected, persons with a greater than one hour drive to their regional renal centre were found to have a greater expected probability of late referral than persons located one hour or less from renal care. Again, those in the unknown category experienced the greatest expected probability of late referral (78.9%); however, there were only 25 out of 2001 patients for whom geographic proximity was unknown.

b) Regional Renal Centre

The expected probability findings indicate significant variation in patients' type of referral across BC's regional renal centres. Persons who initially access renal centre E (Greater Fraser Valley region) have the highest expected probability of late referral (79.4%), followed by patients accessing more rural based renal centres (e.g., renal centres

J, I, K and H). In comparison, patients accessing more urban based dialysis centres had the lowest expected probability of late referral: e.g., renal centre F (Vancouver Island region, at 54.0%), renal centre A (Vancouver Mainland region, at 54.1%), and renal centre C (accommodates a relatively small number of patients in the Vancouver Mainland region).

6.2 Phase II Findings

The Phase II findings comprise both descriptive and regression analysis statistics.

6.2 1 Phase II – Descriptive Statistics

Since the data for the dependent variables in Phase II are continuous data, it was not possible to present the same table of descriptive statistics by category of dependent variable that was presented for the Phase I findings (see Table 7). Instead, presented in Table 11 is the frequency distribution of patient cases for each dependent and independent variable included in the Phase II analysis. The mean number of hospital visits for renal patients over the period one year prior to and one year following initial dialysis was 1.6, the mean number of hospital days stay was 13.8, the mean number of MSP services utilized was 115.8 (note that one visit to a physician can involve multiple MSP services), and the mean cost per total number of MSP services used was $4,305.24.

Table 11 – Phase II Frequency Distribution of Variables Included in Analysis

Variable	Frequency Distribution of Patient Cases Number of Patients	% of Patients
Dependent Variables:		
# of Hospital Visits (range = 0-24)	572	100%
# of Hospital Days (range = 0-190)	572	100%
# of MSP Services (range = 0-412)	572	100%
Cost of MSP Services (range = \$0-\$14,840)	572	100%
Type of Nephrology Referral		
Early Referral (≥3 months)	271	47.4%
Late Referral (<3 months)	301	52.6%
Cause of ESRD		
Diabetes	130	22.7%
Glom./AID.	111	19.4%
Nephropath., Congenital or Polycystic	37	6.5%
Renal Vascular	40	7.0%
Other	32	5.6%
Unknown	222	38.8%
Clinical Conditions		
Hemoglobin level		
Optimal level (≥110)	84	14.7%
Suboptimal level (<110)	241	42.1%
Unknown level	247	43.2%
Calcium level		
Optimal level (<2.5)	215	37.6%
Suboptimal level (≥2.5)	25	4.4%
Unknown	332	58.0%
Phosphate level		
Optimal level (<1.8)	109	19.1%
Suboptimal level (≥1.8)	122	21.3%
Unknown level	341	59.6%
IPTH level		
Optimal level (<20)	58	10.1%
Suboptimal level (≥20)	73	12.8%
Unknown	441	77.1%
Albumin level		
Optimal level (≥35)	88	15.4%
Suboptimal level (<35)	133	23.3%
Unknown	351	61.4%
Creatinine level		
Optimal level (≤600)	133	23.3%
Suboptimal level (>600)	155	27.1%
Unknown	284	49.7%
Gender		
Male	357	62.4%
Female	215	37.6%
Age (range=1-90)	572	100%

Table 11 (Cont'd.)

Variable	Frequency Distribution of Patient Cases	
	Number of Patients	% of Patients
Race		
Race/Ethnicity		
Caucasian	213	37.2%
Other than Caucasian	167	29.2%
Unknown	192	33.6%
English Ability		
Proficient	349	61.0%
Less than proficient	88	15.4%
Unknown	135	23.6%
First Language		
English	181	31.6%
Other than English	75	13.1%
Unknown	316	55.2%
SES		
Income Quintile		
1 (lowest)	122	21.3%
2	132	23.1%
3	115	20.1%
4	93	16.3%
5	76	13.3%
Unknown	34	5.9%
Income Decile		
1 (lowest)	61	10.7%
2	61	10.7%
3	63	11.0%
4	69	12.1%
5	54	9.4%
6	61	10.7%
7	43	7.5%
8	50	8.7%
9	44	7.7%
10	32	5.6%
Unknown	34	5.9%
MSP Subsidy Status		
Subsized	253	44.2%
Not subsidized*	319	55.8%
Social Support		
Marital Status		
Married/Common-Law/Single	237	41.4%
Divorced/Separated/Widowed	35	6.1%
Unknown	300	52.5%
Presence of Next-of-Kin		
No	10	1.8%
Yes	194	33.9%
Unknown	368	64.3%
Proximity to Care		
≤1 hour drive**	473	82.7%
>1 hour drive	99	17.3%

Table 11 (Cont'd.)

Variable	Frequency Distribution of Patient Cases Number of Patients	 % of Patients
Regional Renal Centre		
Urban based Renal Centre	433	75.7%
Rural based Renal Centre	139	24.3%
Type of Initial Dialysis		
Hemodialysis	417	72.9%
Peritoneal Dialysis	155	27.1%

6.2.2 Phase II Logistic Regression and OLS Regression Results

The negative binomial (NB) logistic regression and ordinary least squares (OLS) regression results indicate that a number of the determinants studied have a statistically significant effect on the Phase II measures of hospital and medical services utilization. The regression results for each of the variables found to have a statistically significant effect in the four analyses that comprised Phase II of the research are presented in Tables 12-15 below. Those variables not found to have a significant effect on any of the four dependent variables were: cause of ESRD, English ability, and clinical conditions related to patients' calcium, IPTH, albumin and creatinine levels.

As is indicated by the R^2 results for Tables 13-15, the independent variables explained 17.1% of the variance in number of hospital days used, 22.7% of the variance in number of medical services used (i.e., services covered under the BC Medical Services Plan - MSP), and 22.5% of the variance in cost of medical services used.

Table 12 – Analysis of Effects on Number of Hospital Visits
(NB Logistic Regression, SAS Type III sum of squares results)

Independent	Significance of Effect on Hospital Visits		
Variable	DF	Wald Chi-Square	Pr > Chi-Square
Clinical Conditions			
Hemoglobin Level	2	6.35	0.0417
Phosphate Level	2	7.25	0.0266
Income Decile	10	28.65	0.0014
MSP Subsidy	1	7.99	0.0047
Marital Status	2	6.73	0.0346
Hours Drive to Care	1	7.99	0.0047
Race by Dialysis Type*	2	9.24	0.0099
Late Referral by Dialysis Type*	1	8.56	0.0034
Marital Status by Dialysis Centre*	2	13.71	0.0011

* Interaction effect.

Table 13 – Analysis of Effects on Number of Hospital Days
(OLS Regression, SAS Type III sum of squares results)

Independent	Significance of Effect on Hospital Days		
Variable	DF	F Value	Pr > F
Race/Ethnicity	2	4.12	0.0168
First Language	2	4.60	0.0104
Income Decile	10	2.07	0.0250
MSP Subsidy	1	7.14	0.0078
Hours Drive to Care	1	8.64	0.0034

R^2 = 0.170787; i.e., 17.1% of the variance in number of hospital days is explained by variance in the independent variables Race/Ethnicity, First Language, Income Decile, MSP Subsidy, and Hours Drive to Care.

Table 14 – Analysis of Effects on Number of MSP Services
(OLS Regression, SAS Type III sum of squares results)

Independent	Significance of Effect on MSP Services		
Variable	DF	F Value	Pr > F
Gender	1	4.16	0.0419
Age	1	15.74	<.0001
Race/Ethnicity	2	5.14	0.0062
Next-of-Kin	2	3.66	0.0265
Hours Drive to Care	1	6.88	0.0090
Renal Centre	1	8.42	0.0039
Type of Dialysis	1	40.10	<.0001
Age by Gender *	1	6.23	0.0129
Centre by Hours Drive *	1	6.76	0.0096

* Interaction effect.

R^2 = 0.227359; i.e., 22.7% of the variance in number of MSP services is explained by variance in the independent variables Gender, Age, Race/Ethnicity, Next-of-Kin, Hours Drive to Care, Renal Centre, Type of Dialysis, and the interactions Age by Gender and Centre by Hours Drive.

Table 15 – Analysis of Effects on Cost of MSP Services
(OLS Regression, SAS Type III sum of squares results)

Independent	Significance of Effect on MSP Services Cost		
Variable	DF	F Value	Pr > F
Type of Referral	1	8.11	0.0046
Age	1	10.25	0.0015
Race/Ethnicity	2	5.96	0.0028
Renal Centre	1	6.83	0.0092
Type of Dialysis	1	48.81	<.0001
Age by Gender *	1	6.55	0.0107
Centre by Hours Drive*	1	5.47	0.0197

* Interaction effect.

R^2 = 0.225025; i.e., 22.5% of the variance in cost of MSP services is explained by variance in the independent variables Type of Referral, Age, Race/Ethnicity, Renal Centre, Type of Dialysis, and the interactions Age by Gender and Centre by Hours Drive.

Parameter estimates from the regression analyses for those determinants found to be statistically significant were converted to expected counts for the number of hospital visits, hospital days, MSP services and the cost of MSP services utilized (e.g., the expected number of hospital visits for renal patients across the various income decile levels). The expected counts are presented in Table 16 and subsequently discussed.

Table 16 – Expected Counts for Determinants of Hospital & MSP Service Use

Determinant	Hospital Utilization		MSP Utilization	
(Independent Variable)	Visits	Days Stay	Services	Services Cost
Type of Nephrology Referral				
Early Referral (≥3 months)				$5,373.27
Late Referral (<3 months)				$4,673.36
Clinical Conditions				
Hemoglobin Level				
Optimal level (≥110)	2.0			
Suboptimal level (<110)	2.4			
Unknown level	1.7			
Phosphate Level				
Optimal level (<1.8)	2.0			
Suboptimal level (≥1.8)	2.5			
Unknown level	1.3			
Gender				
Male			111.6	
Female			126.9	
Age by Gender				
Male				
10			85.5	$4.932.46
20			89.8	$5,004.96
30			94.1	$5,077.46
40			98.4	$5,149.97
50			102.7	$5,222.47
60			107.0	$5,294.97
70			111.3	$5,367.47
80			115.6	$5,439.97
90			119.9	$5,512.47
Female				
10			45.0	$3,522.63
20			60.3	$3,954.79
30			75.6	$4,386.95
40			90.8	$4,819.11
50			106.1	$5,251.28
60			121.4	$5,683.44
70			136.6	$6,115.60
80			151.9	$6,547.77
90			167.2	$6,979.93
Race/Ethnicity				
Caucasian		9.6	111.6	$5,373.27
Non-Caucasian		3.2	87.2	$4,670.19
Unknown		3.2	85.1	$4,405.52
First Language				
English		9.6		
Other than English		11.9		
Unknown		16.9		
Income Decile				
1 (lowest)	2.0	9.6		
2	1.8	8.7		
3	2.9	15.7		
4	2.4	13.9		
5	2.4	15.7		
6	3.5	20.9		
7	2.2	11.4		
8	3.1	13.5		
9	2.4	8.2		
10 (highest)	2.3	7.1		
Unknown	3.3	19.9		

Table 16 (Cont'd.)

Determinant (Independent Variable)	Hospital Utilization Visits	 Days Stay	MSP Utilization Services	 Services Cost
MSP Subsidy				
Subsidized	2.0	9.6		
Not subsidized*	1.6	4.0		
Marital Status				
Married/Common-Law/Single	2.0			
Divorce/Separated/Widowed	1.7			
Unknown	1.8			
Next-of-Kin				
No Next-of-Kin			111.6	
Next-of-Kin			113.3	
Unknown			136.6	
Proximity to Care				
≤1 hour drive**	2.0	9.6	111.6	
>1 hour drive	2.6	17.5	59.9	
Regional Renal Centre				
Urban based Centre			111.6	$5,373.27
Rural based Centre			116.9	$5,525.62
Renal Centre by Proximity to Care				
Urban based Centre				
≤1 hour drive			111.6	$5,373.27
>1 hour drive			111.1	$5,664.32
Rural based Centre				
≤1 hour drive			168.1	$6,997.36
>1 hour drive			116.4	$5,816.67
Renal Centre by Marital Status				
Urban based Renal Centre				
Married/Common-Law/Single	2.0			
Divorce/Separated/Widowed	5.4			
Unknown	2.2			
Rural based Renal Centre				
Married/Common-Law/Single	3.1			
Divorce/Separated/Widowed	2.7			
Unknown	2.8			
Type of Dialysis				
Hemodialysis			111.6	$5,373.27
Peritoneal Dialysis			58.6	$3,502.57
Dialysis Type by Race/Ethnicity				
Hemodialysis				
Caucasian	2.0			
Non-Caucasian	1.9			
Unknown	1.5			
Peritoneal Dialysis				
Caucasian	2.0			
Non-Caucasian	1.6			
Unknown	2.4			
Type of Referral by Dialysis Type				
Early Referral				
Hemodialysis	2.0			
Peritoneal Dialysis	1.8			
Late Referral				
Hemodialysis	1.7			
Peritoneal Dialysis	2.8			

* The "not subsidized" category includes a few patients for whom MSP subsidy status was unknown.

** The "≤1 hour drive" category includes a few patients for whom proximity to care was unknown.

Type of Nephrology Referral

When I initially ran separate analyses on each of the four dependent variables using "type of referral" as the only independent variable in each analytical model, I found late referral to have a statistically significant effect on the following three variables: 1) number of hospital days utilized (F Value = 6.25, Pr > F = 0.0127); 2) number of MSP services utilized (F Value = 3.97, Pr > F = 0.0469); and 3) cost of MSP services utilized (F Value = 6.95, Pr > F = 0.0086). Late referral was associated with a higher expected number of hospital days, and a lower number and related cost of MSP services. However, when I re-ran the analyses incorporating all other potential health determinants of interest, type of referral remained a statistically significant independent predictor of the cost of MSP services only. The effect of type of referral on the cost of MSP services was the opposite to what I expected, i.e., those who are early referred were found to have a higher expected expenditure for MSP services utilization compared to those who were late referred (i.e., $5,373.27 for early referred renal patients, compared to $4,673.36 for those who are late referred).

Prior Health Conditions

Of the six clinical conditions analyzed in relation to the four dependent variables (hemoglobin, calcium, phosphate, IPTH, albumin and creatinine), patients' hemoglobin and phosphate levels were found to have a statistically significant effect on the number of hospital visits. Patients with a suboptimal hemoglobin or phosphate level were found to have a higher expected number of hospital visits compared to patients with optimal hemoglobin and phosphate levels.

Demographics

a) Gender

Patients' gender was found to have a statistically significant effect on the number of MSP services utilized; i.e., females have a higher expected number of MSP services (126.9) than males (111.6).

b) Age

Age was found to have a significant impact on both the number and cost of MSP services utilized. For every decade in age increase, there is a corresponding increase in the expected number and cost of MSP services utilized.

c) Age by Gender (*Interaction Effect*)

Similar to the age findings reported above, for both males and females the expected number and cost of MSP services utilized was found to increase with every decade of age increase. However, the interactive effect also points out that the number and cost of MSP services are higher for males than females from ages 10 through 40, and higher for females compared to males from age 50 onwards.

d) Race/Ethnicity

Patients' race/ethnicity was found to have a significant effect on hospital days stay, and the number and cost of MSP services utilized. Similar to the Phase 1 findings that Caucasians experience a higher expected probability of late referral, the Phase II findings indicate that Caucasians have a higher expected number of hospital days, and number and cost of MSP services, compared to non-Caucasians.

Also, similar to the Phase I findings on the effect of English ability on type of referral, the Phase II findings indicate that those whose first language is other than English have a higher expected number of hospital days stay than persons whose first language is English. However, those whose first language is unknown (316 patients or 55.2% of the Phase II sample) were found to have the highest expected number of hospital days stay (16.9 days compared to 11.9 days for those who first language is other than English, and 9.6 days for those whose first language is English), making it difficult to generalize this finding to the larger renal population in the absence of further research using more complete data on patients' first language.

Socioeconomic Status

a) Income Decile

Both income quintile and income decile were found to have a statistically significant effect on renal patients' expected number of hospital visits and hospital days stay, when separately analyzed. A decision was made to retain income decile instead of quintile in the final Phase II SAS models. Patients at income decile level 6 (mid-range level) were found to have the highest expected number of hospital visits and hospital days stay. Patients at income decile level 2 were found to have the lowest expected number of hospital visits, but not the lowest number of hospital days stay – that place was reserved for patients at the highest income level (level 10). However, patients at the lowest income levels (1 and 2) did have the lowest number of hospital visits and close to the lowest number of hospital days stay. In contrast, patients at the highest income levels (9 and 10) have a mid-range number of hospital visits, but the lowest expected number of hospital days stay.

b) MSP Subsidy

In contrast to the Phase I findings on MSP subsidy status, where those who are not MSP subsidized were found to have a slightly higher expected probability of late referral than those who are MSP subsidized, the Phase II findings indicate that patients who are MSP subsidized have a higher expected number of hospital visits and hospital days stay than persons who are not subsidized.

Social Support

a) Marital Status

In contrast to the Phase I findings on the impact of marital status on type of nephrology referral, the Phase II analyses indicated that renal patients who are married, in a common-law relationship, or single have a higher expected number of hospital visits than patients who are divorced, separated or widowed (2.0 compared to 1.7 visits).

b) Availability of Next-of-Kin

The Phase II findings indicate that patients who have next-of-kin utilize a slightly higher expected number of MSP services than patients who have no next-of-kin (113.3 services compared to 111.6); however, the highest number of expected MSP services is for patients whose availability of next-of-kin is unknown (136.6 services). Since the unknown category represents a substantial portion of the patient sample (368 or 64.3% of the 572 patients in the Phase II patient sample), further research with more complete data would be required to confirm the above finding.

c) Marital Status by Regional Renal Centre (*Interaction Effect*)

The interaction "marital status by regional renal centre" provides additional insight to what was noted for the variable marital status (where patients who are married, common-law or single were found to have a greater expected number of hospital visits than patients who are divorced, separated or widowed). The interaction findings point out that patients who access urban based renal centres and who are divorced, separated or widowed have a substantially greater expected number of hospital visits than those who are married, common-law or single (5.4 visits compared to 2.0), while the opposite was found for patients who access rural based renal centres - i.e., those who are married, common-law or single have a higher expected number of hospital visits compared to those who are divorced, separated or widowed (3.1 visits compared to 2.7).

Geographical and Health Service Characteristics

a) Geographic Proximity (hours drive to Regional Renal Centre)

Those patients who have >1 hour drive to their regional renal centre were found to have a higher expected number of hospital visits and hospital days stay than renal patients who live ≤1 hour from their renal centre (2.0 visits and 9.6 days, compared to 2.6 visits and 17.5 days). However, the opposite was found for the number of MSP services utilized, i.e., those living ≤1 hour from their renal centre were found to utilize a higher expected number of MSP services than patients living >1 hour from their renal centre (111.6 services compared to 59.9).

b) Regional Renal Centre

The findings indicate that patients who access a rural based regional renal centre utilize a higher expected number of MSP services and have higher expected costs associated with those services than patients who access an urban based regional renal centre (116.9 services and $5,525.62, compared to 111.6 services and $5,373.27).

c) Regional Renal Centre by Geographic Proximity (*Interaction Effect*)

The findings on the interaction between a patient's regional renal centre and their geographic proximity to care build on the independent effects noted above for each of these variables. Again, patients accessing rural based centres are found to have a higher expected number of MSP services (168.1 compared to 116.4) and related costs ($5,373.27 compared to $3,502.57), and those patients located ≤1 hour from their regional renal centre have a higher expected number and cost of MSP services compared to those patients living >1 hour from their renal centre. However, the proximity to care effect is less noticeable for renal patients accessing urban based regional renal centres - i.e., the expected number of MSP services is almost identical for those living ≤1 hour from care compared to those living >1 hour from care (111.6 compared to 111.1 MSP services), and the expected cost of MSP services is actually less instead of more for those living ≤1 hour from care ($5,373.27 compared to $5,664.32).

d) Type of Dialysis

The findings indicate that patients who choose hemodialysis as their initial treatment type utilize a higher expected number of MSP services (111.6) and have a higher expected cost related to those services ($5,373.27) compared to patients who choose peritoneal dialysis (58.6 services and a cost of $3,502.57).

e) Race by Dialysis Type (*Interaction Effect*)

The interaction effect for race/ethnicity by dialysis type further indicates that for those on hemodialysis, Caucasians have a slightly higher expected number of hospital visits than non-Caucasians (2.0 compared to 1.9, and 1.5 for persons whose racial/ethnic background is unknown). Similarly, for peritoneal dialysis, Caucasians have a higher expected number of hospital visits than non-Caucasians (2.0 compared to 1.6 visits); however, the greatest number of expected visits for patients on peritoneal dialysis is for persons of unknown racial/ethnic background (2.4).

f) Type of Referral by Dialysis Type (*Interaction Effect*)

The interaction effect between type of nephrology referral and type of initial dialysis indicates that for patients who are early referred, those on hemodialysis have a greater expected number of hospital visits than those who are on peritoneal dialysis (2.0 visits compared to 1.8), which is similar to the independent finding on dialysis type reported above (i.e., hemodialysis patients utilize a higher expected number of MSP services and related costs compared to peritoneal dialysis patients). However, in contrast, the interaction effect indicates that patients who are late referred and on peritoneal dialysis have the highest expected number of hospital visits (2.8 visits), and patients who are late referred and on hemodialysis have the lowest expected number of hospital visits (1.7).

CHAPTER 7: DISCUSSION

This study set out primarily to determine why a substantial proportion of new renal patients in the province of BC, Canada, were referred late in the progression of their chronic illness to a nephrologist for assessment. Of secondary interest was the Phase II investigation into the impact of type of nephrology referral and other potential health determinants on indicators of patient morbidity (hospital and medical services utilization). As described in Chapter 6, the findings from both phases of research indicated that a number of the health determinants studied had significant impact on renal patients' access to nephrology care and/or their hospital or medical services utilization. These results both agreed with and contrasted with prior research findings. The findings for Phases I and II are now discussed in relation to the prior late referral research reviewed in Chapter 4.

7.1 Discussion of Phase I Results

The descriptive and logistic regression results for Phase I of the research presented in Chapter 6 demonstrate the utility of using a "determinants of health" framework to understand differential access to renal care in a region of Canada where such specialized health services are free at the point of delivery. The descriptive statistics confirmed that a high proportion of BC renal patients experience late referral to nephrology care – i.e., 42-73% of new renal patients who initiated dialysis between April 2000 and March 2003 were late referred to nephrology assessment depending on the definition of late referral used (from <1 to <12 months referral), with 52% being late referred using a definition of <3 months referral. Fully 35% of new renal patients had no prior exposure to a nephrologist prior to requiring dialysis, a figure that is in keeping with

Canadian estimates of 20-50% (Levin, 2000). Fully 11.4% of the total patients experienced late or no referral accompanied by an acute start onto dialysis. A recent Canadian study by Curtis et al. (2002) indicated that up to 10% of persons with chronic kidney disease may have no advance symptoms of their disease prior to requiring nephrology care. It is therefore possible that the 11.4% who acute started in BC were asymptomatic (unfortunately, patient symptom data were not available for my study); however, Jungers et al. (1993) found that only 18% of their late referred patients were asymptomatic, or approximately 5% of their total patients. By translation, this could mean that only half of the acute starters in BC were asymptomatic. In addition, my study findings indicate that a number of health determinants (social and otherwise) also have an impact on the probability of whether a renal patient would experience late nephrology referral prior to dialysis initiation.

The logistic regression results and presentation of expected probability calculations indicated that the following health determinants had a statistically significant effect on the timing of referral experienced by renal patients: prior health condition (cause of ESRD), age, race/ethnicity (racial category and English ability), gender by English ability (interaction effect), social support (marital status), geographic proximity to care (hours drive), and health system characteristics (regional renal centre where patient is referred and receives initial dialysis). Patients' underlying disease as cause of ESRD was by far the most important determinant of variation in type of nephrology referral (Wald Chi-Square = 117.99, p<.0001), followed by the patients' regional renal centre (Wald Chi-Square = 51.66, p<.0001). Of the social determinants of health, marital status and the income indicator "MSP subsidy" were statistically significant; with the magnitude of effect of these determinants similar to the effects found for patients' age, race/ethnicity, English ability and proximity to care (Wald Chi-Square values ranged from 10.99 to 14.74).

My analysis indicates that a renal patient's expected probability of late referral varies according to their diagnosed cause of ESRD, which concurs with my hypothesis that cause of ESRD has a direct effect on late referral. For example, persons with a diagnosis of renal vascular or "other" disease were found to have the highest expected probabilities of late referral (71.0% and 82.8% respectively, not counting persons whose underlying disease was unknown at 82.5%) compared to different causes of ESRD (such as diabetes, at 57.9%). Prior late referral studies were mixed in their results regarding the relationship between ESRD cause and type of referral; my finding that type of patient referral varied significantly depending on cause of ESRD confirmed the findings on significance of cause of ESRD reported by Jungers et al. (1993) and Ratcliffe et al. (1984). My hypothesis that being diabetic would be protective against late referral when compared to other diseases was born out in the analysis. This finding concurs with half of the studies I located that examined the effect of diabetes on late referral (Holland and Lam, 2000; Schmidt et al. 1998, Winkelmayer et al., 2001). The protective effect of diabetes is likely due to the more rigorous physician monitoring that a diabetic is likely to undergo. In other words, those patients in frequent contact with the public health care system were more likely to be diagnosed with other chronic care conditions such as renal insufficiency.

The results regarding patient age indicated the opposite relationship to what was expected; i.e., rather than increasing age having a direct effect on late referral, younger patients were found to have a greater expected probability of late referral, with the risk decreasing with each 10 year increase in age. In contrast, the majority of prior studies I reviewed (including three conducted in Canada) found increasing age to be a significant predictor of late referral (Curtis et al., 2002; Holland and Lam, 2000; Letourneau et al., 2003; Ratcliffe et al., 1984; Roderick et al., 2002; Winkelmayer et al., 2001). However, my study's results in relation to age confirmed those reported by Steel and Ellis (2002), who found younger age to be associated with late referral, and with Kausz and colleagues (2000), who found younger age to be associated with late dialysis initiation. It is possible that younger persons with CKD may delay nephrology referral and dialysis initiation due to competing employment/other commitments, or may be more likely to be generally healthy and had no prior health care crises which might act as cues to their renal insufficiency. Further research is required to confirm these and other possible explanations regarding the effect of younger age on late referral in BC renal patients.

My prediction that females experience more late referral than males was not born out in the analysis, a finding that is consistent with the majority of prior studies that assessed the effect of gender on late referral (Arora et al., 1999; Curtis et al., 2002; Ifudu et al., 1999; Jungers et al., 1993; Kinchen et al., 2002; Roderick et al., 2002; Schmidt et al., 1998; Steel and Ellis, 2002). However, when testing for potential interaction effects between variables, I found a significant interaction between gender and English ability, which indicated that females who are English proficient have a higher expected probability of late referral than males who are English proficient. This somewhat reflects the findings of prior studies that female gender was associated with late referral (Holland and Lam, 2000), delayed dialysis initiation (Kausz et al., 2000) and suboptimal pre-dialysis care (Obrador et al., 1999). The opposite was found for those who are less than English proficient – i.e., males have a higher expected probability of late referral than females in this group, which agrees with the prior finding by Winkelmayer et al. (2001) that male gender was a factor in late referral.

My findings regarding patients' race/ethnicity indicated that Caucasians had a slightly higher expected probability of late referral compared to persons of other known race/ethnicity. This result was the opposite of what I expected, given the overwhelming prior findings in the literature that non-whites or Blacks had a greater risk of late referral, late dialysis initiation or sub-optimal pre-dialysis care (Iofel et al., 1998; Ifudu et al., 1999; Kausz et al., 2000; Kinchen et al., 2002; Obrador et al., 1999; Winkelmayer et al., 2001). In addition, the excessive burden of renal disease reported in Aboriginal compared to non-Aboriginal populations in Canada (Dyck, 2001; Young et al., 1989) and in Black compared to White populations in the United States (Kutner and Brogan, 2000; Livingston, 1993; Nzerue et al., 2002), as well as prior findings that indicated that race/ethnicity had played a role in Blacks' ability to obtain equitable access to organ transplantation (Gordon, 2002), together led me to expect that those who were "other than Caucasian" would have a greater expected probability of late referral. It is possible that the large proportion of missing values for the race/ethnicity indicator (743 out of 2001 patients) would either alter or corroborate our finding that Caucasians are more likely to experience late referral than non-Caucasians. However, it is also possible that the Canadian health care system is doing a fairly good job of providing comparable access to this specialized health service for otherwise disadvantaged groups, such as women, persons of lower SES, and non-white minorities (despite the greater burden of renal disease found in many minority populations). Potential interactions that were tested between race and other variables (e.g., income) were not found to be statistically significant. Teasing out the differential effect of race/ethnicity on renal patient access is an intriguing problem that warrants further research, including the effect of different cultural ideas about illness and health seeking behaviour.

The findings regarding the impact of patients' English ability somewhat clarify the results on race/ethnicity – i.e., persons who are less than English-proficient have a higher expected probability of late referral than those who are English proficient. In other words, ability to speak the English language may have a greater impact than a person's racial/ethnic background in determining their ability to navigate the health care system and access specialized renal care services in BC and Canada. However, the number of missing values for "English ability" may hamper the generalizability of these findings, or, as noted above, other reasons may exist for the differences found between patient groups that warrant more extended research.

Contrary to my expectation, patients' lower income level (measured by income quintile or decile data) was not found to be directly related to late referral. This result confirmed a prior finding by Jungers et al. (1993) who also used an income-specific indicator of SES (high, medium or low income) and found that low SES was not related to late referral. The majority of prior studies reviewed did not use an income-specific indicator for SES but reported a relationship between lower SES (measured variously as level of health insurance, education, or area of urban disadvantage) and late referral, late dialysis initiation or sub-optimal pre-dialysis care (Cass et al., 2003; Kinchen et al., 2002; Kausz et al., 2000; Obrador et al., 1999). These prior studies were conducted in either the United States or Australia, where different national health care systems may be responsible for the predictive effect of low SES. My other indicator of low SES - whether a patient is on subsidy for their MSP health care premiums - was significantly related to late referral but in the opposite way to what I expected – i.e., patients who are not MSP subsidized have a slightly higher expected probability of late referral than those who are MSP subsidized (57.8% compared to 57.3%). Therefore, although we cannot be sure in the absence of further research, it is possible that the Canadian health care system is working comparably well at providing equitable access to renal care across income groups. Further research is warranted on this variable as well, that includes additional measures of SES (e.g., education and occupation).

As hypothesized, the presence of a spouse or common-law partner, or the state of being single in contrast to having lost prior social support, was found to exert a protective effect against late referral. This finding suggests that the loss of a patient's prior marital/common-law partner may contribute to their probability of experiencing late referral; however, the high proportion of unknown values for this variable (1168 out of 2001 cases) makes such a generalization somewhat problematic. When I ran a cross-tabulation of marital status by gender, the distribution of male and female cases for patients of unknown marital status most closely approximated the divorced/separated category; however, it was not possible to infer with certainty which category(s) the unknown cases match to. Also, it is not known why being single would translate into a lower expected probability of late referral than those who are divorced, separated or widowed; however, we might surmise that those who are single (and never married) may be more independently accustomed to looking after their own needs, and/or may have formed alternate social support networks that may be of assistance in seeking access to health care when chronic disease symptoms surface. The only other prior study I located on the effect of marital status on late referral (Kinchen et al., 2002) did not find a significant effect; however, that study population was relatively small for a US national study (828 cases), in comparison to the substantially larger size of my provincial study (2001 cases). In addition, Kinchen and colleagues (2002) categorized marital status as "unmarried" and "married" only. My different categorization of patients (I included patients who have never been married with those who are in a married or common-law relationship) may be responsible for greater sensitivity in pulling out a marital status or social support connection with patient referral. Additional support for my findings on marital status was found in prior literature on the relationship between social support and the health status of chronic disease patients, which indicates that received or perceived support influences patients' health or course of disease (Kutner, 1987; Kriegsman et al., 1995). Additional measures of social support networks (including adult children, friends, neighbours and community organizations) were not possible to include in my study and are thus worthy of further investigation in research related to the health determinants of late nephrology referral.

My hypothesis regarding the predictive effect of availability of next-of-kin on late referral was not born out in my analysis. It is probable that the large proportion of missing values for this indicator (1275 out of 2001 cases) hampered the ability to tease out potential significance regarding its predictive effect.

Patients' proximity to their regional renal centre was found to be directly related to a late referral, verifying my hypothesis. This finding differs from prior late referral studies that found no association between the proximity or availability of health services and late referral (Cass et al., 2003; Holland and Lam, 2000; Schmidt et al., 1998). However, my finding is consistent with other studies that reported a relationship between proximity to care and whether a patient would ever be referred for nephrology care (Boyle et al., 1996; Mendelssohn et al., 1995). Geographical proximity to care is one of the most vexing problems facing the research site as well as most other provinces in Canada. It is a problem that BC and other provinces have struggled to address in recent years through restructuring health care services under regional "health authorities", and through creating incentives to encourage the system's gatekeepers, physicians, to relocate to more sparsely populated areas and inner cities. Additional studies, such as a representative panel of renal patients by geographical region followed over time, would shed light on the generalizability of this preliminary finding.

Similar to the results on proximity to care, the expected probability calculations verified my hypothesis of regional renal centre differences in late referral. This is similar to a prior finding by Ganz et al. (1997) who reported differences in patients' clinical outcomes between BC's regional dialysis centres. My finding similarly reinforced earlier findings on the predictive impact of a patient's renal care network on late dialysis initiation (Kausz et al., 2000) and suboptimal pre-dialysis care (Obrador et al., 1999). In fact, in my study, a patient's regional renal centre offered the second greatest predictive effect of all indicators included in the conceptual model in determining a patient's referral experience (the greatest predictive effect was cause of ESRD). Generally speaking, my findings indicate that patients who initially access more rurally located regional renal centres have a greater expected probability of late referral than patients who access an urban located centre in the lower mainland or Vancouver Island region of BC. Exceptions to this are the two renal centres located at major urban hospitals (regional renal centres E and B) where severe patient cases are more likely to be referred. It is also possible that some of the impact by renal centre can be explained by service capacity issues that have been faced by various regions in the past few years; however, theoretically, the absence of an available dialysis machine should not impact whether a patient can be assessed by a nephrologist in advance of requiring treatment. It is also possible that regional renal centre differences in late referral may reflect differing referral practices by general practitioners. It is noteworthy in this regard that the BC renal community has stepped up efforts to educate physicians regarding the signs of chronic renal disease and when to refer potential patients for nephrology assessment. Again, this preliminary finding requires further examination before any definitive conclusions can be drawn.

7.2 Discussion of Phase II Results

Similar to my Phase I results, the descriptive statistics and regression analysis results for Phase II of the research demonstrate the utility of using a determinants of health framework to understand the differential utilization of renal-related hospital and medical services in BC for new renal patients who are either early or late referred to nephrology care. The descriptive statistics indicated that for the 572 renal patients studied during the year prior to and year following their dialysis initiation in 2000/01, there was an average of 1.63 renal related hospital visits per patient (range = 0 to 24 visits), 13.83 hospital days stay (range = 0 to 190 days), 115.83 MSP services (range = 0 to 412 services), and an average cost of $4,305.24 for MSP services utilized (range =

\$0.00 to \$14,840). In comparison, over the two year period 2001/02 to 2002/03, the general population of BC utilized the following average number of hospital and medical services per person[6]: 0.17 hospital visits, 1.08 hospital days stay, 32.17 MSP services and \$911.03 in cost of MSP services utilized.

Of the 572 patients, 271 (47.4%) were early referred (≥3 months referral) and 301 (52.6%) were late referred (<3 months referral), which is similar to the ratio of early to late referred patients in the Phase I analysis using the three-year new patient cohort from 2000/01 to 2002/03 (48.4% were early referred and 51.6% late referred in the Phase I new patient population). The negative binomial and ordinary least squares (OLS) regression results indicated that patient referral type and a number of the other health determinants had a statistically significant effect on one or more of the renal related hospital and medical services utilization indicators (each measured for one year prior to and one year following patients' initial dialysis). The social determinant of health "income decile" was found to have the greatest effect on patients' expected number of hospital visits (Wald Chi-Square = 28.65, P = 0.0014), proximity to care on the expected number of days stay (F Value = 8.64, P = 0.0034), and type of dialysis on both the number and cost of MSP services utilized (F Values = 40.10 and 48.81, P<.0001 for both). For the OLS regression models (analyses on the expected number of hospital days, MSP services, and cost of MSP services utilized), variance in the independent variables

---

[6] Average hospital visits, days, MSP services and cost of MSP services for the general BC population were calculated from data received by personal communication from the Ministry of Health Services (source: the PURRFECT data system). Hospital data were based on all acute and rehab discharges and days for BC residents. MSP data were based on all MSP services and costs for BC residents. The population denominator used was the BC population for 2002/03 (N=4,141,272 – source PEOPLE 28, as reported in PURRFECT).

explained 17.1% of variance in patients' number of hospital days, 22.7% of variance in the number of MSP services, and 22.5% of variance in the cost of MSP services used. This indicates that a fairly substantial proportion of the variance in hospital and medical services usage remains unexplained by the determinants of health included in the models. The remainder of variance might be explained by factors such as: patient willingness to accept a diagnosis of end stage renal disease; physician willingness to refer patients to nephrology assessment; and, other clinical, biological and social factors not measured.

When analyzing the effect of late referral only on each of the hospital and MSP services indicators, my hypothesis was born out that late referral is significantly associated with an increased number of days stay in hospital (F Value = 6.25, P=0.0127), which is consistent with prior late referral studies regarding the impact of a late referral experience on hospital days stay. However, despite the fact that it has been reported in prior late referral studies that a late referral experience resulted in increased hospital visits or health system costs, my own analyses indicated that a late referral experience was not significantly associated with an increase in hospital visits, and was significantly associated with *decreased* utilization and cost of MSP services (F Value = 3.97, P = 0.0469 for number of MSP services; and F Value = 6.95, P = 0.0086 for cost of MSP services). In hindsight, the effect of late referral decreasing MSP service utilization and costs makes practical sense if one considers that a patient who is late referred to nephrology care would have less opportunity/requirement for accessing the MSP funded physician, laboratory or other services normally associated with the management of known chronic kidney disease, particularly over the timeframe under study which includes one year prior to patients' initial dialysis. In contrast, prior studies predominantly looked at hospital visits or days at the time of dialysis initiation, and at hospital based costs rather than MSP services costs.

When I revised my analytical models to include the other potential health determinants of interest, my findings indicated that late referral did have a significant effect on increased hospital visits through its interaction effect with dialysis type (i.e., late referred patients on peritoneal dialysis had the highest expected number of hospital visits, followed by early referred hemodialysis patients, early referred peritoneal dialysis patients, and late referred hemodialysis patients); however, late referral no longer had a significant impact on patients' hospital days stay, nor the number of MSP services utilized. Late referral did remain significantly associated with a decreased cost in MSP services utilized (F Value = 8.11, P = 0.0046). Arora et al. (2000) similarly included a range of other potential health determinants when assessing the impact of late referral on hospital days stay, and found late referral to result in an increased number of hospital days only in the first three months following dialysis initiation and not in the period beyond that initial 3 months (i.e., did not find late referral to be associated with increased duration of hospital stay over the long term). The study by Coyne et al (1998) included an assessment of hospitalization in the year prior to dialysis initiation, finding that late referred patients had significantly more hospital visits and days than early referred patients (using a late referral definition of <60 days, similar to my own study's definition of <3 months referral). However, the Coyne et al. study did not control for the potential impact of other health determinants on hospital utilization, which in my own study lessened the impact of late referral on hospital days stay to the point where the late referral effect became statistically non-significant.

Other possible reasons for differences in the results between my own and prior studies regarding the impact of late referral are: 1) as a result of discussions with the BC MOHS and the BCPRA, I included only renal related diagnoses and procedures when tallying patients' total number of hospital visits, hospital days stay, and utilization and cost of MSP services, whereas prior studies appear to have included all patient hospital visits or days and/or those related to non-renal co-morbid events; and, 2) I excluded patients who died before the period of one year following dialysis initiation, which would not have been an issue in the majority of prior studies that looked predominantly at patients' hospitalization at dialysis initiation.

My Phase II results did not indicate a significant relationship between cause of ESRD and hospital or medical services utilization. In contrast, the studies by Arora et al. (2000) and Murphy et al. (2000) found that diabetes as cause of ESRD was associated with an increased relative risk of hospital days stay both in the 3 month period following initial dialysis and the period following that initial 3 months. In terms of patients' clinical condition at time of dialysis initiation, my findings indicated that a suboptimal hemoglobin or phosphate level was significantly related to a higher expected number of hospital visits. In contrast, Arora et al. (2000) did not find an association between suboptimal phosphate level and increased hospital days stay either in the 3 month period following dialysis initiation or in the period following the initial 3 months.

Unlike Arora et al. (2000) and Murphy et al. (2000) who found that female renal patients had a greater relative risk of increased hospital days stay over the long term, I did not find gender to be associated with hospitalization; rather, I found females had a higher expected utilization of MSP services compared to males. These results seem to be consistent with a prior finding that men have more hospitalizations that are of shorter duration, whereas women have more physician visits (Belgrave, 1993).

Unlike the findings reported by Arora et al. (2000), Murphy et al. (2000) and Goransson and Gergrem (2001) pertaining to age, I did not find age to be significantly related to increased days of hospital stay, nor did I find a relationship between patient age and the number of renal related hospital visits. However, my findings indicate that the expected number and cost of MSP services increase with age, which make sense if one considers the number of chronic health conditions often faced by the elderly, particularly those with chronic renal failure (e.g., hypertension, heart disease, diabetes, etc.). In addition, my findings for the interaction effect between age and gender indicated that the number and cost of MSP services were higher for males compared to females at ages 10 through 40, and were higher for females from age 50 onwards - adding new information to the prior claim that women have more physician visits than men (Belgrave, 1993).

Unlike Arora et al. (2000) who did not find a significant effect between race (Caucasian versus non-Caucasian) and duration of hospital stay, I found that Caucasians had a higher expected number of hospital days, as well as utilization and cost of MSP services, compared to non-Caucasians. Since my Phase I analysis indicated that Caucasians were more likely to be late referred than non-Caucasians, one might anticipate that Caucasians' late referral would translate into a higher expected number of hospital days but lesser utilization and cost of MSP services (given my Phase II findings regarding the effects of late referral only). However, it may be that Caucasians have an easier time navigating and accessing the health care system than non-Caucasians, or that the Caucasians who experience a greater number of hospital days are persons whose first language is other than English. Indeed, I did find that patients whose first language is other than English had a higher expected number of hospital days stay than persons whose first language is English (however the high number of missing cases for that variable makes that finding somewhat questionable in the absence of further research). The interaction effect for "race by dialysis type" further indicated that Caucasians had a greater expected number of hospital visits than non-Caucasians for each type of dialysis (hemodialysis and peritoneal dialysis).

Patients' income decile was found to have a significant effect on their expected number of hospital visits and hospital days stay, but the pattern across income decile levels is somewhat difficult to interpret. Patients' at the lowest income levels (1 and 2) were found to have the lowest number of hospital visits and close to the lowest number of hospital days stay; whereas, in contrast, patients at the highest income levels (9 and 10) had a mid-range number of hospital visits but the lowest expected number of hospital days stay, and patients in the middle range income (6) were found to have the highest expected number of hospital visits and hospital days stay. It may be that persons at the lowest income levels find it more difficult to access or take the time off work to utilize hospital care, that persons in the upper income levels find it easier to access hospital care but may similarly find it difficult to take time off for extended hospital days stay (or may be healthier and thus require less duration of hospitalization), and that middle income renal patients have the wherewithal to access hospital services and remain hospitalized for a longer duration. However, additional research is required to understand the reasons behind this discrepancy in hospital utilization across the income decile groups.

In contrast to the finding that patients at the lowest income decile levels have a lower expected number of hospital visits and days stay, the finding that those who are MSP subsidized have a greater expected number of hospital visits and hospital days stay seems to indicate that those who are more financially challenged have a greater probability of utilizing more hospital care. It is possible that being MSP subsidized paves the way for lower income patients to more easily access hospital based care; however, further in-depth research would be required to clarify our understanding of the impact of MSP subsidy on renal patient hospitalization.

The Phase II analyses indicated that renal patients who are married, in a common-law relationship, or single had a higher expected number of hospital visits than patients who are divorced, separated or widowed. Patients who have the social support of a spouse/partner or who have not previously lost such support may have the social support resources necessary to facilitate necessary hospital visits. However, the Phase II interaction effect for marital status by regional renal centre indicates that it is only in rural areas that those who are married/common-law/single have a greater expected number of hospital visits, in comparison to urban centres where those who are divorced/separated/widowed have a higher number of expected hospital visits.

My finding that patients who have next-of-kin utilize a slightly higher number of MSP services than patients who do not have next-of-kin appears to corroborate the above conclusion that persons with social support are better able to access hospital services; however, as mentioned earlier, the high proportion of missing cases for the next-of-kin indicator (64.3%) makes any such conclusion somewhat suspect in the absence of further research with more complete data.

My findings on geographic proximity to care appear to make practical sense, since it might be expected that those patients living further away from their hospital based regional renal centre (>1 hour drive) would have a greater expected number of hospital visits and days stay than those who live closer to health care (≤1 hour drive). Similarly, for MSP services utilization, it makes sense that those living closer to their regional renal centre would be able to visit their physician and/or nephrologist more regularly and avail themselves of other MSP covered services more easily than persons living further from care.

In contrast to the findings on proximity to care, my findings on patients' regional renal centre indicated that those who accessed a rural based regional renal centre had a higher expected utilization and cost of MSP services. However, the significant interaction effect noted between patients' proximity to care and their regional renal centre indicated that, similar to the results for proximity to care, for patients accessing rural based regional renal centres those living ≤1 hour from care had the highest expected number of MSP services and related MSP services costs. Interestingly there was very little proximity to care effect in terms of the difference in utilization and cost of MSP services for patients who accessed urban based regional renal centres.

Similar to the findings by Arora et al. (2000), and unlike the findings by Murphy et al. (2000), I did not find that patients' treatment type (hemodialysis versus peritoneal dialysis) had a significant impact on days of hospital stay. However, my Phase II findings indicate that patients on hemodialysis treatment utilize a higher expected number and cost of MSP services than those on peritoneal dialysis. Hemodialysis patients are often sicker and less able to handle the requirements of peritoneal dialysis, and hemodialysis is considered to be associated with greater health system costs (e.g., is usually performed in a renal centre rather than home setting, requires installation and maintenance of a permanent vascular access, etc.). However, the interaction effect for type of referral by type of dialysis further distinguishes that while hemodialysis patients had a higher expected number of hospital visits compared to peritoneal patients in the early referred group, peritoneal dialysis patients had a higher expected number of hospital visits in the late referred group.

CHAPTER 8: SUMMARY & CONCLUSION

I began my research with the question as to why some people with chronic kidney disease residing in one area of Canada fare better than others, by studying the case example of timing of renal patients' referral to nephrology care. Given the negative consequences of late referral (e.g., reduced opportunity to delay or prevent end stage renal failure, and the related human and health system costs), as well as the continuing growth in renal disease (it has been estimated that the number of people in the world who will require some form of renal replacement therapy will reach epidemic proportions by the year 2015 – see El Nahas et al., 2005), it is important that we understand the non-medical (as well as medical) factors that impact persons' timely access to renal care and health outcomes. Phase I of the research was therefore conducted to assess the impact of social and other potential health determinants on the timing of patients' nephrology referral, using a late referral definition of <3 months referral before start of dialysis and existing health data on BC renal patients. Phase II of the research provided an opportunity to verify past research claims regarding the negative impact of a late nephrology experience on indicators of patient morbidity, when other potential health factors (the social and other determinants analyzed in Phase I) were included in the analysis. The results of both phases of study demonstrated the utility of using a determinants of health framework for research into access issues faced by persons with this chronic disease, offering a number of implications for sociological approaches for understanding health and chronic illness, future lines of research, and health care policy. These implications are discussed below.

8.1 Implications for Sociological Approaches to Understanding Health and Chronic Illness

My research begins to fill a void in the health and chronic illness literatures by providing a secondary analysis of provincial data on the total number of new renal patients in British Columbia who initiated dialysis during the period April 1, 2000 to March 31, 2003 (N=2001 patients). The analysis pointed to the effect of key social and other determinants on renal patients' initial access to renal care and ongoing utilization of hospital/medical services, in a health care system where such services are free at the point of delivery. Sociologists of health in recent years have argued that researchers would do well to focus attention not only on what physicians and hospital authorities recommend as important for patient care but also on the complex web of background characteristics that affect people's health and access to crucial primary care and specialized services such as renal replacement therapy. As mentioned in Chapter 4, prior studies into the issue of renal patient referral have been conducted from more of a "medical dominance" perspective, focusing attention on micro level determinants such as physician attitudes toward patient referral, and patient compliance (sociology "in" medicine). Those studies, as well as research specifically conducted on the determinants and consequences of late referral, made some effort to include potential demographic and economic factors, but gave limited consideration to the social structural determinants of health.

The majority of prior research that specifically studied the determinants of late referral found increasing age and non-white or Black race/ethnicity to be associated with late referral; however, the results were mixed for the effect of other health determinants (i.e., the effect of low income, cause of end stage renal failure, comorbidities, etc.). My own Phase I results on the determinants of late referral suggested that younger and not older age, Caucasian race/ethnicity (but also less than proficient English ability), not being MSP subsidized, the loss of prior social support (in the form of a marital or common-law partner), reduced proximity to care (>1 hour drive to the regional renal centre), accessing a rural based compared to urban based regional renal centre, and cause of end stage renal disease are predictive of a greater expected probability of late referral for persons with chronic renal disease in British Columbia. In contrast to the preponderance of health determinants literature which indicates that socio-economic determinants, particularly income related measures, exert the greatest influence on population health (Raphael, 2004), my findings indicated that patients' physical condition (cause of end stage renal disease), followed by a health system characteristic (patients' regional renal centre), exerted the greatest impact on the probability of patients being referred late to nephrology care. However, my Phase I analysis was focused on the determinants of patients' health care *access*, not their health status, and was somewhat limited in the number and type of social determinants studied, as well as the completeness of data for some of the key socio-demographic determinants. Despite this, the preliminary findings on the importance of social support (marital status) and patient demographics provide valuable new information to the existing late referral and health determinants literature base. As well, the inclusion of a broad range of potential health determinants - from physical health conditions to socio-economic determinants to health system characteristics – brought a new focus to late referral research by locating my study within the sociological population health/determinants of health approach.

The social variable "income decile" was found to be more important in my Phase II research - i.e., patients' income decile was by far the most important predictor of their expected number of hospital visits (Wald Chi-Square = 28.65) during the period one year prior to and one year following initial dialysis. Interestingly, patients at the lowest income deciles had the lowest expected number of hospital visits, patients close to the middle income decile (6) had the highest expected number of hospital visits, and patients at the highest income decile had a mid-range number of hospital visits. Income decile was also a determinant of patients' expected number of hospital days, but was not an important predictor (Wald Chi-Square = 2.07, compared to the most important predictor which was "proximity to care" at Wald Chi-Square = 8.64). In terms of the findings regarding number and cost of MSP services utilized, the most important health determinants were related to a health system characteristic (i.e., the patient's type of dialysis, Wald Chi-Square = 40.10 and Wald Chi-Square = 48.81 respectively), followed by the demographic predictor "patient age" (Wald Chi-Square = 15.74 and 10.25 respectively). Of considerable interest in Phase II was the finding that late referral exerted no independent effect on any of the dependent variables other than cost of MSP services (was the 3rd most significant predictor of cost) once the other health determinants were included in the analysis. This finding represents a significant departure from prior late referral research which has reported a significant relationship between late referral and increased patient hospital visits and/or days (Arora et al., 2000; Coyne et al., 1998; Gorannson and Gergrem, 2001; Ifudu et al., 1996; Jungers et al., 1993; McLaughlin et al., 2001; Muirhead and Blyndal, 1995; Ratcliffe et al., 1984; Roderick et al., 2002; Roubicek et al, 2000).

In summary, my Phase I findings suggest that renal patients' physical health condition and health system characteristics may be more important than their social structural or demographic characteristics in determining probability of a late nephrology referral experience; however, further research incorporating more complete data and additional social determinants of health may shift the balance in this finding. The Phase II findings indicate that patients' social structural and health system characteristics are more important determinants of their hospital and medical services utilization than a late referral experience. The above generalizations are preliminary, based on the use of secondary data that for some key social variables had a high proportion of missing values; therefore, further research would be beneficial to substantiate or disprove the findings presented here on BC renal patients. Despite the limitation of missing data values, and the fact that I did not have data on all health and social determinants (let alone genetic and biological ones), my findings build on the social determinants of health research reported on by Raphael (2004) and others, by including other determinants (physical health and health system factors as well as potential social factors) in my analysis of which variables have the greatest explanatory power regarding health care access and health outcome in this large population sub-group of BC residents. The sociological contribution is therefore a step forward, one that encourages sociologists to think broadly when seeking to explain inequality in health and health care access.

8.2 Implications for Future Research

The results of my research indicate that adopting a determinants of health approach to studying the predictors of renal patients' late referral and health status/morbidity is definitely fruitful, yet much more needs to be done before we can clearly separate out genetic and biological factors and the broad array of social and other determinants that shape the actual health care experiences of persons facing this chronic illness, and how access to key services affects health status. Further prospective study incorporating both qualitative and longitudinal methods of research with renal patients, their social support networks and renal care providers is required to confirm and build on this study's preliminary findings, and to thereby enhance our current limited understanding of how the determinants of health impact renal patients' access of health care services, health status and quality of life. Such research would have the advantage of incorporating the effects of social determinants that were not possible to study here given the lack of pre-existing secondary data – e.g., indicators of early childhood experiences, education, work, adequacy of housing, physician attitudes and patient compliance – as well as enable investigation of the indirect (not merely the direct) effects of renal patients' determinants of health. In addition, as Raphael (2004) has suggested with respect to research on the social determinants of health, it would be beneficial to identify the societal forces (economic, social and political policies) that shape the quality of the determinants of renal patient access to care and health status, in order to tie the research to practical recommendations for healthy public policy.

8.3 Implications for Health Care Policy

One of the key objectives of my thesis research was to provide practical information to BC renal patients, their health care providers and, perhaps more immediately, to the regional and provincial authorities responsible for the effective planning of renal services. The research provided a test of the strength of BC's provincial renal data (maintained in the PROMIS database) to support population health research of this nature, as well as a test of the provincial health databases that maintain hospital and medical services utilization data for BC residents. The data analysis revealed a significant number of missing values in the PROMIS renal patient data across a number of the key social and ethnicity indicators (i.e., marital status, next-of-kin, race/ethnicity, first language, and English ability). The BCPRA has confirmed that social and ethnicity data are not part of the essential data set required for regional renal programs to receive funding; therefore, incompleteness of data simply reflects a lack of understanding of the importance of these data as well as a resource issue. Since my results indicate the need to better understand the social and other determinants of renal patient care, and since the incomplete data indicators reduce the power of statistical analysis and somewhat hamper the generalizability of findings; it is recommended that the Provincial Health Services Authority and regional renal programs allocate sufficient funding/resources to gathering and entering missing data fields for patients' records (including socio-demographic and clinical data) into the PROMIS database. This would include updating patients' race/ethnicity regarding First Nations status, since the MOHS MSP data were more complete than the BCPRA PROMIS data for this indicator (I updated the PROMIS data extraction file with the MOHS data and informed the BCPRA of the updated data field for the 12 patient records affected). In addition, in keeping with the points raised above regarding future lines of research, it is recommended that effort be made to retrieve and store data on additional measures of renal patients' social determinants of health – e.g., education, occupation and work indicators, as well as additional measures of patients' social support resources. Similarly it would be useful to collect data on patients' disease symptoms at time of referral, as well as a more detailed breakdown of patients' cause of disease since that variable was found to be the most important determinant of late referral in my study, and better information could result in more productive dialogue with general practitioners and specialists regarding when best to refer persons with chronic kidney disease to nephrology care. It is also recommended that the provincial Ministry of Health Services (MOHS) streamline its data access approval process, since I experienced significant and unanticipated delay in receiving the necessary MOHS approval required to access the hospital and MSP services utilization data required for my Phase II analyses.

I anticipate that my study's Phase I findings will have some practical benefit in assisting the BCPRA to develop strategies to reach more renal patients early on in their illness careers (e.g., using Telehealth technologies, brochures in English and minority languages, translator services and community awareness campaigns), and at the same time to initiate dialogue with key stakeholders to help explain variation in physician referral patterns that may be affecting access to renal care, as well as differences among the regional renal centres themselves. Not only is it important to know that a patient's cause of end stage renal disease and regional renal centre are important predictors of late referral, but it is also useful to know the other significant health determinants of a late referral experience (i.e., younger age, not being MSP subsidized, and living >1 hour drive from one's regional renal centre) as well as those determinants that may be confirmed as having significant impact if subsequent research is performed using more complete data (i.e., Caucasian race/ethnicity, having less than proficient English ability, and being divorced/separated/widowed). Similarly, it is useful for renal care providers/planners to know that a late referral experience is not necessarily a determinant of, let alone the most important predictor of, increased health services utilization. Rather, there may be other underlying social and health system characteristics that are responsible for variation in renal patients' hospital and medical services utilization. The results of this thesis provide a preliminary knowledge base for the development of healthy public policy related to the determinants and consequences of late referral for persons with CKD in the province of British Columbia, Canada.

BIBLIOGRAPY

Auger, N., Raynault, M.-F., Lessar, R., Choinière, R. “Income and Health in Canada”. Chapter 3 in Social Determinants of Health, Canadian Perspectives, Canadian Scholars’ Press Inc., Toronto, 2004: 39-51.

Arora, P., Obrador, G. T., Ruthazer, R., Kausz, A. T., Meyer, K. B., Jenuleson, C. S., Pereira, B. J. G. “Prevalence, Predictors, and Consequences of Late Nephrology Referral at a Tertiary Care Center.” *Journal of the American Society of Nephrology*, 1999, Vol. 10: 1281-1286.

Arora, P., Kausz, A. T., Obrador, G. T., Ruthazer, R., Khan, S., Jenuleson, C. S., Meyer, K. B., Pereira, B. J. G. “Hospital Utilization among Chronic Dialysis Patients.” *Journal of the American Society of Nephrology*, 2000, Vol. 11: 740-746.

BC Renal Review, 2002 Vol.5 (1): 1-3.

Belgrave, L. L. “Discrimination Against Older Women in Health Care.” Women and Healthy Aging: Living Productively in Spite of It All, The Haworth Press, Inc., 1993: 181-199.

Bernstein, K., Rigatto, C. “Nephrology care in Canada.” *Canadian Medical Association Journal*, November 11, 2003, Vol. 169 (10): 1006-1007.

Blythe, N., Benoit, C. “Who crashes onto dialysis? Health determinants of patients who are late referred to chronic renal care in Canada.” *Research in the Sociology of Health Care*, 2004, Vol. 22: 205-237.

Boyle, P. J., Kudlac, H., Williams, A. J. “Geographical variation in the referral of patients with chronic end stage renal failure for renal replacement therapy.” *Quarterly Journal of Medicine*, 1996, Vol. 89: 151-157.

Bryant, T. “Housing and Health”. Chapter 15 in Social Determinants of Health, Canadian Perspectives, Canadian Scholars’ Press Inc., Toronto, 2004: 217-232.

Canadian Institute for Health Information (CIHI). Improving the Health of Canadians. Ottawa: Canadian Institute for Health Information, 2004.

Canadian Population Health Initiative (CPHI) webpage “About Population Health”, Canadian Institute for Health Information (CIHI) website, accessed 29/10/2002. Website: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=cphi_aboutph_e

Cass, A., Cunningham, J., Snelling, P., Wang, Z., Hoy, W. “Urban disadvantage and delayed nephrology referral in Australia.” *Health and Place*, 2003, Vol. 9: 175-182.

Coburn, D. and Eakin, J. "The Sociology of Health in Canada: First Impressions." *Health and Canadian Society*, 1993, Vol. 1 (1): 83-110.

Conrad, P. "Medicalization and Social Control." *Annual Review of Sociology*, 1992, Vol. 18: 209-232.

Cass, A., Cunningham, J., Wang, Z., Hoy, W. "Social disadvantage and variation in the incidence of end-stage renal disease in Australian capital cities." *Australian and New Zealand Journal of Public Health*, August 2001, Vol. 25 (4): 322-326.

Coyne, D. W., Taylor, L. F., Spivey, G. H., Sanping, C. "Early referral of CRF patients to nephrologists reduces mortality and hospitalizations." *Journal of the American Society of Nephrology*, 1998, Vol. 9: 144A.

Curtis, B.M., Barrett, B.J., Jindal, K., Djurdjev, O., Levin, A., Barre, P., Bernstein, K., Blake, P., Carlisle, E., Cartier, P., Clase, C., Culleton, B., Deziel, C., Donnelly, S., Ethier, J., Fine, A., Ganz, G., Goldstein, M., Kappel, J., Karr, G., Langlois, S., Mendelssohn, D., Muirhead, N., Murphy, B., Pylpchuk, G., Toffelmire, E. "Canadian survey of clinical status at dialysis initiation 1998-1999: a multicenter prospective survey." *Clinical Nephrology*, 2002, Vol. 58 (4): 282-288.

CHSPR (Centre for Health Services and Policy Research), located at the University of British Columbia, 429 – 2194 Health Sciences Mall, Vancouver, BC, Canada, V6T 1Z3, Tel: (604) 822-1949, Fax: (604) 822-5690, Website: www.chspr.ubc.ca

Dyck, R. F. "Mechanisms of renal disease in indigenous populations: influences at work in Canadian indigenous peoples." *Nephrology*, 2001, Vol. 6: 3-7.

Eadington, D. W. "Delayed Referral for Dialysis: Higher Morbidity and Higher Costs." *Seminars in Dialysis*, September-October 1995, Vol. 8 (5): 258-260.

El Nahas, A. M. E. and Bello A. K. "Chronic Kidney Disease: the global challenge". *Lancet*, 2005, Vol. 365: 331-40.

Evans, R. G., Barer, M. L., Marmor, T. R., eds. Why are some people healthy and others not? Aldine de Gruyter, New York, 1994.

Evans, R. "Interpreting and Addressing Inequalities in Health: From Black to Acheson to Blair to…?" 7th Annual Lecture of the Office of Health Economics, May 2002: 1-93.

Fored, C. M., Ejerblad, E., Fryzek, J. P., Lambe, M., Lindblad, P., Nyren, O., Elinder, C.-G. "Socio-economic status and chronic renal failure: a population-based case-control study in Sweden." *Nephrology Dialysis Transplantation*, 2003, Vol. 18: 82-88.

Ganz, G., Singh, S., Djurdjev, O., Levin, A. “Current dialysis practices in British Columbia a cross-sectional study.” *Journal of the American Society of Nephrology*, September 1997, Vol. 8 Supplement: AO898.

Garg, P. P., Diener-West, M., Powe, N. R. “Income-Based Disparities in Outcomes for Patients With Chronic Kidney Disease.” *Seminars in Nephrology*, July 2001, Vol. 21 (4): 377-385.

Goransson L. G. and Gergrem H. “Consequences of late referral of patients with end-stage renal disease.” *Journal of Internal Medicine*, 2001, Vol. 250: 154-159.

Gordon, E. J. “What “Race” Cannot Tell Us about Access to Kidney Transplantation.” *Cambridge Quarterly of Healthcare Ethics*, 2002, Vol. 11: 134-141.

Gordon, E. J. “Patients’ decisions for treatment of end-stage renal disease and their implications for access to transplantation.” *Social Science & Medicine*, 2001, Vol. 53: 971-987.

Hirsch, D. J., West, M. L., Cohen, A. D., Jindal, K. K. “Experience With Not Offering Dialysis to Patients With a Poor Prognosis.” *American Journal of Kidney Diseases*, March 1994, Vol. 23 (3): 463-466.

Holland, D. C. and Lam, M. "Predictors of Early vs. Late Referral Among a Retrospective Cohort of Pre-Dialysis Patients." *Dialysis and Transplantation*, September 2000, Vol. 29 (9): 526-534.

Ifudu, O., Dawood, M., Iofel, Y., Valcourt, J. S., Friedman, E. A. "Delayed Referral of Black, Hispanic, and Older Patients with Chronic Renal Failure." *American Journal of Kidney Diseases*, April 1999, Vol. 33 (4): 728-733.

Ifudu, O., Dawood, M., Homel, P., Friedman, E. A. “Excess Morbidity in Patients Starting Uremia Therapy Without Prior Care by a Nephrologist.” *American Journal of Kidney Diseases*, December 1996, Vol. 28 (6): 841-845.

Iofel, Y., Dawood, M., Valcourt, J. S., Ifudu, O. “Initiation of Dialysis Is Not Delayed in Whites With Progressive Renal Failure.” *ASAIO Journal*, September-October 1998, Vol. 44 (5): M598-M600.

Jackson, A. “The Unhealthy Canadian Workplace”. Chapter Six in Social Determinants of Health, Canadian Perspectives, Canadian Scholars’ Press Inc., Toronto, 2004: 79-94.

Jungers, P. "Late referral: loss of chance for the patient, loss of money for society." *Nephrology Dialysis Transplantation*, 2002, Vol. 17: 371-375.

Jungers, P., Zingraff, J., Albouze, G., Chauveau, P., Page, B., Hannedouche, T., Man, N. K. "Late referral to maintenance dialysis: detrimental consequences." *Nephrology Dialysis Transplantation*, 1993, Vol. 8: 1089-1093.

Kasiske, B. L., Snyder, J. J., Matas, A. J., Ellison, M. D., Gill, J. S., Kausz, A. T. "Preemptive Kidney Transplantation: The Advantage and the Advantaged." *Journal of the American Society of Nephrology*, 2002, Vol. 13: 1358-1364.

Kausz, A. T., Obrador, G. T., Arora, P., Ruthazer, R., Levey, A. S., Pereira, B. J. G. "Late Initiation of Dialysis among Women and Ethnic Minorities in the United States." *Journal of the American Society of Nephrology*, 2000, Vol. 11: 2351-2357.

Kinchen, K. S., Sadler, J., Fink, N., Brookmeyer, R., Klag, M. J., Levey, A. S., Powe, N. R. "The Timing of Specialist Evaluation in Chronic Kidney Disease and Mortality." *Annals of Internal Medicine*, September 17, 2002, Vol. 137 (6): 479-486.

Kjellstrand, C. M. and Moody H. "Hemodialysis in Canada: a first-class medical crisis." *Canadian Medical Association Journal*, 1994, Vol. 150 (7): 1067-1071.

Kriegsman, D. M. W.; Penninx, B. W. J. H., van Eijk, J. Th. M. "A Criterion-Based Literature Survey of the Relationship between Family Support and Incidence and Course of Chronic Disease in the Elderly." *Family Systems Medicine*, Vol. 13 (1), 1995: 39-68.

Kutner, N. G. "Social Ties, Social Support, and Perceived Health Status Among Chronically Disabled People." *Social Science and Medicine*, 1987, Vol. 25 (1): 22-34.

Kutner, N. G. and Brogan D. "Race, Socioeconomic Status, and Risk of a Catastrophic Health Condition in Later Life." *Health, Illness, and Use of Care: The Impact of Social Factors*, 2000, Vol. 18: 151-165.

Kutner, N. G. and Gray, H. L. "Women and Chronic Renal Failure: Some Neglected Issues." *Journal of Sociology and Social Welfare*, July 1981, Vol. 8 (2): 320-333.

Lameire, N., Wauters, J.-P., Teruel, J. L. G., Van Biesen, W., Vanholder, R. "An update on the referral pattern of patients with end-stage renal disease." *Kidney International*, 2002, Vol. 61: S27-S34.

Letourneau, I., Ouimet, D., Dumont, M., Pichette, V., Leblanc, M. "Renal Replacement in End-Stage Renal Disease Patients over 75 Years Old." *American Journal of Nephrology*, March-April 2003, Vol. 23 (2): 71-77.

Levin, A. "Consequences of late referral on patient outcomes." *Nephrology Dialysis Transplantation*, 2000, Vol. 15 (Supplement 3): 8-13.

Levin, A. "Identification of patients and risk factors in chronic kidney disease – evaluating risk factors and therapeutic strategies." *Nephrology Dialysis Transplantation*, 2001, Vol. 16 (Supplement 7): 57-60.

Livingston, I. L. "Renal Disease and Black Americans: Selected Issues." *Social Science & Medicine*, 1993, Vol. 37 (5): 613-621.

McCauley, J., Irish, W., Thompson, L., Stevenson, J., Lockett, R., Bussard, R., Washington, M. "Factors Determining the Rate of Referral, Transplantation, and Survival on Dialysis in Women With ESRD." *American Journal of Kidney Diseases*, December 1997, Vol. 30 (6): 739-748.

McKenzie, J. K., Moss, A. H., Feest, T. G., Stocking, C. B., Siegler, M. "Dialysis Decision Making in Canada, the United Kingdom, and the United States." *American Journal of Kidney Diseases*, January 1998, Vol. 31 (1): 12-18.

McLaughlin, K., Manns, B., Culleton, B., Donaldson, C., Taub, K. "An Economic Evaluation of Early Versus Late Referral of Patients With Progressive Renal Insufficiency." *American Journal of Kidney Disease*, November 2001, Vol. 38 (5): 1122-1128.

Mendelssohn, D. C., Kua, B. T., Singer, P. A. "Referral for Dialysis in Ontario." *Archives of Internal Medicine*, December 11-25, 1995, Vol. 155 (22): 2473-2478.

Muirhead, N. and Blyndal, K. "Potential Cost Savings of Planned Dialysis Start." *Journal of the American Society of Nephrology*, 1995, Vol. 6: 553A.

Murphy, S. W., Foley, R. N., Barrett, B. J., Kent, G. M., Morgan, J., Barre, P., Campbell, P., Fine, A., Goldstein, M. B., Handa, S. P., Jindal, K. K., Levin, A., Mandin, H., Muirhead, N., Richardson, R. M. A., Parfrey, P. S. "Comparative hospitalization of hemodialysis and peritoneal dialysis patients in Canada." *Kidney International*, 2000, Vol. 57: 2557-2563.

NIDDK (National Institute of Diabetes & Digestive & Kidney Diseases) website accessed 14/04/2003: http://www.niddk.nih.gov

Nzerue, C. M., Demissachew, H., Tucker, J. K... "Race and Kidney Disease: Role of Social and Environmental Factors." *Journal of the National Medical Association*, August 2002 Supplement, Vol. 94 (8): 28S-38S.

Obrador, G. T., Ruthazer, R., Arora, P., Kausz, A. T., Pereira, B. J. G. "Prevalence of an Factors Associated with Suboptimal Care before Initiation of Dialysis in the United States." *Journal of the American Society of Nephrology*, 1999, Vol. 10: 1793-1800.

Perneger, T. V., Whelton, P. K., Klag, M. J. "Race and end-stage renal disease. Socioeconomic status and access to health care as mediating factors." *Archives of Internal Medicine*, June 12, 1995, Vol. 155: 1201-1208.

Raphael, D. (Editor). Preface and Introduction in the Social Determinants of Health. Canadian Perspectives. Canadian Scholars Press Inc., Toronto, 2004.

Ratcliffe, P. J., Phillips, R. E., Oliver, D. O. "Late referral for maintenance dialysis." *British Medical Journal*, February 11, 1984, Vol. 288: 441-443.

Roderick, P., Jones, C., Drey, N., Blakeley, S., Webster, P., Goddard, J., Garland, S., Bourton, L., Mason, J., Tomson, C. "Late referral for end-stage renal disease: a region-wide survey in the south west of England." *Nephrology Dialysis Transplantation*, July 2002, Vol. 17 (7): 1252-1259.

Roubicek, C., Brunet, P., Huiart, L., Thirion, X., Leonetti, F., Dussol, B., Jaber, K., Andrieu, D., Ramananarivo, P., Berland, Y. "Timing of Nephrology Referral: Influence on Mortality and Morbidity." *American Journal of Kidney Diseases*, July 2000, Vol. 36 (1): 35-41.

Salvalaggio, G., Kelly, L., Minore, B. "Perspectives on health: experiences of First Nations dialysis patients relocated from remote communities for treatment." *Canadian Journal of Rural Medicine*, Winter 2003 Contents, available at www.cma.ca.

Schmidt, R. J., Domico, J. R., Sorkin, M. I., Hobbs, G. "Early Referral and Its Impact on Emergent First Dialyses, Health Care Costs, and Outcome." *American Journal of Kidney Diseases*, August 1998, Vol. 32 (2): 278-283.

Sekkarie, M., Cosma, M., Mendelssohn, D. "Nonreferral and Nonacceptance to Dialysis by Primary Care Physicians and Nephrologists in Canada and the United States." *American Journal of Kidney Diseases*, July 2001, Vol. 38 (1): 36-41

Statistics Canada. "PCCF + Version 3G User's Guide (Geocodes/PCCF): Automated Geographic Coding Based on the Statistics Canada Poster Code Conversion Files including postal codes to June 2001, Statistics Canada, Ottawa, August 2001, Catalogue No.82F0086-XDB

Steel, J. and Ellis, P. "Do demographic variables affect the timing of referral to the nephrologist?" *EDTNA/ERCA Journal*, October-December 2002, Vol. 28 (4): 185-187.

Turner-Musa, J., Leidner, D., Simmens, S., Reiss, D., Kimmel, P. L., Holder, B. "Family structure and patient survival in an African-American end-stage renal disease population: a preliminary investigation." *Social Science & Medicine*, 1999, Vol. 48: 1333-1340.

Twaddle, A. C. “From Medical Sociology to the Sociology of Health: Some Changing Concerns in the Sociological Study of Sickness and Treatment.” Sociology: The State of the Art, 1982, Sage, Beverly Hills, CA: 323-358.

Wenger, N. S., Lynn, J., Oye, R. K., Liu, H., Teno, J. M., Phillips, R. S., Desbiens, N. A., Sehgal, A., Kussin, P., Taub, H., Harrell, F., Knaus, W. “Withholding Versus Withdrawing Life-Sustaining Treatment: Patient Factors and Documentation Associated with Dialysis Decisions.” *Journal of the American Geriatrics Society*, May Supplement 2000, Vol. 48 (5): S75-S83.

Williams, G. H. "The determinants of health: structure, context and agency." *Sociology of Health & Illness*, 2003, Vol. 25: 131-154.

Williams, S. “Sociological Imperialism and the Profession of Medicine Revisited: Where are We Now?” *Sociology of Health & Illness*, 2001, Vol. 23 (2): 135-158.

Wilson, R., Godwin, M., Seguin, R., Burrows, P., Caulfield, P., Toffelmire, E., Morton, R., White, P., Rogerson, M., Eisele, G., Bont, G. “End-Stage Renal Disease: Factors Affecting Referral Decisions by Family Physicians in Canada, the United States, and Britain.” *American Journal of Kidney Diseases*, July 2001, Vol. 38 (1): 42-48.

Winkelmayer, W. C., Glynn, R. J., Levin, R., Owen, W. F., Avorn, J. “Determinants of Delayed Nephrologist Referral in Patients With Chronic Kidney Disease.” *American Journal of Kidney Diseases*, December 2001, Vol. 38 (6): 1178-1184.

Young, T. K., Kaufert, J. M., McKenzie, J. K. “Excessive burden of end-state renal disease among Canadian Indians: a national survey.” *American Journal of Public Health*, June 1989, Vol. 79: 756-8.

Young, E. W., Mauger, E. A., Jiang, K.-H., Port, F. K., Wolfe, R. A. “Socioeconomic status and end-stage renal disease in the United States.” *Kidney International*, 1994, Vol. 45: 907-911.

APPENDICES

Appendix A - Renal Patient Consent Form

BC Renal Agency

Room 620-16, 1081 Burrard Street
Vancouver, BC V6Z 1Y6
Tel: (604) 808-8845
Fax: (604) 806-8849
e-mail: bcpra@cheos.ubc.ca

Consent to Register in PROMIS

(Patient Records, Outcome and Management Information System)

As an individual requiring renal services in the Province of British Columbia, I, ______________________________ understand that information regarding my clinical, laboratory, and treatment regimens will be entered in a provincial database. This information will only be accessible to authorized staff at the Renal Agency when it is necessary for administrative or treatment purposes related to my care. My personal information will remain confidential at all times. This information may also be used for statistical research purposes, but I will not be identified as an individual at any time.

The purpose of this information is to ensure state of the art delivery of care and to provide my caregivers with efficient, timely and accurate information about my health today and into the future.

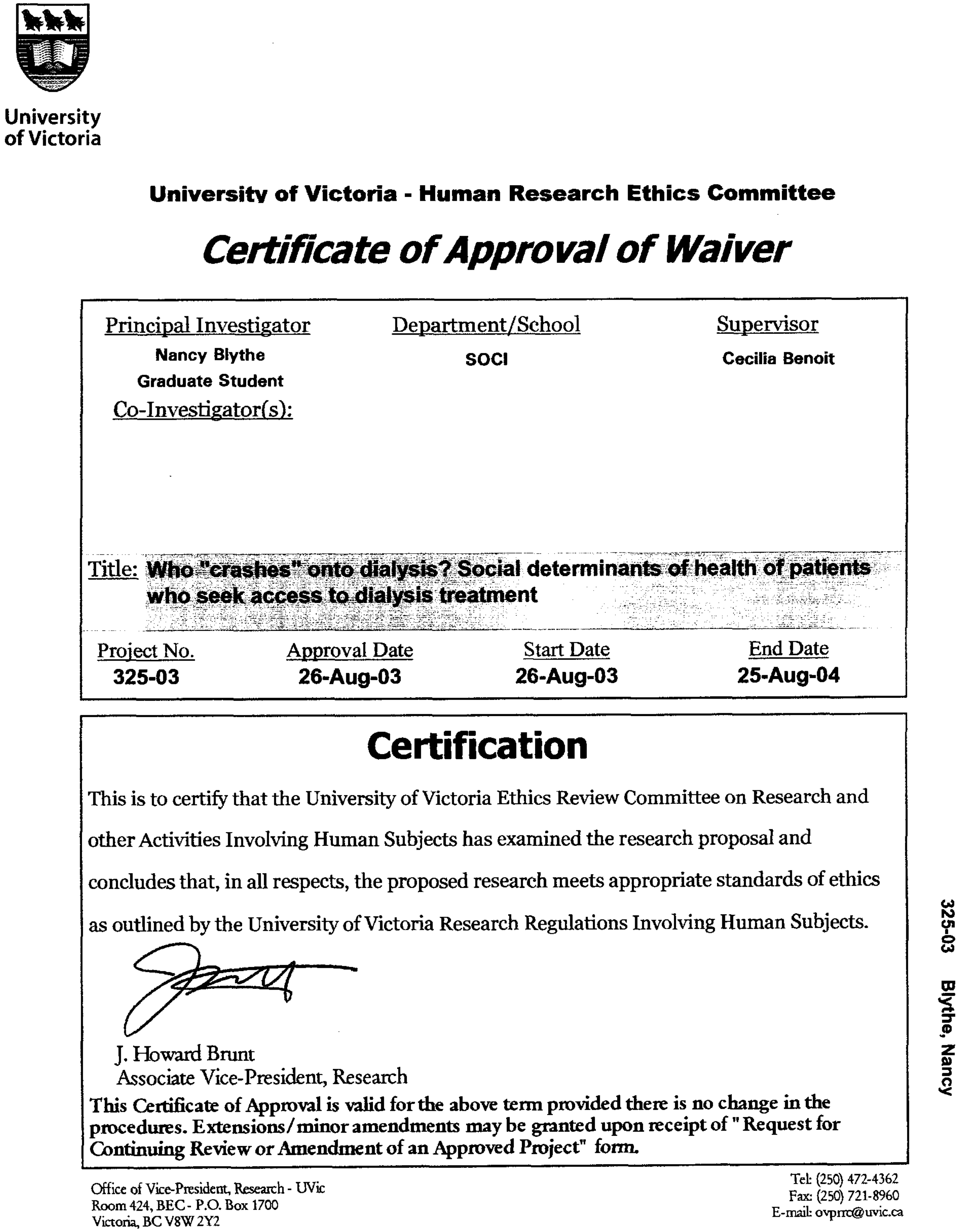
By signing this form I acknowledge that my caregivers, the statistical analysts and data managers in charge of the PROMIS may have access to my personal information.

____
SIGNATURE

____
DATE

____
WITNESS

Appendix B – Ethics Committee Waiver of Approval



University
of Victoria

University of Victoria - Human Research Ethics Committee

Certificate of Approval of Waiver

Principal Investigator	Department/School	Supervisor
Nancy Blythe **Graduate Student**	**SOCI**	**Cecilia Benoit**

Co-Investigator(s):

Title: **Who "crashes" onto dialysis? Social determinants of health of patients who seek access to dialysis treatment**

Project No.	Approval Date	Start Date	End Date
325-03	**26-Aug-03**	**26-Aug-03**	**25-Aug-04**

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

J. Howard Brunt
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

Office of Vice-President, Research - UVic
Room 424, BEC - P.O. Box 1700
Victoria, BC V8W 2Y2

Tel: (250) 472-4362
Fax: (250) 721-8960
E-mail: ovprrc@uvic.ca

325-03 Blythe, Nancy