

Querying everyday scarcity: A feminist political economy analysis of kidney dialysis and  
transplantation in rural British Columbia

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## **Abstract**

This thesis uses a feminist political economy perspective to analyze the findings from a case study regarding kidney dialysis and transplantation in rural and remote British Columbia. This case study was conducted in order to investigate the concept "scarcity," which is very common in organ transfer discourse. Critical ethnography and document analysis were used to examine the ways in which scarcity manifests in policy, practice, and everyday life. The main areas of focus include: the systemic context for the practices; the intersection of social location and geographic isolation; the intersection of gender, work and health; the implications of work in the local resource industry for renal health and renal replacement options; the role of unpaid care work provided by family members; and the implications of shifting care from institutions to families and individuals – particularly in a rural and remote context. Broadly, I argue that the scarcity of transplantable organs remains the dominant public discourse, that this discourse informs policies and practices, and that, despite these trends, lived experiences of scarcity at this site of study have more to do with the scarcity of human and health care resources, particular services, and health and life-sustaining resources for patients.

**Dedication**

For Phil.

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## Introduction

“A lot of people thought that the transplant would take my diabetes away. I said ‘that has nothing to do with the diabetes.’ People just thought that because it was diabetes that caused the kidney to fail, that then my diabetes would be gone. But I said, ‘no, it doesn’t work that way. I’m still diabetic, you know’” (Interview 21, 2013).

When we hear the term “organ scarcity,” many of us conjure up images of sickly patients in hospitals, desperately waiting for a lifesaving transplant that may not come in time. In documentaries such as *65\_RedRoses* or movies such as *Seven Pounds*, we see frail, beautiful young women constantly waiting for their pagers to alert them that a donor organ has become available. In newspapers, we see articles that discuss the number of people who die each year while on transplant waiting lists and the urgent need for more registered organ donors. At government services offices, we see evocative posters that remind us that one donor can save up to eight lives. This is the public face of organ scarcity. The concept of “scarcity” is central to current discussions of organ donation and transplantation. The term typically refers to the shortage of transplantable organs in relation to the increasing demand for them. However, the concept can also extend to include the scarcity of: dialysis machines, medical staff, funds and other resources, and transplant facilities. Scarcity can be employed as a rationale for shifts in transplantation policies and practices, to encourage donor registration, to outline health care options, and to frame debates about organ allocation.

Over the past 30 years, medical anthropologists and other social scientists have identified some of the ways in which scarcity discourses operate. In academic literature and public media, organ scarcity tends to be invoked in relation to saving lives, lifeboat ethics, heroic and miraculous medical advances, and cost-savings for the health care system. While health care professionals, bioethicists, and popular media use scarcity in these ways, the concept itself is seldom queried or empirically investigated. Several thinkers (Scheper-Hughes, 2002; Lock, 2002a; Koch, 2002) claim that organ scarcity is, in fact, artificial and/or a matter of perspective. These thinkers argue that the issue is not that there are too few transplantable organs, but that the pool of potential recipients has

become too large. The focus on the need to increase organ donation limits discussion of why transplants are becoming increasingly routine and required in the first place. It also obscures matters of social justice and the equitable allocation of resources.

In researching this topic, I used critical ethnography and document analysis in order to answer the questions: “how does the concept of scarcity function in local organ transfer policies, practices, and everyday experiences of individuals in the region of study?” and “how is scarcity defined, utilized, and represented and considering it as active discourse, what are the implications of these representations?” In this dissertation, the concept of scarcity serves as a point of entry into the broader political and economic issues surrounding kidney transfer using the example of a rural and remote town in British Columbia, Canada. Through the use of a feminist political economy framework, I unpack the ways in which scarcity is experienced in everyday life, and explore how the discourse is defined, utilized, and represented in popular media, policy, and the related literature. I argue that an unquestioned acceptance of the scarcity discourse can place us on a slippery slope where the ethical standards for organ procurement are increasingly relaxed. My objectives were to illuminate the complex and invisible aspects of kidney treatment and to explore and reveal the gross oversimplification of the idea of organ scarcity. I argue that increased donor registration is not an adequate remedy to scarcity because kidney transplantation alone cannot treat or prevent the conditions that lead to renal failure. The scarcity of food, housing, and employment security; of health care system funding in rural and remote areas; of safe, affordable, and reliable transportation; of education about chronic kidney disease prevention; of healthful workplaces with adequate accommodations for labourers who have kidney disease; and of support for unpaid care workers are more pressing forms of scarcity in the lives of my participants and yet, these issues receive less public attention than the shortage of kidneys.

The project was designed to be one of re-contextualization, of shifting the inquiry back to the contexts and conditions in which people’s kidneys fail. I wanted to better understand the experiences of those who are waiting for kidney transplants, those who have received them, and those who provide paid and unpaid care for these individuals.

For most people who are waiting on a kidney transplant – and for those whose transplants have failed – everyday life involves dialysis treatments. As a result, much of the discussion in my interviews and throughout this dissertation focuses on dialysis, rather than/in addition to transplantation.

I designed and interpreted the research with the assumption that people make choices about their health and their treatment based on a complex web of factors, primarily to do with the social and material resources that are available to them. I worked under the assumption that rural and remote health occurs in geographically isolated spaces, but is also determined by a range of macro level systems and structures. Lastly, I assumed that gender is a social institution<sup>1</sup> (Martin, 2004) with implications for our work, health-seeking behaviours, lifestyle habits, and our everyday lives.

### **Key concepts**

Chronic kidney disease (CKD) is defined as “the presence of kidney damage or a decreased level of kidney function for a period of three months or more” (Kidney Foundation of Canada, 2014a). There are five stages of CKD that are ranked based on the severity of damage to the kidneys or the level of their function. Stage 5 of CKD involves 15% kidney function or less (ibid). This is also known as End-Stage Renal Failure (ESRF) and patients at this stage will require hemodialysis or kidney transplant in order to survive. Though CKD can be diagnosed and treated prior to ESRF, its early stages can be difficult to detect. The leading causes of CKD are diabetes and high blood pressure.

Our kidneys filter about 115-140 litres of our blood each day in order to remove waste and fluids that are then expelled through urine (National Kidney and Urologic

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<sup>1</sup> Martin (2004) argues that unlike biological sex, gender ought to be regarded as a social institution because institutions: are characteristic of groups; endure across time and space; entail distinct social practices that are repeated by group members; constrain and facilitate behaviour; have social positions/relations that are characterized by particular norms, expectations, and procedures; are (re)constituted by agents; are internalized and displayed; have a “legitimizing ideology proclaiming their rightness”; are inconsistent, contradictory, and “rife with conflict”; continuously change; are organized in accord with and permeated by power; and are mutually constitutive with individuals (p. 1256-1258).

Diseases Information Clearinghouse, 2014). When kidneys fail to function properly, waste and fluids build up in the body. Hemodialysis is a blood-cleaning treatment that involves having a patient connected to a machine that acts as an external, mechanical kidney. During treatment, blood is removed from the body, filtered through the machine, and then returned to the patient's body. Hemodialysis "runs" are approximately four hours long and the average person needs at least three runs per week (Kidney Foundation of Canada, 2006). Dialysis is normally performed in hospital dialysis clinics with trained nurses and nephrologists, but patients can also receive dialysis in their homes. Patients and their relatives must receive special training in order to perform home dialysis. Peritoneal dialysis performs the same function as hemodialysis, but the blood is cleaned inside of the body rather than outside of it. The inside of the abdomen is called the peritoneal cavity and is lined with a membrane called the peritoneum (Kidney Foundation of Canada, 2006). In PD, the peritoneal cavity is filled with a dialysis fluid through a permanent tube in the abdomen. Similar to the hemodialysis machine, the peritoneum filters the blood. The waste is filtered into the dialysis fluid, which is then drained from the body into a PD bag and discarded (ibid). This process is performed four to six times each day. There is also a treatment called "Automated Peritoneal Dialysis" in which the dialyzing solution is changed by a machine overnight while the patient sleeps.

Kidney transplantation is another form of renal replacement therapy that involves having a healthy kidney removed from one person and surgically transplanted into the person with kidney failure. Donor kidneys are obtained from both living and deceased individuals. Once patients who are experiencing renal failure meet the eligibility criteria for a kidney transplant, they are put on a waiting list for a cadaver donor or must wait for the offer of a living donation from someone they know. The kidney must be a blood type match and there is a considerable amount of testing required throughout the process to determine the viability of the transplant. Unless it is chronically infected, the failed kidney is not actually removed from the recipient's body (Kidney Foundation of Canada, 2006). Deceased organ donation involves removing an organ from someone who has met the legal and medical criteria for "death." In most cases, this involves "brain death" – the

irreversible loss of brain function – but it can also include cardiac death. Life support machines keep blood and oxygen circulating through the brain dead donor’s system in order to keep the organs viable for transplant. In Canada, donations from deceased donors are anonymous (Kidney Foundation of Canada, 2014). Recipients are not informed as to the identity of their deceased donor, but transplant organizations can pass thank you cards along to a donor’s family. Living organ donation is when a living individual decides to donate one of his or her organs to a friend or family member. In the case of “altruistic donation,” the donor may donate an organ to a stranger. Living donation is popular for kidney transplantation because donors can live with only one of their two kidneys. Those in the transplant field see living donation as preferable because the donated kidney is usually healthier and lasts longer than a “cadaver kidney” (Kidney Foundation of Canada, 2014). Living donation also requires less waiting time for recipients, less dialysis treatment, and more time to plan for the transplant.

### **Contents of the Dissertation**

Chronologically, this dissertation begins with a discussion of the theoretical literature in this area of study. I examine critical organ transfer literature from scholars in the fields of medical anthropology, sociology, bioethics, and health geography. By “critical” literature, I mean the innovative, alternative, and sometimes skeptical perspectives that challenge the dominant accounts of organ transfer. These texts outline the social, political, and economic contexts for the practices of organ donation and transplantation. In critically reviewing this literature, I identify some of the major tensions and debates in this field of study, what it means to exchange human organs in a neo-liberal context, the critical use of “scarcity” in organ transfer discourses, the ways in which political and economic contexts are considered, and the benefits of using a feminist political economy approach to study health equity in organ transfer. I then identify some of the gaps in current organ transfer scholarship. These gaps include minimal qualitative Canadian content, little attention explicitly paid to sex and gender, little discussion of how these issues might play out in rural and remote settings, minimal discussion of the

experiences and implications of paid work and unpaid care work, and our limited understanding of the daily challenges associated with life on dialysis.

I conclude that scarcity is fundamentally a matter of health equity and that the allocation of scarce lifesaving resources is bound to matters of social justice. This chapter sets the theoretical landscape for my project and identifies a number of the central themes and issues in this area of study. I conclude this chapter by outlining the methodology used in designing, performing, and interpreting this research: feminist political economy. I discuss feminist political economy's strengths and history and explain why this was an appropriate methodological lens for this project. Given the intricate relationship between theory and method, feminist political economy also determined the research questions, areas of focus, data collection, and the interpretation of the findings.

In Chapter 2, I outline the qualitative methods used in this research. I designed an explanatory case study (Yin, 2009) in order to query the discourse of scarcity, explore how it informs kidney transfer policies and practices in a rural and remote Canadian setting, and understand the implications that these policies and practices have for the everyday lives of those involved. In other words, this study presents a case of how particular policy decisions and institutional/organizational systems influence renal replacement needs and treatment choices. I discuss my choice to use the research methods of critical ethnography and document analysis, the processes of site selection and participant recruitment, and relevant ethical considerations. I also outline the structure of the interviews and how exactly the study was designed, performed, and interpreted.

Drawing primarily on the document analysis and interviews with health care professionals, Chapter 3 outlines my findings related to the systems involved with providing care for renal patients. I discuss the broad health organizations that provide services and supports for renal patients. These include the Kidney Foundation of Canada, the BC Transplant Society, the British Columbia Provincial Renal Agency, and the regional renal care system. I outline the services that they offer and examine the challenges and successes that they experience in serving the renal population of this

region. Through a collection of their documents and websites, I analyze the discourses that these organizations use to communicate their messages, shape public opinion, and direct policy. I suggest that at different levels of care there are different treatment foci and different scarcity discourses at work. This variation reflects the needs, goals, and priorities at each level of care as well as the proximity to patients' everyday lives. Based on my findings, I suggest that the discourse of organ scarcity remains the dominant message across the province and that current public education and outreach initiatives primarily focus on donor awareness, registration, and procurement, rather than on prevention and/or determinants of health. I found that new practices have, indeed, emerged in response to this perceived kidney shortage. At the local level, the limited number of rural and remote staff members can lead to workload and communication issues, and challenges with the remote care system sometimes allow patients to slip through the cracks. This chapter provides evidence of scarcity discourse in action and contributes concrete, real life examples of the ways in which this discourse manifests in policy and practice in British Columbia. It confirms that the concerns expressed in the critical literature have merit.

Chapter 4 addresses my health and place-related findings. This chapter focuses on the specific site of study, its geographical isolation, rural demographics, and what these mean for renal patients in rural and remote BC. The chapter highlights the relevance of both physical place(s) and social space(s). I outline these findings with a focus on geographic isolation as it relates to access to dialysis and transplant services, travel and transportation, compliance with treatments, and the local resource industry. I discuss the ways in which geographic location and social location(s) intersect to create the conditions for kidney health, treatments, and care. I argue that geographic isolation can exacerbate inequities that result from other determinants of health and that rural residence is, itself, a determinant of health. Those most deeply affected by the barriers posed by geographic isolation include individuals with low incomes, multiple health conditions, low levels of formal education, Aboriginal status, and inadequate employment accommodations. Additionally, many of my participants were seniors. I argue that it is my participants'

geographic isolation paired with broader social, political, economic, and health system that prevent them from accessing various goods and services. Some American research on geographic disparities in access to kidney transplantation (Patzner & Pastan, 2014; Srinivas, 2014) identifies race, socioeconomic status, and poverty as factors that contribute to high rates of renal failure and low kidney transplantation. However, this is often credited to the fact that individuals from vulnerable populations/areas in the United States likely do not have health insurance. One of the major recommendations for addressing these disparities is to improve access to health care services via the Affordable Care Act or by extending Medicaid (Patzner & Pastan, 2014). Chapter 4 of my dissertation contributes to this discussion by offering insight into how socially and/or spatially marginalized Canadians can experience an inequitable distribution of illness and limited access to care and support services *despite* having universal health insurance.

Chapter 5 looks at the intersections of gender, work, and health as they relate to work in the resource extraction industry. There are several resource extraction industries in rural British Columbia. These primarily include: mining, logging, forestry, and oil and gas production. All of the male dialysis patients and kidney transplant recipients I spoke with worked in these industries or had done so in the past. In this chapter, I discuss the culture of work in the local resource industry, its impact on labourers and residents of the region, its relationship to gender and concepts of rural masculinity, and its political and economic significance. I highlight the province's Gold Rush history and argue that it echoes in the present through an ethos of frontier living, which impacts how local men perform their work and their gender. Through the narratives of these men, I discuss the impact that these performances of work and gender have on the health of their kidneys, as well as the structural and organizational barriers that they face in terms of obtaining and maintaining effective renal treatments. By examining the context in which they spend much of their lives, this chapter reveals the complex and often invisible barriers to good renal health and effective renal replacement therapies that these men experience. Until 15 years ago, very little attention was paid to the ways in which gender impacted the health

of men (Doyal, 2001). This chapter provides insight into how gendered norms, traditions, and workplaces can affect the health of men in this region.

In Chapter 6, I continue the discussion of gender, work, and health as it relates to unpaid care work performed by family members. I identify the various types of care that these individuals provide for dialysis patients and transplant recipients and note the interesting ways in which families structure and restructure themselves in order to support unpaid care work. Through some of the most compelling family care provider narratives, I address some of the major challenges that unpaid care workers face in their daily lives. Using a feminist political economy lens, I discuss the gendered nature of work in this context, what it means for familial economies of care, and the implications of offloading care from health institutions onto families and individuals – usually women. Ultimately, I suggest that the current shift towards home-based renal care reflects a broader trend toward a reduction of public health services, gendered assumptions about the feasibility of unpaid care work, and an increasing reliance on individuals – rather than the state – to support dependency and produce healthy citizens. This chapter confirms the challenges that come with providing daily care to a loved one with a chronic disease and the gendered nature of unpaid care work. It extends the discussion to include how these challenges can be further complicated by rural and remote residence and how this state of affairs can be read as indicative of larger social and political trends.

Chapter 7 draws together the analyses made in the previous chapters in order to provide closing thoughts and recommendations. I conclude that organ scarcity discourse is somewhat artificial and yet it has been powerful in terms of influencing organ transfer policies and practices. In spite of its power, the discourse stands on ethically dubious grounds where the regulations around organ procurement are becoming increasingly relaxed. Organ donor registration and living donation are presented to the public as remedies for the increasing number of Canadians who experience chronic kidney disease and renal failure. However, this solution is too limited in its focus. This discourse masks other forms of scarcity that renal patients experience and ignores the complexities of their lives, their locations, and their health conditions. In present political and economic

contexts, scarcity discourses are also invoked in order to justify the individualizing of health and reductions in public service provision.

Lastly, Chapter 7 considers the implications of this work for other areas of policy and practice and highlights several areas worthy of further research. I discuss the contributions that this thesis makes to organ transfer discourse, rural health and health equity scholarship, and feminist political economy. The following chapter begins this discussion with an overview of critical perspectives on organ transfer.

## **Chapter 1: Critical Perspectives on Organ Donation and Transplantation: Theory and Methodology**

### **Introduction**

#### *Interdisciplinary dialogues on organ transfer*

In this chapter, I review critical, interdisciplinary perspectives on the practices of organ donation and transplantation and identify areas in need of further research. This project originally began with inquiries about whether or not organ transfer was a worthwhile area of study for a scholar focused on health equity and feminist political economy. In popular Canadian media, I had seen organ donation and transplantation presented as unquestioned social goods and often framed in terms of organ scarcity. Though a number of thinkers have discussed the ethical issues that organ transplantation confronts us with, the practice is generally portrayed as uncontroversial. Biomedical accounts of organ transplantation often discuss the practice as a micro level surgical procedure that is typically abstracted from social, political, or economic contexts.

Within this clinical context, biomedical literature on the topic addresses issues such as cancers and/or infections that occur post-transplant (Euvrard, Kanitakis, & Claudy, 2003) as well as immunosuppression and transplant rejection (Eid & Razonable, 2010). While these technical, medical perspectives are important for surgeons and follow-up care professionals, these accounts often neglect the elements of patients' lives outside of their clinical transplant care. For instance, post-transplant lives are measured in terms of survival years and morbidity levels. In contrast, Lock (2002a) notes that a transplant recipient who she spoke with told her about being "married to the transplant unit," being out of work, having to relocate for treatment, not having a support group available in the language that he speaks, and being unsure that transplant had been the right choice for him. The surgeon who performed this man's transplant then told Lock that the patient has continued to do very well in the five years since his transplant (ibid). This gap in understanding of the lived realities of transplant patients indicates the rarity of qualitative firsthand accounts.

Bioethical accounts of organ transplantation typically concern themselves with issues of organ procurement and allocation. They consider questions such as “should a living mother be allowed to donate her uterus to her daughter?” (Smith, 2011), “should those over the age of 70 be eligible for the transplant waitlist?” (Veatch, 2000), “should alcoholics receive lesser priority on the wait list for liver transplants?” (Glannon, 1998), as well as many other clinical, legal, and procedural questions of permissibility. While these types of questions get at some very important allocation issues, they often focus primarily on specific recipients and exchanges while seldom querying the broader political and economic contexts of organ transfer. Additionally, bioethical discussions tend to privilege formal philosophical principles (utility, justice, beneficence, etc.), rather than local ethical dialects (Brodwin, 2000), personal values (such as “home,” quality of life, burial with body intact, etc.) and goals/interests.

In order to better understand the context(s) for organ transfer and their implications for health equity, I sought out critical perspectives on the practice. The majority of the critical work on the subject comes from medical anthropologists (Scheper-Hughes, 2002,2006; Sharp, 2006,2007; Lock, 2002a, 2002b, 2008, 2010; Dickenson, 2008; Joralemon, 2000; Cohen, 2002; Brodwin, 2000; Hamdy, 2008). In contrast to many bioethical and biomedical accounts, medical anthropologists tend to be more aware and critical of the anxieties and socio-political contexts that inform organ transfer. The critical perspectives I discuss also include important theoretical contributions from bioethicists (Hoeyer, 2007), health geographers (Koch, 2001), sociologists (Healy, 2005; Fox, 1992), and medical historians (Swazey, 1992). The major themes discussed by these thinkers include: the shortage of transplantable organs, the transgression and blurring of boundaries through organ transfer, bodies in neo-liberal economic contexts, and organ transfer practices as reflective of broader cultures of exchange and social interaction.

Given their different disciplinary traditions, these authors do not always engage with one another. They often reference each other’s work (Hoeyer, 2007; Joralemon, 2000), but sometimes they engage in parallel, distinct, or divergent conversations. As a

result, this chapter is not a comprehensive review of the canon of literature on organ transfer. Instead, this chapter serves to introduce readers to critical, multidisciplinary perspectives on organ transfer and health equity and the major themes and points of tension in this area of study. Many of the debates that I identify result from scholars approaching organ transfer from a single disciplinary or methodological vantage point. For this reason, I suggest that an interdisciplinary approach is most appropriate for addressing the complexity of organ transfer practices and the multiple realms (medical, social, economic, political) in which they take place.

This critical literature speaks volumes about the context(s) for organ transfer, but it also reflects that which is often left unsaid. The content discussed in this chapter is intended to resonate during silences in future chapters. That is, in my findings, participants and organizations often speak from a biomedical perspective and the concepts identified in this chapter will help to supplement some of the theoretical gaps in those conversations. The insights I gleaned from this literature informed my research design and serves as the theoretical landscape for my own research.

#### *Origins of the scarcity discourse & contents of this chapter*

The key questions that I asked of the literature were: what are the points of tension, contradiction, and debate in critical organ transfer scholarship? How does neo-liberalism<sup>2</sup> influence organ transfer policies and practices? Why is “scarcity” so ubiquitous and what are the implications of its use? To what extent are political and economic context(s) of organ transfer considered? [How] can feminist political economy contribute to scholarship in this field? The following sections of this chapter address each of these questions.

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<sup>2</sup> Neo-liberalism is the ideology that drives economic globalization. It favours privatization and relaxing of economic rules and regulations. According to the World Health Organization, the four main principles of neo-liberalism are: economic growth is paramount, free trade benefits everyone, government spending is inefficient and wasteful, and “in the distribution of economic goods, individual responsibility replaces the concepts of public goods and community” (World Health Organization, 2014a, para 5).

In what follows, I first address some of the points of contention that surface around the definitions of bodies, death, and organs as resources. I outline the simultaneous and conflicting accounts of: the individual body and the social body; brain death and cardiovascular death; and organs as parts of persons and also as commodities and/or objects of exchange. I identify the ways in which these definitions are at odds with one another, as well as the ways in which some of the conflicts can be embraced or reconciled. I then address what it means to exchange human organs in a neo-liberal context, noting that the social, political, and economic systems in which Canadians live certainly inform our relationships with our bodies, with one another, with our finances, and with the state. The discourses used by medical professionals, organ procurement organizations, and other public figures to speak about organ transfer both shape and reflect attitudes towards the practice. I identify the importance of parsing these discourses and discussing the centrality of the concept of “scarcity” in conversations about organ transfer. Organ scarcity discourse surfaces in the data that I have collected, is apparent in organ donor awareness initiatives across Canada, and is critically taken up by the scholars discussed in this chapter. I agree with these scholars that organ scarcity discourse has been somewhat manufactured. It has been rationalized with economic metaphors and has become the generally unquestioned narrative with which we evaluate kidney failure and renal treatment. It also conceals the real life experiences of patients and their family members. Throughout this dissertation, I employ a broader understanding of scarcity that includes the scarcity of health and life-sustaining resources, as well as access to them. This broader discourse recognizes that scarcity is inequitably distributed and experienced, it is deeply contextual, and it is political. In this chapter, I discuss the literature and themes as they relate to this understanding of scarcity.

Though the critical literature fills a number of theoretical gaps in organ transfer scholarship, it too has its oversights. Some of these gaps include: minimal qualitative Canadian content, little attention explicitly paid to sex and gender, how these issues might play out differently in a rural and remote context, the roles of waged labour and unpaid care work, life on dialysis, and how ‘scarcity’ can function as an “active

discourse” (Mykhalovskiy, 2001) in the public arena(s). I also highlight the absence of a feminist political economy analysis of organ transfer and explain why I chose to use this framework to guide my research design and analyze my findings.

### **What are the points of contention and debate in critical organ transfer scholarship?**

#### *Compartmentalizing organ transfer practices*

In what follows, I use the term “organ transfer” to discuss the process in which an organ is extracted from one human body and surgically inserted into another. Sharp (2007) introduces this term to show the interdependence of the transplantation, procurement, and donation processes – practices that she points out are often decontextualized and compartmentalized. Organ transfer is thus distinct from ‘organ donation,’ which refers to the process of voluntarily having one’s kidney removed so that it can be surgically transplanted into someone else. This term captures the role of the donor (living or deceased) in the exchange process. When referring to ‘organ transplantation’ rather than ‘organ transfer,’ the focus tends to be primarily on the roles of the surgeons and recipients. It is important to explicitly acknowledge those who provide the human organs to make this practice possible.

Organ transfer is fraught with anxieties and ethical issues around the transgression of various boundaries. These boundaries include the divisions between: self and other, life and death, natural and artificial, human and machine, and subject and object, to name a few. These transgressions have the capacity to both subvert and maintain dominant ideologies; they can empower individuals, improve and extend life, make meaning out of accidental death, and create heterodoxical physical and emotional relationships between donors and recipients and their family members (in various combinations). However, the practice can also reinforce inequitable social and economic systems and benefit some at the expense of others. These transgressions also provoke anxiety because organ transfer affects aspects of our lives that are sacred to most of us: our life, our health, and our loved ones.

### *The individual body vs. the social body*

Despite some popular rhetoric discussed below, organs are not simply resources or commodities; they are, first and foremost, parts of people's bodies. I would be remiss to discuss transferring organs between bodies without first examining bodies themselves. According to Brodwin (2000), the biomedical worldview conceives of the human body as "an object of technical intervention, as a natural thing-in-itself, indifferent to human purpose or relationships" (p. 3). This perspective implicitly (by not noting otherwise) and explicitly (through the participants chosen for clinical trials and the images used in anatomy text books, etc.) treats the human body as singular and normative, as ahistorical and abiographical. This is reflected in the use of the popular term "the human body" rather than the plural "human bodies," which can better accommodate categories of difference. In the Western world, the dominant or prototypical human body is one that is healthy, able, male, Caucasian, and young to middle aged. This is evidenced by the general absence of [non glamourized or sexualized] female, disabled, racialized, and elderly bodies in mainstream media, advertising, educational materials, medical research, and other print and film sources. Digressions from the 'norm' are often medicalized, pathologized, considered anomalous, or ignored altogether. This view treats the body as an organism that "ends at the skin" and is inhabited by an "I" who is its owner (Haraway, 1991). Petchesky (1995) argues that this view of the body is trapped in conventional bourgeois and Lockean notions of property and that *owning* a body necessarily means reducing it to a commodity.

However, some philosophers (Hacking, 2007) and critical anthropologists (Sharp, 2006; Scheper-Hughes, 2006) argue that there is a professional denial of bodily commodification in the medical realm. This denial reveals some of the contradictions in this area. Namely, that in the medical profession, organs are said to be mechanical parts devoid of meaning and personhood that can be transplanted readily and anonymously between individuals; and yet, it is simultaneously said by health professionals and transplantation networks that the donor "lives on" through the recipient's survival and that organs are particularly "precious things" (Sharp, 2007, p.17). Indeed, this

contradiction permits the technocratic death<sup>3</sup> required for organ procurement as well as the capacity for physicians to perform the ‘miracle’ of transplantation ‘rebirth’ (Lock, 2002a). This also shifts the focus of the discourse from one of ethics and personal values to one of technical medical expertise. Rather than denying that commodification exists, critical scholars suggest that we ought to examine the ways in which bodies and their parts are commodified and determine which types of commodification we might deem permissible.

Anthropological accounts of bodies allow for more depth, narrative, and complexity. These perspectives treat bodies as maps of power and identity (Haraway in Goslinga-Roy, 2000) and as cultural texts and artifacts (Brodwin, 2000). Bodies are then seen as sites of [and distractions from] social truths (Klinenberg, 2006), social skins through which we display ourselves (Sharp, 2007), and metaphors for larger social phenomena (ibid). From these perspectives, bodies are individual representations of collective phenomena, but they are also the matter through which we, as embodied beings, experience and interact with the world.

There are several conceptual challenges that emerge around bodies in this context. First, bodies are conceptualized as both individual and social. Challenging neo-liberal ideas of individualism, Petchesky (1995) argues for an ethics of women’s bodily integrity that is communal and extended, as opposed to individual and privatized. While this perspective tackles many of the problems around bodies-as-property, some scholars (Scheper-Hughes, 2006; Dickenson, 2008) express concern for the ways in which women’s bodies, particularly those that intersect with other categories of difference or marginalization, have historically been more susceptible to exploitation. This does not mean that they disagree with Petchesky about the need for a focus on the social body. Rather, these authors are concerned with the slippery slope whereby, “a frailing [sic] and ailing human looks at another living person and realizes that *inside* that other body is something that can prolong his or her life. The desire is articulated: ‘I want that; I need

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<sup>3</sup> By “technocratic death” I mean a death that is determined by technical experts relying on the authority of their scientific expertise.

that even more than you” (Scheper-Hughes, 2002, p. 50). So while a focus on the social body and the collective good are certainly desirable and important for projects of equity and social justice, these projects also require ensuring the bodily autonomy and integrity of individuals, and not just normative ones. This is particularly true in terms of gendered bodies, given that women become organ donors much more often than do men (Lock & Nguyen, 2010). In Mexico, for instance, it is mothers who are expected to donate, “their sacrifice is part of their prime role as nurturer of the household, and ultimately their bodies are thought of as more expendable than those of working men” (ibid, p. 249). This concept is revisited in Chapter 6.

*Bodies as sites of inequity: Implications of the individual/social body debates*

This negotiation between the concepts of individual and social bodies has implications for how we view and treat health. From a broader biopolitical perspective, health is not simply a bodily state, though that is certainly part of it. The individual and society are seen as holding shared responsibility for good health. This broad understanding of health includes the well being of the individual body *and* the social body, as well as consideration of the production and determinants of health at both of these levels. For instance, if someone is on a low income, in poor living conditions, has a physically taxing job, and is living with diabetes, replacing his or her failing kidney can only do so much towards improving his or her health. This is not to downplay the therapeutic benefits of kidney replacement, but rather, to highlight the ways in which organ transfer advocates treat illness as located within individual parts of individual bodies<sup>4</sup>, and how this can limit their perception of the lifesaving resources that are necessary for improving health.

Bodies are also sites of inequity. Some of the most common forms of discrimination are based on: the sex of one’s body, the sexual organs of the person one is attracted to, one’s disability or disfigurement, the colour of one’s skin, the size or age of

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<sup>4</sup> In the case of organ donors, treatment is also seen as located within individual parts of individual bodies.

one's body, and so forth. According to Brodwin (2000), "[a]nxieties emerge about the conventional social hierarchies which are rooted in the body and which the body's truth silently certifies" (p. 9). Some authors (Scheper-Hughes, 2002; Dickenson, 2008) emphasize that while it is already problematic that some bodies are considered more valuable than others, it is especially problematic in the case of organ transfer and trade because some of these bodies can be considered more valuable dead than alive. Kidney donors need not be dead in order to donate, but heart or lung transplants, for instance, require deceased donation. The anthropological literature is filled with concern over the risk that impoverished, racialized, female, and other undervalued bodies could become reservoirs of spare parts for privileged persons seeking transplants (Joralemon, 2000; Cohen, 2002; Scheper Hughes, 2006). Tales about organ theft are often dismissed by the elite as folklore of the poorer classes – especially when these tales act as allegories for systemic inequality or as medical/social critique (Campion-Vincent, 2005).

Unfortunately, these concerns are not mere legend or science fiction. In an interview with an organs' broker in California, Scheper-Hughes (2006) was told, "[t]here's no reason for anyone to die in this country while waiting for a heart or kidney to materialize. There are plenty of spare organs to be had in other parts of the world" (p. 42). In other words, race, class, sex, disability, geography, and other equity considerations are central to the study of organ transfer. Those looking to increase organ donation and provide communal and caring social bodies are also confronted with the challenge of protecting individuals from exploitation. The authors who offer critical perspectives on organ transfer remind us that the social also embodies particular hierarchies and inequitable systems. As a result, it is important to recognize the geopolitical and biopolitical contexts in which organs are exchanged. In other words, the politics (policies, laws, norms) that surround and regulate bodies and populations are very much relevant to the discussion of organ donation and transplantation.

*Transgressing boundaries: re-defining the natural*

Another point of contention is the unease that some patients, family members, and members of the general public experience around the fluidity and flexibility of the definition of living human bodies. For instance, with the introduction of brain death as the legal and medical death of the person, health professionals must speak about deceased donor bodies in ways that indicate that the mechanically breathing body is no longer a person or a patient. Instead, he or she is a “living cadaver” or a “neomort”<sup>5</sup> whose organs will be “harvested” (Lock, 2002a). Lock (2002a) and Joralemon (1995) both argue that the discomfort around these terms, and around explaining them to the families of the deceased, reveal that the brain death criterion that is critical to the practice of cadaveric organ donation may not be as universally accepted as the medical establishment would suggest.

Those on ventilators or dialysis machines also confront us with cases of human-machine hybridity, with what the biotechnology literature sometimes refers to as “cyborgs” (Haraway, 1991). Lock (2002a) and Sharp (2006) for instance, discuss patients’ discomfort with being constantly tied to dialysis machines, or with the thought of a foreign kidney being transplanted into their bodies.<sup>6</sup> Biotechnological advances such as these consistently challenge our notion of the natural body and its limits. Brodwin (2000) suggests that members of the public perceive the flexibility of these limits as threatening for a number of reasons, but one central reason is that, “the figure of the

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<sup>5</sup> The term “neomort” means “newly dead” and was coined by Gaylin (1974) in a *Harper’s Magazine* article titled “Harvesting the dead: The potential for recycling human bodies.” He uses this term to distinguish brain dead bodies from living persons. Gaylin (1974) proposes using neomorts for training “uneasy “or “embarrassed” medical students to perform physical examinations (including, but not limited to, rectal and vaginal exams), the testing of drugs and surgical procedures that would be “inconceivable with the living human being” (p.27), and medical experimentation (for instance, testing antidotes by injecting poison or inducing cancer into the ‘neomort’). The term is still used by academics and bioethicists, though often with critique and/or disapproval. It is unclear whether or not the term ever became popular in the medical community.

<sup>6</sup> I was surprised to discover that virtually none of my participants spoke about this. There was no expression of discomfort with the breakdown of the boundaries between humans or between human and machine. I had anticipated that there would be more of this. This may reflect a disconnect between the theoretical academic literature and the lived experience of dialysis.

natural body, like the concept of nature itself, is a moral arbiter of acceptable behaviour and legitimate political relations” (p.7). He is careful to point out that our perceptions of the objective world, and our notion of it as “natural,” are products of repeated social learning (ibid, p. 8). Enforcing and normalizing certain uses of bodies allows us to maintain a particular social order (ibid). Additionally, these types of biotechnologies render human bodies dependent upon machines and those who operate them. Reliance upon the proper functioning of the devices, the diligence of medical staff, and the funding and functioning of the health care system renders patients extremely vulnerable, particularly in states that are lacking in public health care provisions.

So, on the one hand, biotechnology, including hemodialysis and organ transfer, can be threatening to our conceptions of the limits of life and death. It requires us to place great trust in the authority of the medical profession, and it creates sites of opportunity for Foucault’s (1978) concepts of biopower (the ways in which bodies are subjugated, controlled, and regulated by those in power) and biopolitics to operate. Both individual and social bodies can serve as sites of inequity. On the other hand, biotechnology creates numerous and complex possibilities. It can allow for the extension of life, for the treating of illness, for meaning to be made out of accidental deaths, for improved quality of life, and for individuals to exercise newfound power and control over their bodies and their health. In the critical organ transfer literature, bodies are seen as individual and as social, and good health requires ensuring the wellness of both. From this perspective, organ transfer practices should not be understood in isolation from one another or independent of their broader individual and social contexts. Organ transfer practices have changed the ways we think about human identity, connectedness, and the limits of the lifespan (Brodwin, 2000). To say that these changes are in no way political would be naïve.

### **How does neo-liberalism influence organ transfer policies and practices?**

In order to transfer organs between bodies, organ procurement and transplantation must be deemed legally and medically permissible practices. In North America, organ donation and transplantation are publicly presented as social goods. Organ donors are

deemed altruistic heroes and the lives extended by transplants are considered miraculous. Transplant surgeons are then presented as the heroic saviors responsible for ‘giving life’ to dying patients, drawing upon the, “particularly American theme of a triumphant medical science challenging death, of men in white coats (the majority of surgeons are still male) facing down the Grim Reaper” (Joralemon, 1995, p. 342). Our economic, geographical, and political locations can influence our perspectives on these issues. One example of this is the varying acceptance of brain death across cultures.

### *The acceptance of brain death in North America*

Lock (2002a) points out that approval of organ transfer from deceased donors is not universal. She cites the extensive public debate and controversy in Japan over the acceptance of the ‘brain death criterion’ (which was legally recognized there in 1997) and notes that such widespread, transparent, public discussion has been largely absent in North America. North American media coverage is generally limited to sensational news pieces and organ donor recruitment initiatives (ibid; Chapter 3). Lock’s (2002a) research demonstrates that death is not always apparent. She suggests that the borders between life and death are “socially and culturally constructed, mobile, multiple, and open to dispute and reformulation” (ibid, p. 11). Similarly, Joralemon (1995) argues that the rhetorics of altruism and individual rights<sup>7</sup> that are used to support and promote organ transfer in North America function as “ideological equivalents to immunosuppressant drugs, designed to inhibit cultural rejection of transplantation and its view of the body” (p. 335). In short, there may be more cultural and political resistance to organ transplantation in North America than it appears in the mainstream media. This tenuous acceptance of brain death as death might explain the disconnect between high rates of survey-reported

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<sup>7</sup> Joralemon argues that organ transfer proponents make use of culturally familiar concepts in order to “legitimize what is in fact a profound transformation in the way we think about an act towards the human body” (1995, p. 342). He says that the language of gift-giving and altruism are invoked to encourage donation and donor registration. At the same time, from a different perspective, the language of autonomy and individual rights is used to support an understanding of kidney ownership/possession (as distinct from self or personhood) that allows individuals to treat their kidneys as commodities.

support for organ donation in Canada (Ipsos Reid, 2010) and relatively low donor rates in practice (Baxter & Smerdon, 2000).

Taking into account this quiet dissensus, it is important to question why there has not been more public debate on the matter. Lock (2002a) argues that this is medical hegemony effectively at work. Many questions or criticisms that probe at inequities are dismissed, ignored, or silenced with the claim that, “[y]es, [there are moral dilemmas with some forms of procurement], but it will save a life!” (Scheper-Hughes, 2006, p. 49). Once organs have been procured, there is also the ethical matter of who receives them. An American study on access to cadaver kidney transplants revealed that, “30 to 65 waiting list spots or transplant operations per 1,000 patients would shift from economically advantaged to disadvantaged persons if socioeconomics no longer influenced organ allocation decisions” (Ozminkowski et al, 1998, p. 1398). Additionally, Scheper-Hughes (2002) argues that, “one has to be relatively ‘healthy’, affluent, and white in the USA to be a candidate for a cadaveric organ” (p. 59). On a global scale, it is said that the traffic in organs follows the routes of capital and labour flows. This is because, “[i]n general, the organs flow from South to North, from poor to rich, from black to brown to white, and from female to male bodies” (ibid, p. 45). In other words, inequities in our current economic system are reproduced in systems of organ exchange. As a result, public debate about brain death and other organ transfer practices may be undesirable for those in power because it requires addressing this inequity and may undermine people’s trust in the medical establishment or their willingness to donate. The priority and emphasis placed on saving lives – particularly privileged lives – has cut short or silenced much debate and critical inquiry into the national and international politics of organ transfer.

### *The commodification of human organs*

In a neo-liberal context, de-regulation and market-driven solutions are seen as essential. Organs are commonly referred to as “precious commodities” and “natural resources” in the biomedical or health economics-related literature (Lock, 2002a). The

question becomes: when we speak about organs in this way, are we commodifying them? If so, is the commodification of organs necessarily harmful? Most authors who critique the commodification of organs derive their notion of commodities from Marx (1967).

According to Marx, a commodity is:

“... a thing that by its properties satisfies human wants of some sort or another. The nature of such wants, whether, for instance, they spring from the stomach or from fancy, makes no difference. Neither are we concerned to know how the object satisfies these wants, whether directly as a means of subsistence, or indirectly as a means of production” (1967, p. 41-2).

To commodify bodies, by this definition, is to dehumanize them; to treat them as divisible, alienable, objects of commerce and desire for others. Scheper-Hughes (2006) notes that she and a number of colleagues opt for a broad concept of commodification that encompasses “all capitalized economic relations between humans in which human bodies are the token of economic exchanges that are often masked as something else – love, altruism, pleasure, kindness” (p.2). Under this definition, global capitalism, paired with medical advances, has created desires and demands for people’s parts. In this context, it is natural for market-based analogies to emerge in response to these demands. The concern with thinking about human parts in this way is that by extending the market to include organs, we also subject them to the under-regulated, free market system that benefits those at the top of the social hierarchy at the expense of those at the bottom.

A large problem with accepting a notion of bodies with alienable parts is that this understanding of bodies allows for the decontextualization of organ donation, procurement, and transplantation processes discussed above. In this context, the living or deceased donor *person* is often abstracted out of the picture. Referring to these individuals simply as “organ donors,” as the dominant organ transfer literature often does, identifies them primarily as ‘providers of resources’ without consideration of their lives or interests outside of the surgical context. In other words, organs become commodities because the practice disconnects the organ from the donor and the procurement of parts. When regulations for organ transplant candidacy are amended to include eligibility for infants, patients over 70 years old, patients with comorbidities, and

patients who have had transplants that were rejected, there is little conversation about who will provide this supply of organs.

In other words, the pool of potential recipients is expanding at rates that far exceed the potential donor pool. Even if more people register as organ donors – and organ donation *has* more than doubled in both Canada and the United States since 1984 (Lock, 2002b) – very few registered donors actually die in ways that are conducive to organ donation. In fact, our society actively strives to prevent the types of fatal accidents, gunshot wounds, head traumas, strokes, and other conditions that can lead to brain death. According to Lock & Crowley-Matoka (2008), there are two major consequences of this growing demand for organs. The first is that increasing numbers and types of organs for transplantation are being acquired from living donors, and the second is that desperate patients are increasingly likely to consider ‘transplant tourism’ (seeking an organ abroad). Additionally, in a North American context where individuals are accustomed to generally high standards of living and have expectations of long lives, people may begin to feel entitled to existing surgeries; and, more disturbingly, entitled to the organs of people healthier than they are. Some waitlisted recipients and their families will speak openly about the hope and guilt that they experience on rainy nights when traffic accidents rise (Scheper-Hughes, 2006; *65 Red Roses*, 2009). Additionally, the push for living donors can place tremendous pressure on the family members and friends of patients to offer their own kidneys for donation. Having healthy individuals undergo major surgery is something that would have been considered bizarre prior to the 1950s.

There is debate within the literature about whether capitalism commodifies organs or, in fact, protects them from commodification. Hoeyer (2007) argues that the notion of commodification is inadequate to analyze the dynamics at play in the establishment of exchange systems for biological materials:

“[r]ather than focusing merely on what capitalist forms of exchange do to biotechnology and the body, we might begin to appreciate what biotechnology and the socio-cultural significance of the body do to capitalism and its property structures – or, more precisely, how people’s engagement with and concern about biotechnology contributes to the shaping of multiple capitalisms” (p. 327).

Hoeyer (2007) outlines what he calls “the commodification hypothesis” that is put forward by Sharp, Scheper-Hughes, and other critical anthropologists. He argues that their account oversimplifies the matter and denies a tremendous amount of agency. Great efforts have gone into protecting and securing human bodies and parts from commodification and trade. In fact, there are many international policies, recommendations, and documents drafted specifically to do so (i.e. the Council of Europe’s *Convention on Human Rights and Biomedicine*, UNESCO’s Universal Declaration on the Human Genome and Human Rights, and the WHO’s *Guiding Principles for Organ and Tissue Donation and Transplantation*). Additionally, Hoeyer argues that patent laws have evolved in such ways that only novel modifications to biological materials can be patented (ibid). Patent laws have developed such that they protect and prevent natural human biological materials from becoming objects of property rights and ownership. However, Hoeyer does not consider how Brodwin’s (2000) claims about the social construction and malleability of “the natural” might be relevant here; rather, he claims that the widespread anxieties around the prospect of human parts as commodities reveals the extent to which they are very much distinct entities. He also fails to address the fact that, despite the legal protections, illegal organ trade continues to take place.

Though a well-regulated organs exchange system could ideally reduce the amount of transplant tourism and illegal organs trafficking, there is no evidence that suggests that it would reduce, as opposed to exacerbate existing markets, or that it would equalize the risks and benefits between the vulnerable and the well-to-do. In fact, much of the evidence suggests otherwise. In Iran, where kidney sales are legal, “[e]veryone who needs a kidney... gets one, which is quite an accomplishment. However, they’re doing it at the expense of the most marginal people in society” (Scheper-Hughes in Lawless, 2004, p. 3). In other words, though the benefits appear to be equal, the risks are not. So, while Hoeyer rightly points out the need to acknowledge the formal and informal efforts put into resisting the commodification and commercialization of human parts, he seems to overlook the ways in which existing practices can and do subvert those regulations, as

well as the fluidity of the regulations themselves. At present, the commodification debate remains unresolved.

Despite this debate about human/commodity boundaries, organs can be considered commodified in several ways: through their alienation from their donors, through their new social meaning as exchangeable items of value, through their fetishization by those desiring transplants, and, most explicitly, through commercial organ trade. Viewing organs as exchangeable is not necessarily harmful. Organs that are transplanted between relatives or loved ones are less likely to be viewed as purely mechanical parts, despite their alienation from their donor. These exchanges are often, according to Crowley-Matoka (2008), “experienced as an extension of the shared bodily substances that characterize family relations more generally” (p. 156). This is reminiscent of Petchesky’s notion of the shared body that challenges the self/other boundary. In light of this, I argue that the commodification of organs is problematic insofar as it decontextualizes their procurement, presents human parts as potential medical resources that others may have claim to, and makes them eligible for market exchange.

### *Organ sales and health equity*

Even though organ donation is deeply couched in language of “the gift of life,” many donations defy the traditions of gift giving (Mauss, 1990; Titmuss, 1971). For instance, deceased donors and their recipients do not know one another; there is no reciprocity or social relations involved with a deceased donor; and deceased donor anonymity is required. There are also limited ways to express gratitude to a deceased donor or repay their gift, since many transplant recipients are ineligible to become organ donors themselves (Sharp, 2007). In the case of living donation, there are also a number of “gifts” that result from coercion, guilt, family obligations, or other forms of pressure. This is why Fox & Swazey (2002) have referred to organ recipients’ senses of guilt or indebtedness as “the tyranny of the gift.” Because of the complexity of these exchanges, organ transfer can easily become less traditionally gift-like and more of a clinical or commercial transaction.

Some argue that if there are benefits for a recipient or middle-person (profit for a company, prestige for a hospital or university, and so forth), it would be inequitable and exploitative not to compensate donors as well (Dickenson, 2008; Lock, 2002a). This is a compelling argument, particularly when those benefiting are accruing large profits or extended life, or if the donor is from a vulnerable socio-economic group. However, any proposed form of compensation will also serve as an incentive. For instance, if an organ donor's funeral costs were covered by the state, then there would be an additional pressure on low-income persons to register as donors, even if they are not entirely comfortable with the idea, in order to relieve their families of that potential expense. In the context of blood donation, Titmuss (1971) also argues that unpaid donation, "represents the relationship of giving between human beings in its purest form because people give without the expectation that they will necessarily be given to in return. A system that depends on such voluntary giving effectively institutionalises altruism" (p. 8). He claims that a market in blood would be degrading to society and would replace altruism with self-interest. Additionally, the need for money on the part of the seller presents a conflict of interest and a disincentive for honest disclosure about his or her health status (ibid).

In short, if there is compensation for donation, those who are most financially desperate are most likely to provide the organs. Economic insecurity also intersects with other forms of marginalization based on sex, race, disability, immigration status, Aboriginal status, and others. As a result, any form of a market in organs is likely to draw its supply from the world's most vulnerable citizens. Indeed, this is why kidneys are referred to as "the organ of last resort" (Scheper-Hughes, 2002), because individuals tend not to risk their health – and there *are* health risks for donors<sup>8</sup> – and sell of themselves unless they feel that they have no other options. Scheper-Hughes (2002) argues:

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<sup>8</sup> Though rare, some of the potential risks that living donors face include: usual side effects from major surgery such as infection at incision site, blood clots, hemorrhaging, and others; hypertension or kidney failure; a number of lung and liver conditions (bile leakage, pancreatitis, postoperative pulmonary artery thrombosis, bronchial stricture,

“[c]ommercialized transplant medicine has allowed global society to be divided into two decidedly unequal populations –organ givers and organ receivers. The former are an invisible and discredited collection of anonymous suppliers of spare parts; the later are cherished patients, treated as moral subjects and as suffering individuals. *Their* names and their biographies and medical histories are known, and their proprietary rights over the bodies and body parts of the poor, living and dead, are virtually unquestioned” (p.4).

Some proponents of markets in organs claim that in a neo-liberal context and a globalized world, paid organ exchange is simply inevitable. Others claim that the market is inevitable, but that its legalization is not. For instance, when Michael Brown, who was arrested for illegally extracting and selling bones and tissue from bodies sent to his crematorium, was asked about whether he thought organ, tissue, and bone selling should be made legal, he noted, “It would be an arduous task to try and regulate it...it’s not going to happen, not in a capitalist society... there’s too much money to be made” (Dickenson, 2008, p. 19). To some extent, he is right. Local and international medical regulatory agencies have little or limited control over (or awareness of) the activities of doctors, patients, and brokers who circumvent the transplant waiting lists and seek out illegal organ sales.

In *Why Some Things Should Not be for Sale: The Moral Limits of Markets*, Satz (2010) argues that while there are already many services that the poor provide for the rich without reciprocation or equal benefit, a market in human kidneys is “noxious.” She claims that political and moral questions are relevant and that assessing markets requires examining their effects on social justice, human relationships, and society as well as economics (ibid). In her assessment of a market in kidneys, she determined that sellers have weak agency; that there are unequal status considerations (wealthy buyers and poor sellers, as well as race and gender constructs); and she expresses concern about the prospect of kidneys becoming viewed as collateral or assets. For instance, what if someone were denied social assistance because he or she still had both kidneys? How would debt collection agencies respond to this market? A market in kidneys could not

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etc.); bowel obstructions; psychological changes (sadness, anxiety, resentment); or death (Transplant Living, 2011).

operate entirely independently of the broader economic market of a nation. Debates about the merits of financial incentives for organ donation continue to surface in response to the scarcity of transplantable organs.

### **Why is “scarcity” so ubiquitous and what are the implications of its use?**

As evidenced above, the discourse of scarcity is central to discussions of organ donation and transplantation. The term “scarcity” typically refers to the shortage of transplantable organs in relation to the increasing demand for them, but a broader definition can also extend to include the scarcity of: willing donors, dialysis machines, medical staff and equipment, funding, education, care, services and supports, and transplant facilities. In *Scarce Goods: Justice, Fairness, and Organ Transplantation*, Koch (2002) discusses the concept of lifeboat ethics and how this approach is currently applied in cases of allocating and transplanting human organs. “Lifeboat ethics” is a term that has been used historically to refer to the dilemma of determining who will live when not everyone can live. Or rather, “[w]here scarcity reigns, who is to be sacrificed so that others might live?” (Koch, 2002, p.5). The term has come to describe a class of problems in which, “the presumably inflexible limits of existing resources are assumed to create a special circumstance in which otherwise sacrosanct principles are greatly relaxed if not wholly in abeyance” (ibid). This presents the idea that crisis situations are times and/or spaces of ethical exception. It is for this reason that Koch argues that conditions of scarcity are where issues of justice “acquire their bite” (2002, p.21).

Elster (1992) argues that there are at least three distinct degrees of scarcity: natural, quasi-natural, and artificial. Natural scarcity exists when supply is absolutely limited. His example is all of the existing signed paintings by Rembrandt – their supply cannot be increased with government or social intervention. The shortage of transplantable organs can be considered a form of quasi-natural scarcity because, though the scarcity is real in virtue of the limited numbers, it could be remedied by “efficient, though perhaps socially unacceptable, measures” (ibid). This scarcity does not exist independently from social structures and policy decisions – or from the capabilities of

biomedical science and practice. Koch (2002) argues that the U.S. health care system serves as an example of artificial scarcity because coverage is denied to over 40 million Americans, but this is not the result of a shortage of resources; universal health coverage could be provided simply with a change in policy.

The organ scarcity discourse can be employed as a rationale for shifts in transplantation policies and practices, to encourage donor registration, to outline and project health care options, and to frame debates about organ allocation. For instance, the *Toronto Star* series on organ donation repeatedly emphasized the 229 people who died in 2010 waiting for organ transplants that never came (Ogilvie, 2012). Similarly, a report written for the British Columbia Transplant Society claims that by the year 2040 there will be a 221% increase in the need for organs, leading to a 291% increase in the transplant gap between supply and demand (Baxter & Smerdon, 2000). Organ transfer is frequently framed in these market terms, as a matter of scarce resources, and yet the concept itself is seldom queried or empirically investigated. Several thinkers (Scheper-Hughes, 2006; Lock, 2002a; Koch, 2002) claim that organ scarcity is simply a matter of perspective. These thinkers respectively argue that the issue is not that there are too few transplantable organs, but rather, that the pool of potential recipients has become too large. The focus on the need to increase organ donation limits discussion of why transplants are becoming increasingly routine and required in the first place. Scheper-Hughes (2006, p. 49) claims that the very idea of organ or kidney scarcity is what Illich (1992) would call “artificially created need.” She argues that it is a need that is, “invented by transplant technicians, doctors, and their brokers, and dangled before the eyes of an ever expanding sick, aging, desperate, and dying population” (2002, p. 49). In other words, this is not a demand that naturally emerges from patients. For most of us, it would not be intuitive to expect someone else’s body part because our own is failing – though this may increasingly be the case. Instead, this desire results from the hope for improvement or extension of our lives. A disproportionate focus on scarcity also leaves out a great deal of nuance. It focuses on individuals, but only insofar as they are organ donors or transplant recipients. Scholars engaging in the critical literature on organ

transfer are able to talk about these individuals without isolating them from the context(s) in which they live.

Additionally, with a focus on scarcity alone, we fail to recognize that this problem also results from biotechnological advances. In other words, without surgical advances, dialysis machines, cyclosporine, and other anti-rejection drugs, transplants would not be possible and no such organ shortage would exist. The expansion of transplant recipient eligibility criteria over the last 20 years also means that the donor pool could never meet such a demand with our current means of organ procurement. Infants, patients over 70 years old, patients with comorbidities, and patients who have had transplants that were rejected are now eligible for the kidney transplant wait list. The surge in kidney failure in Canada is credited to growing rates of diabetes and vascular disease, caused primarily by high blood pressure (Picard, 2011). These conditions are attributed to the population aging as well as rising rates of obesity and hepatitis C (Lock & Nguyen, 2010), but can also be understood to reflect the social determinants of health (ibid, 2010; Dinca-Panaitescu et al., 2011). According to Lock & Nguyen, “these are diseases associated with poverty and social inequality, many of which could be prevented” (2010, p. 235). To look at transplantation in isolation from the social, political, economic, environmental, and cultural contexts in which people become ill is to ignore the origins of organ scarcity. Additionally, if someone’s health is poor and her kidneys are failing in contexts of poverty, social exclusion, or inadequate living conditions, it is too limited (and somewhat bizarre) to focus primarily on kidneys as the resource necessary for remedying her situation.

Despite the criticisms of the above-mentioned thinkers, my findings suggest that the language of scarcity remains dominant in discussions of organ transfer in Canada. Repeated emphasis on the scarcity of human organs and the number of people dying each year, month, or day on the transplant wait list paints the picture of a desperate organ crisis in Canada and abroad. With a crisis in mind, many may feel that desperate times call for desperate measures. Policymakers and practitioners are increasingly entertaining ideas regarding models of organ procurement that have previously been dismissed or deemed

unethical. For instance, L.R. Cohen (1991) infamously advocates for a market in human organs by claiming that he is privileging the living rather than the dead. Cohen also supports organ procurement from death row prisoners and proposes that suicidal people be encouraged to kill themselves in ways that leave their organs viable for transplant (Joralemon, 1995). Joralemon notes that such proposals used to be quickly dismissed, but they are increasingly (and more so since he wrote the piece) being entertained in academic journals and popular media. Similarly, transplant tourism and organ trade and trafficking are “fueled by the simple calculus of ‘supply and demand’ and by the specter of waiting lists, organ scarcities, and organ panics” (Scheper-Hughes, 2006, p. 49).

Even unpaid organ transfer can discriminate against vulnerable individuals and populations. For instance, Koch (2002) claims that the scarcity of organs is exacerbated and even created by racial and regional inequalities in the American health care and transplant systems<sup>9</sup>. Similarly in Canada, Special Olympic gold medalist Terry Urquart was denied access to the heart transplant eligibility list in Alberta on the grounds of his having Down Syndrome (ibid). People with disabilities and other intersections of marginality are often discriminated against when ‘scarce organs’ require allocation (Ne’eman et al., 2013).

What is also, though less often, discussed in this context is the scarcity of funds and resources in our eroding universal health care system and the implications that such scarcity has for policies and treatment practices. Within Canada, our publicly funded health care system is constantly under threat by those who advocate for lower taxes, privatization, and reduced social services (Armstrong, 2001). Discussions around health care are framed in market terms of supply and demand. Provincial governments struggle with long wait times for health care services, as well as increasingly limited funds, staff, and resources. Currently, one in ten Canadians lives with some level of kidney disease and the number continues to rise (BC Transplant Society, 2013d). In British Columbia, kidney disease is one of the province’s fastest growing illnesses and over the past ten

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<sup>9</sup> Koch argues this with reference to individuals who are disqualified from donor and recipient candidacy due to health problems associated with poverty, and a lack of health care insurance for vulnerable and marginalized populations.

years, the number of British Columbians affected by the disease has increased by 60 percent (ibid). Dialysis treatments cost the government nearly ten times as much as kidney transplantation – about \$2.2 billion annually – and with about 38,000 Canadians living with kidney failure (Picard, 2011), it becomes clear as to why the shortage of transplantable organs creates such a crisis. Dialysis treatment is about \$50,000 - \$60,000 per patient annually, whereas a kidney transplant costs the system about \$23,000 for the surgery and then \$6,000 annually for anti-rejection drugs (ibid). From political and economic perspectives, increasing the number of transplants performed is highly desirable. Thus, policy discussions around transplantation involve, “the entwined issues of financing, distribution, justice, and the rationing of health care” (Rettig in Koch, 2002, p. 55).

Upon engaging with these works, I was left with the understanding that scarcity – that is, the perceived and actual shortage of valuable resources – is central to discussions of organ transfer. I argue that scarcity is fundamentally a matter of health equity. That is, the allocation and distribution of scarce lifesaving resources are issues of social justice because they require determining who will live when not everyone can live. These deliberations do not take place outside of the social systems that we experience every day. Additionally, the procurement of organs requires sacrifices on the part of donors. When the bodies of some individuals are used to benefit others, it is important to question: whose bodies? Which men and which women? Individuals who face various forms of discrimination are not immune from prejudice in the medical arena, despite efforts to minimize or eliminate bias. Barriers and discrimination may also result from systemic structures, rather than individual prejudices.

### **To what extent are political and economic context(s) considered in organ transfer research?**

Political economy analyses are not especially common in organ transfer literature. However, as a theoretical framework, political economy is particularly useful in identifying unequal and inequitable distributions of resources; matters of access, power,

and health outcomes; and the points of intersection between health, politics, economics, and the social (Coburn, 2006). Few of the critical perspectives on organ transfer include an explicit political economy approach, but several authors include consideration of the impact of political and economic contexts.

In “The Political Economy of Presumed Consent,” Healy (2005) uses a comparative social analysis to investigate the sources of variation in organ procurement rates among 17 OECD countries. His intent is to determine whether or not presumed consent (opt-out donation) models are responsible for higher procurement rates in some countries. He found that the effect of presumed consent is actually fairly weak and that the legal system is more a marker for other organizational practices, rather than a causal mechanism. He notes, “procurement takes place within societies that have institutionalized different relationships between the individual, the market, and the state” (ibid, p.1). Healy situates his findings within a welfare state typology and reveals that while organ donation often appears to be a private gift exchange independent of the economy, the methods of procurement are institutionalized in fluid, middle-range organizational practices such as organ procurement organizations and strategies, or hospital investments and policies. Citing Titmuss (1971), he notes an explicit connection between forms of welfare capitalism and the social organization of the gift relationship. This work nicely illustrates how a political economy analysis can facilitate a deeper understanding of organ transfer at the macro and meso levels of practice. In other words, Healy not only identifies the significance of the type of welfare state and the broader systemic structures, but also emphasizes that organ procurement and exchanges must be examined at the institutional and organizational levels of practice where they occur. While this account of the relationship between the health care system(s) and the broader economy is valuable for understanding and contextualizing organ procurement, it still overlooks the personal experiences of individuals within these systems.

Hamdy (2008) shifts from the broad, comparative level and uses micro level ethnography to discuss political etiologies in an Egyptian dialysis ward. Through the use of individual narratives, she describes how patients living in poverty experience their

illnesses in terms of the country's larger social, political, and economic ills – an implicit political economy analysis. The patients reveal a lack of trust in the medical system and state resources on which they rely for their dialysis treatments (less than 3% of dialysis patients in Egypt receive kidney transplants). Patients describe “the breakdown of their kidneys as a direct outcome of the breakdown of the welfare state” (ibid, p. 1). These individuals are extremely aware of the limited resources available and the cost/benefit analyses taking place about their treatments. Many object to the prospect of a transplant if it means subjecting a healthy loved one to surgery in the unreliable health care system (ibid). Hamdy (2008) illustrates that social and political transformations can shape our views of our bodies and our experiences in/of them. She eloquently notes:

“[u]nderstanding disease in terms of social inequality has particular salience in the realm of organ transplantation, a practice that presumes illness to be located discretely in particular body parts that can be isolated, exchanged, and replaced. Anthropologists have demonstrated that biotechnological approaches to health more often exacerbate than erase social divisions, disproportionately intervening in diseases that are often themselves the end result of gross social inequalities” (p. 563).

Hamdy's micro level analysis permits a qualitative, nuanced account of the type of phenomena that Healy's macro level discourse identifies. Not only are her methods effective for generating insightful data, but her understanding of the location(s) of health resonate with my theoretical perspective on health – and with my critique of organ scarcity discourse. In other words, she acknowledges the decontextualization and depoliticization of kidney failure and the limitations of pursuing kidney transplant as its primary remedy. It is because of this larger scale understanding of health that, throughout this dissertation, I draw attention to the shortage of resources other than kidneys. I am not only concerned with individuals' biomedical, quantifiable, functional health; I am also concerned with them enjoying qualitatively healthy lives.

Lock also speaks about the structural conditions that shape organ transfer practices. In her work with Crowley-Matoka (2008) on cultural and familial contexts for organ transfer, she identifies intrafamilial ethics that influence donation decisions and points out that the “moral economy of health care and aging is heavily weighted in favour of life extension at any cost” (for recipients), making organ transfer the “ethical

imperative” for potential donors and “difficult to refuse” for potential recipients (p. 155). The authors point to local laws and institutions that affect organ procurement. For instance, in North America there are now fewer fatal car accidents because of improvements in vehicle safety devices, drinking and driving legislation, and seat belt usage, and there are more effective trauma units that can help prevent brain death. Paired with an aging population, this leads to the high demand and low supply of transplantable organs. In Mexico, Crowley-Matoka’s (2008) research reveals that, “the political economy of health care in Mexico significantly impedes the diagnosis and support of brain dead patients in practice” (p. 156). Scarcity of the appropriate hospitals, staff, and resources – coupled with great skepticism and mistrust in the Mexican government – create barriers to a functional organ transfer system.

Similarly, Lock (2002a) has noted that when ventilator support of a brain-dead patient is deemed ‘wasteful,’ and continued care deemed ‘futile’, it is not difficult to imagine that economic and resource based-factors may make the body of a legally brain dead person appear to be of better medical use elsewhere. She notes that physicians in Japan are not as likely to employ this type of utilitarian reasoning. She credits this to the fact that, “commodification of the human body in the name of scientific progress has a long history in Europe and North America but a relatively short one in Japan” (ibid, p. 9) and their health care system reflects this. Similar to the work of the authors mentioned above, Lock’s work reveals the extent to which the political/economic structures, and social organization of a nation shape its organ transfer practices.

In this field of study, when Canada is mentioned at all, it is typically lumped with the United States. This is likely because of Esping-Andersen’s (1990, 1999) welfare state typology, the countries’ proximity, and their other cultural similarities. However, because of the differences in their politics, policies, health care systems, immigration patterns, and other complex social organization factors, there are some interesting and important differences between the two countries that are worth exploring. Dickenson (2008) touches on this when she notes that perhaps the US is the furthest developed in terms of commodifying bodies because of its health care system, “[s]ince US residents with no

health insurance regularly have to make decisions about how to set the value of their health against their cash, Americans already think in terms of their body parts as ‘worth’ dollars and cents” (p. ix). Greater attention to Canada’s unique organ transfer context, needs, and practices is required.

### *Gaps in the literature*

Despite the high quality of the critical literature about organ transfer and scarcity, there are several areas that remain under-researched. For instance, there is little discussion about those living in rural areas. There is some quantitative work reporting on access to transplants in rural Canada, but there is not a great deal of qualitative or ethnographic research on the matter, or its complexity. This is noteworthy, given that between 19 -30% of Canadians are formally defined as living in rural Canada (Kulig &William, 2011, p. 2) and rural residence is considered a determinant of health. Individuals in rural and remote regions are affected by different geographical considerations and are presented with different renal care options than their urban counterparts. Issues of kidney scarcity may manifest differently in contexts where other forms of social and/or material scarcity are present.

There is also little literature about the experiences and perspectives of those on kidney dialysis. In British Columbia, kidney transplant wait list candidacy is calculated from the time that a patient begins dialysis treatment. As a result, dialysis is the lived reality for those awaiting and/or rejecting transplants for many years. During this time, patients are often depicted as desperately waiting for transplants without much discussion of the nuances of their day-to-day lives. We seldom hear about those who refuse transplants and their rationales for staying with dialysis or conservative care. While we often hear about the perspectives of transplant surgeons and recipients, we seldom encounter the narratives of family members who provide unpaid care for renal patients, of dialysis nurses, and of social workers. These individuals also face kidney scarcity from the perspective of the frontlines.

Feminist political economy analyses are seldom explicitly applied to the issue of kidney transfer in Canada. The absence of a feminist political economy perspective on kidney transfer is significant because this framework has the capacity to provide rich insight into the impact that gender, work, scarcity discourses, social location, and geographic location have on kidney health and experiences of renal failure and treatment. Such insight is incredibly valuable, given the equity concerns identified by critical organ transfer scholars earlier in this chapter. Gender, race, class, and geographic location play a large role in shaping renal health and health care. For instance, up to 30% of Canadian dialysis patients are living in poverty (Kidney Foundation of Canada, 2014) and people of non-Caucasian ethnicities (First Nations, Asian, South Asian, Pacific Island, African/Caribbean, and Hispanic) are at higher risk for kidney disease due increased rates of diabetes and high blood pressure (ibid). In fact, the risk of end stage renal disease is 2.66 times higher for Aboriginal Canadians than for non-Aboriginal Canadian adults (Samuel et al., 2014).

Sex and gender – categories that very much shape the way we experience the world – are rarely explored in discussions of kidney transfer in Canada. According to the policy of Health Canada, gender is one of the 12 determinants of health (Public Health Agency of Canada, 2010) and merits special attention in health research. It is important to consider gender in the context of kidney transfer because gender informs our social interactions, our identities, our health-seeking behaviours, our interactions with the health care system, our paid and unpaid work, as well as the care that we provide and the care that we receive. Socially constructed concepts of masculinity and femininity – and the work that is deemed appropriate for each gender – expose women and men to different, gender-specific health risks. For this reason, feminist political economy is just as important for understanding men’s realities.

### **Feminist political economy as a research methodology**

#### *Understanding feminist political economy*

Feminist political economy serves as the epistemological perspective – that is, the way of knowing and understanding the world – that is used in my research. It was used in designing the research (selecting the appropriate research methods, developing the research questions, participant selection, crafting the interview protocol) and in the theoretical analysis of my findings. This approach has its roots in Marxism and class-based analyses of systems of oppression. Feminist political economy emerged from second wave feminism in the 1960s-1970s in response to political economy analyses that examined the formal labour economy to the neglect of the informal, domestic sphere and its social, political, and economic implications. This approach revealed that it is inadequate to analyze capitalist class and social structure without examining gender, unpaid household labour, or the family structure (Mutari, 2000). In other words, the economy of reproduction – childcare, domestic duties, and work traditionally done by women – is just as important to examine as the formal economy of production. Traditional Marxist and early political economy work will have different implications for women than they will for men of the same class. Similarly, discussions of paid childcare or housekeeping will have different implications based on race (Arat-Koc, 1992). As Vosko (2002) illustrates, Canadian scholars (e.g. Armstrong & Armstrong, Connelly, Cohen, Luxton, Miles, MacDonald, and Fox) have played a central role in the evolution of feminist political economy.

Vosko (2002) claims that, through the works of these scholars, the field has undergone four phases over the last 30 years. These include raising the issue of gender blindness; “level of analysis” debates; theoretically grounded applied case studies; and, most recently, intersections of gender with other forms of marginalization. More succinctly, feminist political economists have been influential in identifying the social construction of gender, its varied cultural and historical meanings, its interactions with race and class, and its implications for different modes of social relations (Mutari, 2000).

*Structure vs. agency*

Feminist political economy research typically involves a project of contextualization and exploring the tension between structure and agency. This tension deals with the notion that individuals make choices about their lives and their health, but not within social, economic, or political conditions of their choosing (Armstrong, 2001). The tension addresses macro and meso level institutions, as well as the more abstract systems and regulations that structure our lives and the opportunities available to us at the micro level. It draws very much on the historical aspect of political economy work, which situates individuals in particular social locations, relations, discourses, and understandings of the world (ibid). Feminist political economy analyses also consider who benefits from, and who is harmed by, particular arrangements (Doyal, 1979).

Feminist political economy highlights the importance of women's agency within existing structures and emphasizes that understanding these structures and finding opportunities for action are the most effective ways to create change:

“[a]utonomy signifies the capacity and freedom to decide, to give one's opinion, and to act. It is the result of a process of humanization of relationships previously based on subordination, oppression and domination. Autonomy, then, signifies the authentic possibility of a woman to define herself for herself, and by herself, and not as an appendix of others” (Inter Pares, 2004, p. 2).

Feminist political economists also take a critical perspective in which health is viewed as inherently political in nature. According to Bambra, Fox, and Scott-Samuel (2005), health is political because some social groups have more of it than others, because its social determinants are amenable to political interventions, and “because the right to ‘a standard of living adequate for health and well being’ is, or should be, an aspect of citizenship and a human right” (p. 187). As a result, studying kidney transfer from a feminist political economy perspective requires studying political decision-making and the location(s) and distribution of power.

This broader understanding of health acknowledges that health is largely socially and economically determined. In other words, factors such as age, sex, gender identity, race, ethnicity, income, employment status, housing, geographic location, socioeconomic status, immigration status, Aboriginal status, disability, education, and countless

intersections thereof create unjust and often avoidable inequities in health (Hankivsky & Cormier, 2009). The roots and the intersections of these inequities are significantly under-acknowledged in dominant health and political discourses. With a more contextual approach, health is not simply located in doctors' offices, hospitals, other medical institutions, fitness centres, and nutritionists' offices. Instead, health is located in families and communities, in public and private spaces, in boardrooms, government offices, courtrooms, policy documents, classrooms, prisons, back alleys, and many other important, but often overlooked spaces. It is this broad, biopolitical definition of health that I used when conducting my research.

Another way that this tension between structure and agency manifests in the political economy of health is through the assigning of responsibility for health (Doyal, 1979). In neo-liberal societies, responsibility for health and well-being is typically placed on each individual, rather than on their governments and communities to provide the conditions that will allow health to flourish. Each person is expected to adequately educate herself about healthy and risky behaviours and then make responsible choices regarding diet, exercise, sexual activity, hand washing, doctor's visits, and so forth. This position assumes, of course, that everyone has access to this information, that they will understand it, that they have the resources required to access these choices, and that they will be risk averse and 'rational' in their decision-making. This notion is certainly challenged when I discuss my participants' social locations and living conditions.

Most feminist political economists frame matters in terms of collective well-being and treat health and prosperity as collective aims rather than solely individual ones. This communal approach acknowledges that our fates are intertwined and that in many ways, the health of the people who make up a nation is reflective of the health and well being of that nation as a whole. For instance, rather than question why individuals choose not to exercise often enough or eat healthful foods, we might instead question the type of society in which so many people have difficulty doing those things. This is not to alleviate all of the responsibility that individuals have for their respective health, but to frame it within a culture where the distribution of health, education, and prosperity is

vastly inequitable. In other words, the individualistic approach to health and governance is based on the belief that there exists a level playing field on which each person has equal opportunities to be healthy and/or successful. The collective approach recognizes this as mythical and seeks to make it a reality.

### *Theory in action*

In her influential work *The Everyday World as Problematic: A Feminist Sociology*, Smith identifies the extent to which women have historically been excluded from the making of culture and proposes a feminist methodology for performing a more equitable form of sociology. She (1987) claims that to know a society through sociology has traditionally been “to take on the view of ruling and to view society and social relations in terms of the perspectives, interests, and relevances of men active in relations of ruling” (p. 3). Her account involves exposing the subtexts of gender and class in the relations of ruling and then developing an approach that examines the organization of societies from “where we are actually located, embodied, in the local historicity and particularities of our lived worlds” (ibid, p. 8). Applying this lens to health and policy research can mean identifying and addressing gender-based inequities, offering context and narratives to accompany existing forms of data, and using experiences of the everyday world as the basis for our analyses.

Smith’s work reinforced the use of applied case studies in feminist political economy research. She problematizes not only the limited scope and perspective of what is often researched, but also how data are collected. She unpacks the observer/observed power dynamic in social science research and reverses the role of expertise (1987, p. 111). In other words, rather than presume that the academic interviewer is the expert who requires testament from a person with experience in the area of research, Smith would assume that the person living in the given conditions is the expert on the matter and should be viewed as sharing her wisdom with the interviewer. Smith’s contributions have been extremely valuable for inclusive social science research and for my own research design and practices.

I chose to use feminist political economy as a theoretical framework for this research not only because I thought that its application would make for an interesting dissertation, but also because it resonates with how I actually view the world. With a feminist political economy perspective, I chose to look at people's everyday personal and professional lives. I treated participants as the experts on the topics discussed and have written myself into the project in terms of my experiences and my observations. I include the contextual dialogue for many of the selected quotations as a reminder that these quotations arose in the context of specific conversations. I then consider these personal narratives in terms of how they relate to or reflect broader systems and structures, and the ways in which any inequities or challenges resulting from social determinants can be meaningfully addressed through changes in policy and/or practice. Because I used feminist political economy as a theoretical lens, it drove the questions that I asked and, in turn, the types of answers that I obtained.

## **Conclusion**

In this chapter, I have discussed the critical organ transfer literature, as well as the social, political, and economic contexts for the practices of organ donation and transplantation. I have identified some of major theoretical issues and debates in this field of study, paying special attention to what it means to exchange human organs in a neo-liberal context and the critical use of "scarcity" in organ transfer discourses. I have highlighted the minimal qualitative Canadian content on organ transfer and the absence of attention to rural and remote locations.

After reading Hamdy's piece about Egyptian dialysis wards, it was unclear to me how rural Canadians on dialysis might respond to her questions. Would Scheper-Hughes' polemical concerns about exploitation be relevant in this context? Are the Canadian and British Columbian governments making policy decisions in response to the perceived kidney crisis? Would Joralemon's observation about ideological immunosuppressants resonate with how kidney donation and transplant are represented and promoted in

Canada? With the mainstream media serving as opinion leaders on this issue, it is important to examine the narratives they use to shape their message(s).

The discourse of a severe shortage of these critical lifesaving resources can create a rationale for previously unacceptable forms of organ procurement. This discourse also ignores contextual elements of our health and heightens the possibility for inequity in organ distribution. Little is known about how and to what extent scarcity functions in Canadian policy and practice because the concept is seldom scrutinized and the majority of the research on this topic comes from, or refers to, the United States. For these reasons, I designed the research project discussed in the following chapter. In Chapter 2, I outline the qualitative methods used in this research. I discuss the processes of site and participant selection as well as the strategies for data collection, coding, and interpretation.

## **Chapter 2: Research Methods**

In Chapter 1, I established that organ scarcity remains the dominant discourse in organ transfer literature. I suggest that this understanding of scarcity has been somewhat manufactured, decontextualized, and depoliticized. This discourse is largely disconnected from the everyday experiences of patients and their family members and typically overlooks matters of inequity and social/distributive justice. Drawing from the theoretical content reviewed in the previous chapter, and the research gaps that were identified, I designed an explanatory case study (Yin, 2009) to query the how organ scarcity discourse informs kidney transfer policies and practices in a rural Canadian setting and the implications that these policies and practices have for the lives of those involved. In other words, this study presents a case of how particular policy decisions and institutional/organizational systems influence renal replacement needs and treatment choices. This type of case study was appropriate given that my research questions took the form of “how” or “why” queries, I had a focus on contemporary events over which I have no influence, and I wanted to directly observe the events in question and speak with the people involved in renal care. A strength of the case study method is its ability to deal with a range of forms of evidence, such as documents, interviews, and observations (ibid). Additionally, I wanted my findings to be generalizable to theory, rather than to populations or universal claims (ibid).

In this chapter, I outline the research questions and the methods used for conducting my research and interpreting my findings. Issues of feasibility, richness of data, and relevance to the research questions determined the site selection and the qualitative methods used. Critical ethnography, via in-depth interviews, and document analysis were the methods used to perform this project. In what follows, I will explain my decision to use these approaches, and outline in greater detail how exactly the study was designed, performed, and interpreted.

### **Research Design**

From September 2012 until June 2013, I resided in a remote and rural town in Western Canada. This experience illuminated for me the ways in which rural communities are dynamic, can be very different from urban Canadian centres, and present different conditions and supports for health and well-being. I quickly became interested in conducting a case study in a rural context. However, organ transplantation does not take place in rural or remote Canadian cities. Transplant recipients are required to temporarily or permanently relocate to larger urban centres where there are transplant teams and facilities, and adequate follow up care is available. In designing my study, I wanted a relatively small sample of participants with whom I could have lengthy, more engaged discussions.

My focus was narrowed to address kidney transplants specifically. This decision was made because kidney transplantation is relatively common, because patients often know their living donors and this introduces interesting social dynamics, and because hemodialysis wards are accessible spaces where a number of people waiting for transplants are congregated. In this context, the focus on kidneys meant primarily addressing issues related to dialysis, transplant, chronic kidney disease prevention, and unpaid care work provided by family members. The project extended beyond kidney transfer to include renal care more generally. I wanted to know if and how scarcity manifests in the lives of renal patients in this region. “Scarcity” was used to refer to the shortage of kidneys, funding, staff, services, care, equipment, and other resources. The case study provided examples of making do with limited resources. It also provided real life examples of how the social determinants of health (particularly geography, gender, class, Aboriginal status, and working conditions) influence renal care and kidney transfer practices and opportunities. Or, from a feminist political economy perspective, how power, resources and social relations shape the context for kidney transfer. By hearing specific stories of people’s lived experiences, I was better able to understand how the system serves those in marginal locations and to identify areas in need of greater attention.

I decided to conduct my research in a town in British Columbia that is both rural and remote. For ethical reasons discussed below, the specific site of study will remain confidential, but some information about it will be provided in the following chapter. The dialysis clinic's proximity to my place of residence made the study feasible – the importance of which I cannot overstate. Aside from relatively close proximity, this site was desirable for recruitment for several reasons. First, as a rural and remote town, residents experience a shortage of services and resources that are more plentiful in urban centres. For example, retaining dialysis nurses – many of whom come to the town only temporarily with partners or spouses who are in the resource industry – can be a challenge. Rural and remote places are also typically under-represented in health services and policy research. I considered doing a comparative study with an urban area, but the cost and required travel time made that unfeasible. I decided instead to focus on the rural locale as it is, rather than in contrast to an urban centre. In the end, I think that this decision was beneficial in allowing me to see the remote region in its own context, rather than how it is perceived in comparison to a more resource-rich location.

I began by establishing a relationship with the head nurse at the satellite community dialysis unit. I visited her in person and explained my project. She quickly became my key informant and gatekeeper for the remaining months of the study. I informed her that I was looking to interview roughly 30 participants, primarily dialysis patients (~10), transplant recipients (~5), and related health care professionals (~10), as well as some family care providers (~5). The final sample, discussed below, is actually very close to these targets. I was hoping to recruit a mix of people who had both positive and negative experiences with the renal care system. Fortunately, the sample that I ended up with included a diverse array of experiences and perspectives.

Having worked in the region and the field for over 20 years, my key contact was able to, at times, paint a broader picture of the issues than I was able to capture in the snapshot of time that my study covers. Using purposive sampling – that is, sampling of a particular population because of the research objectives (Creswell, 2009) – she asked past and present patients if they were interested in and comfortable with speaking to me and

put me in contact with the majority of my participants. Snowball sampling – that is, when existing participants in the study seek out new participants (Bryman & Teevan, 2005) – was also used once some patients and health care professionals spoke with one another. Allegedly, there is a:

“tension between those who espouse a rather pure type of ‘theoretical’ sampling, designed to generate theory which is ‘grounded’ in the data, rather than established in advance of the fieldwork (Glaser and Strauss, 1967; Strauss and Corbin, 1990), as opposed to those who promote forms of ‘purposive’ sampling suitable for qualitative research which is informed a priori by an existing body of social theory on which research questions may be based” (Curtis et al., 2000).

I chose to use purposive sampling in order to confirm and/or extend feminist political economy theory, rather than attempting to create an entirely new theory from my data. In short, this sampling strategy was relevant to my theoretical framework as well as my research questions.

### *Research Questions*

My preliminary research on the topic had painted a picture of a kidney shortage and crisis situation across Canada. I suspected that this was not the entire story, but was also interested in how this lack manifests itself in a remote location where other forms of social and material scarcity are apparent. My central and corollary research questions were:

- 1) How does scarcity function in the organ transfer practices, policies, and experiences of residents of this region?
  - a) How do dialysis/transplant patients, their unpaid care providers, and health care professionals experience scarcity?
  - b) How have local and provincial policies responded to the notion of increasing kidney scarcity?
  - c) Do constructs of class, race, gender, disability and intersections thereof limit access to scarce goods? How does location of residence impact one’s participation in dialysis and kidney transfer?
  - d) What is the relationship between the concept of scarcity and the commodification of kidneys? What are the attitudes towards transplant tourism of those who already have to do large amounts of traveling for their care?

- 2) How is scarcity defined, utilized, and represented (in media, policy, academic literature) and, considering it as active discourse, what implications do these representations then have for policy, practice, and personal experience within the system?

Qualitative research methods are often used in order to understand how experiences, attitudes, and life circumstances can affect people's health needs and behaviours. These methods can arguably be seen as a more organic form of data collection, since they involve observing and documenting the experiences of individuals. Two strengths of this method include the depth of understanding that it permits and the flexibility of the research design to accommodate changes in the process or the findings (Creswell, 2009).

Qualitative methods were chosen for this project because I wanted to understand the views and experiences of particular individuals and how these exist within the structure of the system(s). These methods were appropriate for obtaining the contextual, rich, descriptive, and relevant data that was required to address my research questions. I was not looking to quantify or measure the experiences of scarcity, as there has already been sufficient research outlining the need for transplantable kidneys and the shortage of staff and health care resources in rural regions. In other words, I was more interested in exploring the stories of scarcity than in reinforcing its scope. In large-scale quantitative inquiries, individuals (particularly individuals who are marginalized or underrepresented) can be overlooked in efforts to treat the broader population. I wanted to understand the policies that govern kidney care and transfer, as well as the implications that these policies and procedures have for the lives of the people who have to interact with the system. Armstrong (2001) identifies the "richness" that comes from including narratives and emotion in health services research and utilization; "[f]or feminists, experience is both evidence and expertise" (p. 130). Given my academic background and training in philosophy and bioethics, a qualitative research design also better utilizes my analytical strengths and skill set. Some of the existing quantitative work on this topic surfaces in the literature review and document analysis portions of this project, so related numerical data are not entirely absent. I retained aspects of medical anthropology by writing myself into

the process, through the use of an ethnographic case study (Yin, 2009), and by developing some of the chapters around the most compelling narratives.

### *Critical Ethnography*

I investigated organ scarcity through the methods of critical ethnography and document analysis. According to Thomas (1993), “[c]ritical ethnography is conventional ethnography with a political purpose” (p. 4). Conventional ethnography utilizes field research to gain insight into the culture and meanings of a particular group and/or phenomenon. Critical ethnography is not at odds with traditional ethnography, “[r]ather, it offers a more direct style of thinking about the relationships among knowledge, society, and political action” (ibid, p.vii).

Critical ethnography typically takes the form of interviews and observational data (Creswell, 2009). This approach unites critical theory with ethnographic research and allows the researcher to situate his or her findings in a theoretical worldview. Theory informs the research design, interview guide, and analysis process. This is done so that the findings can be contextualized and the research problem can be addressed in meaningful and/or transformative ways. Soyini-Madison (2005) notes that the critical ethnographer “will use the resources, skills, and privileges available to her to make accessible—to penetrate the borders and break through the confines in defense of—the voices and experiences of subjects whose stories are otherwise restrained and out of reach” (p. 5).

The interview component of the project was not aimed at ‘truth-finding’ or gathering objective data. Rather, it was performed in order to understand the experiences of individuals who are faced with scarcity in kidney care at the ground level of care and the meanings that they attach to their experiences. Critical ethnography is not only critical of its findings, but also of its process. Qualitative researchers are increasingly encouraged to be reflexive about the biases and assumptions that they might bring to their work (Bryman & Teevan, 2005). I also had to be aware of my position in the process and the implications of the process itself for the data. For instance, despite an appropriate

introduction and the information provided on the informed consent form, one participant indicated near the end of the interview that he thought I was a physician. I clarified that I was not, explained that I was a PhD student in health policy, and he replied, “Oh... so you’re a nurse?” Despite further clarification, I walked away aware of the fact that his perception of me being a health care professional may have influenced the content and structure of his responses to my questions.

In qualitative research, neither the process nor the data are value-neutral. Soyini-Madison (2005) claims that doing fieldwork is a personal experience. This is not to discredit the validity of social scientific data, but rather, to recognize the human involvement in gathering it. By developing such a project, I recognized that I am, “inviting an ethics of accountability by taking the chance of being proven wrong” (Thomas, 1993). My research serves as a case study of a particular place during a particular period of time, investigated by a particular researcher. While it may not be reproducible, it does reflect the views and experiences of individuals immersed in this system during this time.

An excellent example of this method at work is Hamdy’s (2008) use of critical ethnography to discuss political etiologies in an Egyptian dialysis ward. As noted in the previous chapter, she interviewed dialysis patients and related clinical care professionals (nephrologists, urologists, and transplant surgeons) and outlines the ways in which participants’ discussions about the breakdown of their kidneys can be seen as reflective of the broader breakdown of the welfare state. Her work offers brilliant insight into the ways in which disease is treated as located in particular organs, bodies, populations, or systems. My work utilizes a similar approach to understand the experiences of patients and professionals, but includes transplant recipients, family care providers, policy representatives, social workers, and dialysis nurses. This was done in order to capture the experiences of those providing care and support work in the formal and informal systems. Care work is critical to health care and it is important to identify who picks up the slack when resources are scarce.

The interviews took place along with an analysis of related documents and reports. The use of multiple forms of data improves the credibility of the results and presents a more complex picture of the issue. This is a common way to ensure “validity” in qualitative research.

### *Document Analysis*

Document analysis involves a systematic review of text documents in order to gain insight on a particular program, institution, experience, or phenomenon. Atkinson and Coffey (1997) refer to documents as, “social facts’ that are produced, shared, and used in socially organized ways” (p. 47). By reviewing these ‘facts’, I aimed to gain a richer and more thorough understanding of how scarcity is discussed, represented, and utilized – as well as the structure of the renal care system in BC. According to Bowen (2009) document analysis serves several main functions: to provide data on the context in which research participants operate; to inform research questions and avenues to be pursued in other components of the study; to provide supplementary research data; to provide a means of tracking change and development; and documents can also be analyzed to verify findings or corroborate evidence from other sources. This method alone cannot reveal the lived reality of how the system functions, but it can provide important context and historical/supplementary data for the ethnographic component of the project. This element of the project allowed me to situate the events of the rural locale within the broader policy context.

The documents analyzed cover donor awareness initiatives, dialysis and transplant policies, and related practices. They include: The Kidney Foundation of Canada’s *Living with Kidney Disease* Manual, The BC Provincial Renal Agency *Organizational Structure and Function* report, the BC Provincial Renal Agency *Guidelines for Renal Programs*, the BC Transplant *Clinical Guidelines for Living Donor Kidney Transplantation Program*, the BC Transplant *Clinical Guidelines for Kidney Transplantation*, the BC Renal Agency *Guide to Dialysis Options in BC*, the BC Transplant Facebook site, the BC Renal Agency Facebook site, the Canadian Blood Services *Call to action: A strategic*

*plan to improve organ and tissue donation and transplantation for Canadians*, the BC Human Tissue Gift Act, and several other relevant documents. These documents were selected because they outline the structure of the system, the central values and priorities of the organizations, and the ways in which kidney health, treatment, and replacement are represented in this context. These documents were conceptually relevant and very accessible. All of the documents are publicly available and were retrieved from related websites. The documents were read and highlighted then later thematically coded by hand.

### *Photo Elicitation*

Initially, there was a photo elicitation component in the interview protocol. This consisted of five photos from the BC Transplant's 2012 "LIVE LIFE, PASS IT ON" organ donor awareness campaign. This campaign is featured on the organization's Facebook page and all of their donor awareness materials (pamphlets, posters, postcards, bookmarks, donor registration and reminder cards – all of which are available as part of a free mini-campaign kit that can be ordered from their website). Eva Markvoort and photographer Cyrus McEachern originally created this collection in 2007. Eva was a British Columbia resident, transplant recipient, popular blogger, and the star of an award-winning documentary *65\_RedRoses*, which tells the story of her battle with cystic fibrosis and her double-lung transplant. The images are of Eva and other BC transplant recipients. The photos are black and white with the organs that were transplanted painted onto their torsos in bright pink and blue. Eva's photo also features her bright red hair and lips. Generally, the models are Caucasian, fit, attractive, and relatively young.<sup>10</sup> One model has visible tattoos of the Canadian flag and a crucifix, and another has a tattoo of the cancer awareness ribbon. After Eva's death in 2010 at the age of 25, she has been featured as the face of organ donor awareness in British Columbia.

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<sup>10</sup>After the time of my study, a middle aged gentleman of Asian descent was added as the face of this campaign on BC Transplant's Facebook page.

I thought that these images might evoke discussion of who needs and who gets transplants, views regarding donor recruitment initiatives, and other topics related to the public perceptions of scarcity and sacrifice. This component was removed after it was piloted in the first five interviews. Neither health professionals nor patients said much about the photos and their inclusion was not eliciting information related to my research goals. Comments were generally along the lines of, “sure, this would probably grab your attention,” and did not extend much further, even with prompts. None of the people that I showed the photos to were familiar with Eva’s story. Additionally, as telephone interviews became more common, the photo elicitation became more challenging. In the end, the photo campaign became a part of my document analysis instead.

### **Ethics regarding the Site of Study**

Upon approval from my supervisory committee, my dissertation proposal was submitted to York University’s Ethics Review Committee for evaluation. This process required my completion of the “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans” course on research ethics. York’s Ethics Committee and the Faculty of Graduate Studies later approved my research proposal.

As Kulig and Williams (2011) identify, health research in rural and remote communities presents unique ethical considerations. In small communities, confidentiality and anonymity pose considerable challenges (ibid). Discussion of local narratives, events, or industries could present potentially identifiable information. Protecting the identities and stories of the participants is, of course, first and foremost. This context also presents a number of practical challenges for researchers. For instance, a number of researchers are wary of conducting research in rural communities in fear that they will not be able to publish their findings (ibid). Additionally, triangulating data with document analysis can mean potentially identifying regions, and yet too much distance from the details can mean losing the thick, rich, descriptive data that is central to qualitative research. De-identification “takes the focus off of the community, strip the stories from their origin and strips the experiences of research participants of their

reference to a concrete phenomenal world of specific contexts and history” (Kulig & Williams, 2011, p. 287). Therefore, a responsible and ethical balance must be struck between relaying the stories that participants wanted to share, and respecting the confidential and trusting environment in which they shared them. I have made every effort to achieve this balance, but at times, this was somewhat of a struggle. For instance, citing local news sources or reports meant either identifying the region or making the authors of these works anonymous – either one being somewhat of an ethical compromise. Under the advisement of my supervisory committee, I ended up handling this by citing the year of the publications and including footnotes to explain the omission of additional details.

By residing in a relatively nearby (~100km) town for the duration of the project, I developed an “ethics of familiarity” (Simpson & Kirby, 2004) with participants. Dialysis patients and staff frequently saw me at the clinic and my key contact came to know me fairly well. This also meant that I shared an understanding of particular challenges that participants discussed. For instance, there was a terrible snowstorm on the day of one particular interview and, knowing that I had driven for over an hour to get there, the participant spoke about the travel required for her care with comments to the effect of, “well, you know how it is here!” However, because I lived outside of their communities and only saw them in the dialysis clinic context, I had no overlapping role in participants’ lives that could create a conflict of interest or trust. Nor was any information informally collected from them.

Interestingly, many of the patient participants seemed unconcerned with anonymity. On several occasions I had to insist that we cover all of the informed consent form because people told me that they did not care what I did with their stories. Perhaps this is because renal disease and kidney dialysis treatments are not stigmatized in the ways that, say, mental illnesses or sexually transmitted infections are. In that sense, discussion of dialysis and transplant may be less sensitive than other forms of health research. Additionally, the main barriers, challenges, and negative perceptions that were discussed are fairly well known by those in positions of authority in the province; so

perhaps these participants were less concerned with their views being “out-ed.” While every effort has been made to keep their identities confidential, it was interesting to note that the sharing of their narratives seemed most important for many participants.

## **The Interview Process**

### *Recruitment*

In addition to the liaising done by my key contact, I placed posters in the dialysis unit in order to recruit participants. However, word of mouth was certainly more effective as a means of recruitment in this small town. I also sent out emails to a number of representatives from related provincial organizations (BC Transplant, BC Renal Agency, Kidney Foundation of Canada BC chapter, and others). Of these groups, representatives from two organizations got back to me and two individuals ended up following through and participating in one interview. Three nephrologists from the regional centre were approached in order to secure one interview. Interestingly, this particular nephrologist is the only one who has made it out to the community dialysis centre in person, though all of them have been invited and encouraged to visit. I interviewed all of the dialysis patients attending the clinic who were able to participate. There were no individuals who came forward for the study who were considered unsuitable participants.

Overall, 30 semi-structured, in-depth interviews took place in person (n=18) and via telephone (n=12) with individuals who have had direct experience as: hemodialysis patients at the community clinic (n=7), home-hemo (n=2) and peritoneal dialysis patients (n=4), kidney transplant recipients (n=4), family care providers (n=5), and related health care professionals (n = 10). This included nurses (n= 4), a nephrologist (n= 1), a transplant coordinator (n=1), social workers (n=2), and representatives from a related provincial organization (n=2). A couple of patients shared stories about their experiences on multiple types of treatment, so a single person may have counted as someone with experience with both peritoneal and home hemodialysis, or with both transplant and dialysis. In terms of sex: there were 9 female health care professionals and 1 male, 3 female unpaid care providers and 2 males, 2 female and 2 male transplant recipients, as

well as 5 female and 6 male dialysis patients. All but two participants were Caucasian<sup>11</sup>. Of the non-health professionals who identified their level of education, 4 participants had graduated from high school; 4 had completed some high school; 3 had completed elementary school; and 2 had completed only some elementary. Of the patients and family care providers who provided their age, 2 were between 30 – 45 years old, 4 were between 45 - 60 years old, 4 were between 60 – 75 years old, and 5 were over 75. Of the patients and/or family care providers who identified a political affiliation, 3 identified as Conservatives and 1 as a Liberal. Of the health care professionals who identified a political affiliation, 4 identified as New Democrats, 2 as Liberals, 1 as ‘left-leaning,’ and 1 as a Conservative.

This range of participants allowed me to explore the issue from the perspectives of various stakeholders. The participants are experiential experts on this topic, but their experiences and areas of expertise are diverse. This variety proved useful for comparing and contrasting perspectives. The inclusion of health professionals who have post-secondary education and have been trained in clinical settings also provided me with insight into the views of those who might be more familiar with academic organ transfer literature – or medical/health literature more generally – than the patient population in the region. By speaking with these 30 people, I was able to reach theoretical saturation (Glaser, 1992) for the central issues. In other words, the concepts and conceptual relationships that emerged were repeated enough times to solidify them as significant themes.

There were no incentives offered for participation, but I did make a \$500 donation to the dialysis unit’s charitable fund when the project was complete. Given that I had a limited budget and was well aware of the resource shortage in the unit, it seemed that a lump sum donation to the clinic would be of greater assistance than a token amount to individual participants. Donations to this fund go to support patient care needs in the unit. For example, one recent purchase was an ice machine. Patients receiving dialysis are

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<sup>11</sup> I have avoided mentioning the race of the other two people because, in a predominantly Caucasian community, this could potentially compromise their confidentiality.

fluid restricted, so they require ice chips to stay hydrated. Another major purchase that the fund made possible was a blanket warmer. This was an important contribution to the unit since patients spend an average of 12 hours per week sitting attached to the dialysis machines and this purchase contributed to their warmth and comfort during treatment. In short, this seemed like a valuable way for me to give back to the staff and patients at the unit.

### *Interview procedures*

All of the interviews began with reviewing and signing the informed consent form (Appendix I). This was done orally or via e-mail for the telephone interviews. The interviews were digitally recorded using an iPod and were later transcribed by a professional transcriptionist and myself. Participants also filled out a brief demographics survey (Appendix II) to supply me with additional context for their responses. Once again, this was done orally or via e-mail for those who were interviewed by telephone. My interview guides (Appendix III) were semi-structured and tailored to the appropriate participant groups: patients, kidney transplant recipients, unpaid care providers, and health professionals. The use of a semi-structured guide offered me the ability to follow themes as they emerged and follow up on them in later interviews until they reached saturation. Questions were designed to elicit participants' experiences with various forms of scarcity, their perceptions of scarcity, and their thoughts regarding how to remedy scarcity. As I gained confidence and experience with the interviewing, I consulted the guides less frequently and allowed the interviews to flow.

The interviews lasted between 30 and 90 minutes. For the in-person interviews, speaking with patients and family members while the patients were dialyzing was ideal, as they were at the clinic three to four times a week for roughly four-hour sessions. During this time, both patients and their drivers often get quite bored and were generally welcoming of the conversation with me. Interviews with dialysis patients were typically done at their bedside and interviews with family care providers, transplant recipients, and staff took place in the head nurse's office. A couple of family members preferred to speak

with me along with the dialysis patient. While they were quite candid about the system and their lives, the presence of the person that they provide care for may have limited the extent to which they articulated the emotional challenges of care work.

I provided the option of telephone interviews for several reasons. First, these interviews provided flexibility for individuals who were unable to get into town for reasons to do with their health or the weather. The interviews took place from January to June of 2013. There was a minimum of one foot of snow on the ground from the beginning of the study until late April and opportunities to avoid lengthy drives were appreciated by all. Second, telephone interviews worked well for those who were no longer attending the dialysis unit and would not necessarily be in town. This includes those on home hemodialysis or peritoneal dialysis and those who have received transplants. Lastly, the catchment area for this health region is geographically quite large. Telephone interviews worked for patients and health care professionals who do not work or reside in the town of the community dialysis centre. Several of the health professionals who I spoke with work in other parts of the province. Given that travel was one of the largest challenges and expenses discussed in the interviews, I did not want to unnecessarily impose that burden upon my participants – or myself.

### *Analysis*

As the study progressed, new themes emerged. For instance, I had not anticipated the extent to which the local resource extraction industry, notions of rural masculinity, and home hemodialysis would feature in this project. Once these themes became significant, I pursued them more in the conversations. Leipert et al. (2012) note that researchers of gender and rural health topics need to be responsive to unexpected findings. With the health care professionals, the conversations were somewhat more structured and centred on their professional experiences, policies, and the system. The conversations with patients and unpaid care providers were less structured and tended to be more about people's lives and their experiences with their illnesses and the health care system.

Interview transcripts were coded and critically analyzed using the constant comparison method (Glaser, 1965; Creswell, 2009). After reading over the interviews, I used coloured pens and highlighters to identify and associate repeated ideas. NVivo data analysis software was also used for second-round coding and for producing thematic reports of interview quotations. Categories and themes emerged and were organized into the chapters that follow. During my analysis and writing, I performed informal member checking. Member checking or “member validation” is done in order to, “seek corroboration or criticisms of the researcher’s account” (Bryman & Teevan, 2005). I discussed my findings with my key contact in a telephone meeting to ensure that she felt that my observations were accurate and did not identify any of the participants. This conversation centred on the main themes that I uncovered, my central claims, and the tensions that I identified. She will be provided with a copy of the full dissertation for review prior to its final submission. My key contact supported my analysis and her account confirmed a number of my findings. She said that several of my observations really resonated with some of her thoughts about the system, though they were expressed differently. She did not have any concerns regarding confidentiality. Member checking was also useful for noting the ways in which things had – and had not – changed since the time of the study.

### **Site of Study**

“The description of a landscape is never neutral; it is always infused with the perspectives and preferences of one’s guides” (Sutherns & Haworth-Brockman, 2012, p. 29). My description of the site of study is designed to provide a richer and more contextualized understanding of the findings. In an effort to be transparent, I acknowledge that this description comes with a feminist political economy perspective, with special attention paid to gender, work, politics, economics, and the implications that these systems have for everyday life.

As noted earlier, my study took place in a small town in rural and remote British Columbia. The town’s population is under 20,000 and has a primarily resource-based

economy. Much of the surrounding region is farmland. Historically, their elected representatives have been predominantly Conservative. This town offers a satellite community dialysis clinic for residents and neighbouring communities in a very wide catchment area. Patients who attend this clinic come from all across the region and have one-way commutes ranging from a 10-minute drive to a 4.5-hour drive. At the time of study, there were four nurses working at the clinic. Their experience in the clinic ranges from ~20 years to ~1 year. In what follows, this clinic will be referred to as the community dialysis clinic/centre. This clinic provides essential dialysis services, but for meetings with nephrologists, dieticians, social workers, pharmacists, an Aboriginal support worker, and other renal care services, patients must visit a full dialysis centre. The nearest full centre is ~450km away from the community clinic. This centre will be referred to as the regional clinic/centre. The regional centre houses the full renal care team and additional medical technologies. While I did not visit this site, I spoke with several health care professionals who are placed there, and patients told me about visiting that location.

The closest hospitals that perform transplants are in major urban centres (over 1000 km and over 500 km away, respectively). Patients and potential donors must visit these hospitals during transplant assessment and preparation. In order to visit the regional clinic and the transplant hospitals, patients travel by car, regional health bus, and/or plane. This varies depending on their age, mobility, finances, travel companions, the weather, and the urgency of their visits. Some patients I spoke with live right in town and can, for instance, pick up their medications at the local pharmacy quite easily. Others live on reserves without in-house heating or running water. So the accessibility of services and the conditions for care varied quite a bit. Travel to and outside of the community clinic town is often required for visiting family physicians, specialists, and for receiving specialized testing. These types of visits can become increasingly necessary and onerous as local residents age.

The natural resources located in this region also lead to living and working conditions that shape the health of local residents. The related industries very much

contribute to the culture and identity of the region (Fiske et al., 2012; Coward et al., 2005). The working conditions for those in resource extraction professions, the industry's impact on families and the natural environment, and the social transience of the local population all have noteworthy effects that are explored at greater length in Chapter 5.

### **Limitations of the Study & Research Challenges**

There are several limitations to this study. First, this case study presents a snapshot of a specific place and time. The documents that were analyzed and several of the interviews with health care professionals have painted a broader picture of the system, but my findings are still specific to this period. Several of the health care professionals noted that during the time I was there, the patient demographics were somewhat atypical. For instance, there were more elderly persons than they usually see at this particular clinic. One health professional said that young patients dealing with drugs and addictions is something that they see quite often, but there were no patients fitting this description at the time. As a result, this issue does not receive significant exploration in my study – however, it is discussed briefly when I address work in the resource industries. Several participants told me that the nursing situation at the time of the study was unusual. Generally, the clinic is under-staffed and nurses are notably over-worked. The nurses take on multiple roles and work long hours. The heavy labour was still an issue, but given the low number of patients and a relatively recent hire on the nursing staff, the nurses said that this was the first time that they could remember feeling as though there were enough hands on deck. During member checking with my key contact, I discovered that this had, indeed, changed. In late fall 2013, there was a huge influx of new patients and my key contact was juggling that alongside the training of new staff members. We had to reschedule our telephone meeting twice as a result.

Another limitation is the relatively small sample sizes. This can often be an issue in case studies more generally, given that there are only so many people at a particular organization to speak with. This is especially relevant in a remote location with a small population. It is unfortunate, for instance, that I was only able to speak with five family

care providers. The *extent* to which care work played a role did not become apparent until later in the study. However, theoretical saturation of this concept with participants from all roles and demographics helped to reinforce the challenges and necessities involved in this work.

Most of the health care professionals spoke about the overrepresentation of Aboriginal peoples in the renal care system. Though I touch on Aboriginal health issues in later chapters, this group is underrepresented in my study. This speaks to the nature of the clinic's demographics at the time of study, as well as the demographics of health care workers in the field.

Though I spoke with several kidney transplant recipients, I did not speak with any donors. This was partially due to the fact that they had not been patients at the dialysis clinic and my key contact did not know most of them very well. Additionally, the recipients who received a kidney from a relative spoke about how busy with work their donors were. I told two transplant recipients that I would happily speak with their donors, but never heard from them. Both of these donors work in the local resource industry and were not home or available all that often. For those who received kidneys from cadaver donors, my inability to speak with their donors is obvious. The donor perspective on scarcity – and on reducing it via kidney donation – is valuable and an interesting avenue for future research. However, in my study, there were so few accessible donors that I thought it best to focus on those who have ongoing engagement with the system.

## **Conclusion**

As the project and my analysis unfolded, I was confronted with my own biases about rural and remote places. I recognized my urban prejudice insofar as I had framed the project with a “deficit approach” – by focusing primarily on forms of scarcity in this region. I navigated this bias in the writing of the dissertation, by aiming to present a balanced and empathetic account of rural and remote living – with a focus on the agency, effort, and care that goes into living with limited resources and geographical isolation. I also acknowledge the benefits of rural and remote living expressed by residents.

The project evolved in ways I had not anticipated. I began rooted in medical anthropology literature. I was focused on bodies and biotechnologies, human-machine hybridity, transplant tourism, and the commodification of human organs. However, my data also introduced new themes and bodies of literature, which are outlined in the subsequent chapters. I quickly learned that I could not study dialysis and transplant in this location without sufficiently discussing rural and remote health itself. As a result, I allocated a chapter to the discussion of health and place and draw from health geography scholarship. As noted earlier, I retained aspects of medical anthropology by writing myself into the process, through the use of an ethnographic case study, and by developing several chapters around some of the most compelling narratives. Some of the issues that I was initially very focused on (commodifying bodies, transplant tourism, etc.) ended up being fairly marginal to the discussions. The dominant themes that emerged were: health and *place*; various *systems* and how they interact at different levels to create the conditions of care; *care work* and family structures; gender, *work*, and health in the local resource industry; and the social determinants of health. The chapters have been organized according to these themes and the related findings. I have realized that while kidney transplantation is such a fraught area of study, experiences of kidney failure are not determined as much by cultural ideas about the body/gifts/commodities/etc. as they are by our everyday living conditions and the broader systems that govern our lives and interactions. This is why I felt that a feminist political economy perspective was most appropriate as a theoretical lens for interpreting my findings.

Over the past several decades, many researchers have attempted to determine our future need for transplantable kidneys. In doing so, they have identified a notable gap between the number of kidneys desired for transplant and the number that are available. Despite the wealth of research that has been conducted regarding kidney transfer, how scarcity manifests in particular Canadian communities and particular people's lives is still relatively unknown. The aim of this case study was to uncover the experiences, representations, and policy implications of scarcity in rural and remote British Columbia. In order to address this research gap, I employed a research design in which qualitative

data were collected using critical ethnography and document analysis. The findings were analyzed using feminist political economy as a theoretical guide. These findings are discussed thematically in the following chapters, beginning in Chapter 3 with a focus on the various systems that structure renal health and care at the site of study.

### **Chapter 3: Structure of the System(s)**

“Because a ‘health system consists of all the organizations, institutions, resources, and people whose primary purpose is to improve health’ (WHO, 2011, p.1), rural health systems reflect a complex interaction of health policies, funding bodies, advocacy groups and professional organizations... the voices of rural consumers, political debate and decisions, media representation, and numerous structures that influence rural health priorities, decisions, and funding” (Bourke et al., 2012, p.500).

In this chapter, I discuss how various health care organizations, structures, and renal policies shape dialysis care and kidney transplant in the region of study and across the province. This is done in order to provide a ‘lay of the land’ of BC’s renal care system and to explore: the priorities of the leading renal organizations, the discourses used in presenting these matters to the public, and how the system(s) currently operate. Drawing from my document analysis, I begin by outlining the organizations that make up the local renal care system. I address how these organizations influence the services and supports that are available in the region. Local health programs, services, and activities are shaped and constrained by the broader health system, and yet they are produced by individuals in the community in response to local needs and available resources. With this in mind, I then draw from my interviews with health care professionals to explore how professionals serving remote residents manage with the limited resources that they have, as well as the changes in local policy and practice that have resulted from the perceived scarcity of kidneys.

My findings suggest that at the national and provincial levels, the discourse of organ scarcity remains dominant, particularly for transplant and kidney care organizations. Public education and outreach initiatives primarily focus on donor awareness, registration, and procurement, rather than prevention and/or determinants of health. At these levels, there is a notable push towards kidney transplant as the renal treatment of choice. My data suggest that new practices have emerged across the province in response to a perceived kidney shortage. For instance, this discourse of kidney scarcity had led to a more accessible online donor registration, the outreach to younger people via social media portraying organ donor registration as “hip,” the Living

Organ Donor Expense Reimbursement Program, the Paired Kidney Exchange Program, organ retrieval from patients in a permanent vegetative state, and Living Anonymous Donation. Efforts to increase donor awareness and registration have translated into improved rates for both registration and transplantation.

At the provincial level, renal care organizations and the health care system increasingly place emphasis on home hemodialysis or peritoneal dialysis. This shift is explored further in Chapter 6. The discourse at this level has more to do with the scarcity of human and health care resources than with transplantable kidneys. This version of the scarcity discourse is also apparent at the regional and community levels. I found that at the regional level, the transience and limited number of health care professionals in the region leads to challenges with workload and professional communication. Limited public funds also leave health professionals feeling as though they cannot provide care to the fullest of their abilities and their remote patients sometimes slip through the cracks.

Lastly, at the community level, the emphasis is primarily on patient compliance and on maintaining treatment programs. This involves ensuring that patients can and do receive dialysis, follow the kidney-friendly diet, purchase and take appropriate medications, follow other instructions for preventing progression of the disease, and take time for self-care. The barriers to following these prescriptions largely result from socioeconomic considerations and are addressed in each of the following chapters. In short, the health care professionals at the regional and community levels speak to the scarcity of health and life-sustaining resources that their patients experience. I argue that this variation in emphasis reflects different needs and goals at each level of care, as well as their varying proximity to renal care patients and their daily lives.

## **Relevant organizations**

### *Background*

Both the federal and provincial governments fund the health care system in British Columbia. The system is known as the Medical Services Plan (MSP). As part of Canada's universal health care system, the MSP provides "essential" health care services

to Canadian citizens or permanent residents who reside in British Columbia<sup>12</sup> via public funding. Unlike Ontario, where health care is funded through public tax dollars, BC residents pay for the MSP through monthly premium payments. The monthly cost of coverage for an individual is \$69.25. For a couple, the cost is \$125.50 and for a family of three or more, the premium is \$138.50 (BC Ministry of Health, 2014a). Some employers will cover the premium payments, but people who are out of work or do not have employer coverage must make these payments themselves. People with lower incomes may be eligible for regular or temporary premium assistance (BC Ministry of Health, 2013a). There are five levels of subsidies. An individual or family's subsidy level is calculated based on their net income, adjusted for any other forms of government assistance that they receive (ibid).

The services that are covered by this insurance include medically required care from primary care physicians, maternity care, diagnostic services recommended by a health care professional, referred services by health care specialists (i.e. nephrologists, podiatrists, dermatologists, gynecologists, urologists), as well as most emergency and hospital services (BC Ministry of Health, 2014b). Hemodialysis (in clinic and at home) and PD services are also covered. The province also has a PharmaCare program that subsidizes the costs of eligible pharmaceutical drugs. Coverage and family deductibles are calculated based on net income<sup>13</sup>.

MSP provincial coverage does not include prescription drugs, chiropractic care, massage therapy, physiotherapy, naturopathy, preventative services or screening tests that are “not supported by evidence for medical efficacy,” such as annual complete physicals or full body CT scans (BC Ministry of Health, 2014b). The coverage also excludes eyeglasses, hearing aids, dental services, regular eye exams for those between 19-64 years of age, sessions with counselors or psychologists, other equipment and appliances

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<sup>12</sup> New residents to British Columbia are subject to a three-month waiting period before their health coverage begins (BC Ministry of Health, 2013a).

<sup>13</sup> For those with the lowest income level (less than \$15,000/year), there is no deductible, PharmaCare pays 70% of eligible costs, and the family maximum (after which 100% of costs are covered) is equal to 2% of family net income (BC Ministry of Health, 2013b).

related to health care, and services deemed medically unnecessary (BC Ministry of Health, 2014b).

Unlike most economically developed countries in the world, Canada does not have a coordinated national organ donation and transplant strategy (Sher, 2012). Kidney allocation and transplantation takes place within each province and in particular transplant regions. In other words, a patient waiting on a kidney in the Greater Toronto Area may not receive one that becomes available in London, Ontario, as he or she would be on a separate regional wait list. In 2012, Canadian Blood Services released a “Call to Action” report that outlined the blueprints for a national strategy on organ and tissue donation and transplantation. Though a national strategy has not yet been put into place, the report has led to further research that is paving the way for this possibility.

Within British Columbia, there are several organizations that govern kidney dialysis and transplant care. These include, most prominently, the British Columbia Provincial Renal Agency (BCPRA), the BC Transplant Society, and the BC branch of the Kidney Foundation of Canada. These groups offer an array of valuable resources and supports for renal patients. I found that through the work of these groups, British Columbia has become a leader in terms of donation and procurement practices. I outline the roles of these broad organizations because they provide the policy and practice guidelines that structure the choices and experiences of those who interact with the renal care system. Additionally, policy acts as, “an indicator of the salience and energy behind a topic, gauging the extent to which research findings have percolated into real-life decisions that guide behaviour” (Sutherns & Haworth-Brockman, 2012, p. 29). In other words, these documents reveal which scholarship on kidney dialysis, transplant, and scarcity has translated into legislation and/or practice and how they have done so. Below is a brief outline of how each of these organizations operates and the services that they provide.

#### *Kidney Foundation of Canada – BC Branch*

The Kidney Foundation of Canada is a national health charity, created in 1964, that is committed to kidney health and improving the lives of people with kidney disease.

They have provincial and regional chapters across the country. The Foundation offers education, support, and advocacy for those with chronic kidney disease or kidney failure (Kidney Foundation of Canada, 2013). They also provide funding for kidney research as well as financial and practical assistance for renal patients. The financial assistance they provide includes short term and emergency assistance to cover medical or other expenses associated with kidney disease and its treatment (Kidney Foundation of Canada, 2013). This can include bursary programs for kidney patients who wish to improve their education/training, travel loan programs to help with the upfront costs of temporary out-of-country dialysis treatment, home renovations to install a dialysis machine, and compassionate loans in emergency scenarios (ibid). However, this assistance is provided only when all other sources of funding have been exhausted and it does not cover all expenses associated with renal care. Patients are still required to pay for travel and transportation to dialysis, for the food required for the kidney diet, and other long-term expenses related to their renal care and overall health. The Kidney Foundation is responsible for primary prevention and liaises with the province's diabetes and cardiac groups, but not with the BC Renal Agency. According to one participant, the lack of partnership with BCPRA is because of differences in their mandates (Interview 28, 2014). The participant did not elaborate about the nature these differences, but may have been referring to the difference between treatment and prevention objectives.

In general, the Kidney Foundation offers an impressive array of referral services and supports and increasingly engages in public awareness-raising initiatives about transplant and kidney health. Many of my participants have taken advantage of some of the Foundation's services at one time or another (e.g. staying in their Kidney Condo while visiting Vancouver). Many of the events and services provided are quite good. Unfortunately, they are not all available or easily accessible for residents in remote and rural regions. Health care professionals remain the gatekeepers to the majority of these services. Most supports listed in the Kidney Foundation's *Living With Kidney Disease* manual or on their website instruct the reader to visit a social worker for further information and assistance with determining eligibility and/or accessing these resources.

Given that remote residents do not see a social worker often, there may be limitations to accessing these services. The Kidney Foundation typically refers patients to services and supports in their own community. Residents of rural and remote areas are less likely to have these services available. Patients cannot apply or register for most of these services on their own. As discussed in the following chapter, those who are spatially, socially, and/or economically marginalized are less likely to attend dialysis treatments, visit a social worker, or access health care professionals. Perhaps this is why I found that few of my participants were aware of the Kidney Foundation services that are available.

### *BC Transplant Society*

The BC Transplant Society was established in 1986. It is a charitable organization that directs, delivers or contracts all organ transplant services across the province. It is primarily funded through the BC Ministry of Health Services, and is an agency of the Provincial Health Services Authority (BC Transplant Society, 2013a). They contract inpatient and outpatient transplant services from three transplant hospitals and operate seven regional clinics throughout the province for outpatient care (ibid). The organization's philosophy is that "the health-restoring benefits of organ transplant services should be available to those individuals who meet the suitability and eligibility criteria for transplantation in British Columbia" (ibid, para 6) and their vision is that all British Columbians who are eligible for a transplant will receive one (ibid). Their website provides: organ donor registry information, donor family supports, clinical guidelines for health care professionals, news and events, living donation and volunteer program information, research updates, transplantation statistics, and responses to frequently asked questions about organ donation and transplantation (ibid). A transplant coordinator or social worker would be the gatekeeper to most of the services provided by the Transplant Society. Generally, only those who donate or receive a kidney would make use of their services. Most of the services and supports that the Society provides would be available for post-transplant care in Vancouver and not necessarily accessible for those in a remote location.

*The British Columbia Provincial Renal Agency (BCPRA)*

The BCPRA is a branch organization under the Provincial Health Services Authority and reports to the Ministry of Health. The BCPRA was established in 1997 as a, “virtual network designed to optimize kidney patients’ quality of life and health outcomes, and to support sound fiscal management and system sustainability” (BCPRA, 2012a, p.3). They are an organization without a physical location or office. They are responsible for secondary prevention of kidney disease; that is, fighting the progression of the disease and any complications that can arise from it. The agency has “a matrix reporting structure” in which renal programs report to the regional health authorities and the BCPRA to ensure communication at every level of the system and to avoid additional levels of bureaucracy (ibid). The organization has received accolades and recognition from other provinces, from the federal government, and from other nations (the UK and Australia) for their provincial database, patient-centred funding model, and their patient safety initiatives (ibid). They also cover the cost of renal medications for dialysis patients.<sup>14</sup>

The BCPRA has developed provincial renal program guidelines that provide a framework and a set of principles for health authorities to follow in the management and development of renal care programs (BCPRA, 2012b). The guidelines were created with the renal community to support equitable distribution of renal care to patients across BC, and to guide the priorities for future program development (ibid). The BC Ministry of Health then formally endorsed the guidelines. They are the first of their kind in Canada. The guidelines describe the structure, function, and expectations of regional renal programs. They generally outline the conditions that are required for dialysis care in various forms and deal predominantly with technical, clinical care.

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<sup>14</sup> However, they do not fund renal medications for patients who have received a transplant. The province will cover anti-rejection drugs for transplant recipients, but post-transplant, a number of the medications that were previously covered will become out of pocket expenses.

Their regular activities include: planning and monitoring the delivery of BC's kidney care services, developing province-wide clinical standards and guidelines, developing funding models to support best health outcomes, measuring and reporting on patient and system outcomes, and supporting knowledge-development through research and teaching (BCPRA, 2012b). They have also built and funded kidney care clinics throughout the province. Lastly, the BCPRA is responsible for the entire province's renal budget, which is about \$163 million, and they have come in on budget every year to date (ibid).

### **Scarcity discourses at work**

#### *Public education and outreach initiatives: Scarcity discourses at the national and provincial levels*

At the national and provincial levels, the Kidney Foundation plays a large role in increasing public awareness and advancing kidney health through organ donor recruitment and registration, as well as fundraising. Little public attention is paid to the risk factors for kidney failure or the inequitable distribution of kidney disease amongst vulnerable populations. In a news release from the Kidney Foundation, the authors note that in population-based surveys, “less than 10% of Canadians were able to identify diabetes as a risk factor for kidney disease” (Kidney Foundation of Canada, 2010, para 1). This reveals limited public education about preventing kidney disease – particularly in contrast to widespread knowledge about the need for more organ donors.<sup>15</sup> The National Executive Director of the Kidney Foundation of Canada claims that, “[p]ublic knowledge is not keeping pace with medical advances... and it's why our branches coast-to-coast hold community and public education activities on World Kidney Day and throughout the month of March to remind Canadians about the important link between diabetes, kidney health and heart health” (Kidney Foundation of Canada, 2010, para 3). However, the

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<sup>15</sup> This is not to suggest that public awareness initiatives must address either prevention *or* treatment. There is certainly room for both. I simply want to illustrate that kidney transplant has received substantially more media and public attention than the determinants of kidney disease have.

World Kidney Day events listed say very little about these links. The main World Kidney Day event is the “Door-to-Door” campaign that involves soliciting funds for the Kidney Foundation. Other events throughout the year include: the “Give the Gift of Life” walk, the Halloween Campaign, and specialty fundraising events such as golf tournaments, gala dinners, and spaghetti dinners (Kidney Foundation of Canada, 2012). Not all of these events happen in each region across the province and very few take place in rural and remote areas

The town at the site of study seems to primarily focus on the Kidney Walk, which launched for them in 2012. This walk requires participants to solicit sponsorship for a 2.5km indoor walk. The funds that are raised support the local Kidney Foundation branch’s programming. In an interview with a local paper, the event’s organizer<sup>16</sup> noted that the Kidney Walk is not only a fundraising event, but also a campaign to help find more organ donors (Anonymous citation<sup>17</sup>, 2012). The walk’s slogan is “Be a Hero!” and those who visit the event’s website will find a link to the online donor registry, as well as statistics about the number of British Columbians on dialysis who are waiting for a transplant. When I spoke with the dialysis nurses and patients at the community unit, it became apparent that only one person, a patient, had heard about or attended the walk. I was surprised that the Kidney Walk organizers had not connected with the local dialysis clinic. Numbers from their 2013 walk indicate that they raised 26% of their targeted fundraising goal (Anonymous citation, 2013). It is unclear how much awareness about organ donation and kidney health was raised in the community.

Given the financial assistance that the Kidney Foundation provides for renal patients, fundraising is essential. They are a charitable organization and their continued existence depends upon donations. However, these events – and the corresponding materials – provide limited information about the prevention and broader determinants of

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<sup>16</sup> I arranged an interview with the event’s organizer, but another commitment on her end prevented the interview from taking place. I did not hear back after my attempts to reschedule.

<sup>17</sup> Under the advisement of my supervisory committee, I have anonymized the citations for articles and reports that could potentially identify the site of my study. There are two local newspapers that I reference in this chapter.

kidney disease. For instance, the Kidney Foundation’s website notes, “members of certain ethnic groups [First Nations, Asian, South Asian, Pacific Island, African/Caribbean, and Hispanic] are also at high risk because of the greater incidence of diabetes and high blood pressure” (Kidney Foundation of Canada, 2014b, para 2), but there is no additional information provided to allow the site’s visitors to better understand why these ethnic groups are at higher risk of diabetes or high blood pressure or what can be done to address this inequity. The site also offers an online risk assessment quiz and links to research in Manitoba and Saskatchewan where there has been implementation of screening programs for participants from Aboriginal communities. Unlike the very public donor recruitment initiatives, these tools are only available on the Foundation’s website for those who are already, presumably, seeking out information about kidney health. So, in spite of the Foundation’s role in primary prevention and their intentions to raise awareness about the risk factors for kidney disease, the events that they host and the related materials tend to focus more on the scarcity of donor kidneys.

BC Transplant is largely responsible for organ donation awareness and registration initiatives. Because of their presence and paraphernalia (posters on buses, t-shirts, shoelaces, stickers, etc.) at numerous sites and events, their work is very visible across the province. Through their Facebook page, they share updates about their ongoing participation in awareness-raising and educational events. These include: Operation Popcorn (where festive tins of popcorn are delivered to transplant professionals by recipients who share their stories), participation in BC Kidney Days conferences for health professionals, and other instances of donor awareness and fundraising initiatives across the province – often through schools and/or athletic events.

Their social media accounts allow supporters, donors, and recipients to share stories, connect, and spread awareness and information, but are also widely used for donor recruitment. BC Transplant has formally declared its support for Facebook creator & CEO Mark Zuckerberg’s decision to allow Facebook users to share their organ donor status as a “Life Event” on Facebook (BC Transplant Society, 2012a) in order to generate interest and reach more potential donors. By adding one’s donor status to one’s social

media profile, becoming a registered donor can contribute to digital identity-building and show friends, family, and acquaintances how altruistic the registered individual is – and can encourage others to register as well. When the Facebook initiative was launched in the United States, the impact on donor registries was “immediate and profound – with organ donor registries reporting increased sign-up in the thousands” (ibid, p.1). The feature was then rolled out in Canada in late 2012, but there are no reports as of yet about its influence on Canadians’ donation rates.

In April 2014, BC Transplant launched an online “donor blitz” called *#48in48* where they aimed to register 48,000 new organ donors in 48 hours (BC Transplant Society, April 17, 2014). Their final number was just under 6,000. The Transplant Society has also partnered with Canadian organ donor awareness star Helene Campbell for various events and promotions. The 21 year-old transplant recipient is known across North America for getting pop star Justin Bieber to re-tweet her donor awareness message on Twitter and for later appearing on the Ellen Degeneres show to discuss organ scarcity. The increasingly viral awareness of Canada’s ‘organ shortage’ really highlights the impact that social media has had for donor awareness and registration in Canada, particularly for a younger demographic. It also raises potential concerns regarding the encouragement of making speedy advanced medical directives.<sup>18</sup>

Many of BC Transplant’s initiatives, social media and otherwise, make use of the “Live Life. Pass it On.” campaign mentioned in Chapter 2. The photos from this series are used in the registration section of the website, in a section highlighting Eva’s story and documentary, and in the mini-campaign kits that can be ordered from the site. The images feature Eva, who died of cystic fibrosis in her 20s while waiting for a second lung transplant, as well as several living transplant recipients who currently act as transplant activists. The campaign’s success is likely due, at least in part, to Eva’s local and

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<sup>18</sup> Registering to be an organ donor can be considered a form of advanced medical directive. In other words, it informs families and medical professionals about a person’s wishes prior to an event where he or she is no longer able to express them. One could argue that perhaps such decisions require more nuanced discussion and more than 48 hours of contemplation.

heartbreaking story, her youth and beauty, the striking images, and her use of social media to connect with fellow patients and the broader public. In the messages of both Eva's blog and the BC Transplant Society, there is a strong emphasis on the shortage of transplantable organs and registered donors. The focus is fairly consistently on the extensive waiting list and on the recipients whose lives have been saved by transplantation. The message is that Canadians are dying and it is up to each of us to "be a hero," "give the gift of life," and "live life and pass it on" by registering as a donor.

In sum, the majority of public education and outreach initiatives across the province are targeted towards fundraising and increasing donor awareness, registration, and procurement. At present, there is limited public information regarding primary prevention and other important issues faced by those who experience kidney failure. Most of the related initiatives are framed and motivated by a supply of organs that does not meet transplant demands. The organ scarcity discourse is embodied in the mandates of these organizations, in the types of initiatives that they prepare and the related materials, on their websites, and in how they educate the public. As a result, the organ scarcity discourse has become commonplace and is generally unquestioned by the public. This is a discourse that has been constructed by clinical medicine and provincial policies and has been promoted to the exclusion of other more complex pictures of renal failure. These more complex pictures might involve preventative measures, attention to complex health problems, and acknowledgement that renal failure requires more than a surgical fix. Additionally, the organ scarcity discourse does not speak to the scarcity of health care system resources or of health and life-sustaining resources in renal patients' lives. The discourses employed by these organizations are significant because they provide the broader context for the regional renal program's activities. They also inform the public's perception and education about organ failure and inspire changes in policy and practice. In the following section, I discuss some of these changes.

#### *Responding to scarcity: Changes in policy and practice*

British Columbia was a fruitful site of study because, in addition to having the first provincial renal agency and first renal program guidelines in the country, the

province has been a leader in terms of organ transfer innovation. As noted above, the discourse of kidney has led to several changes in policy and practice. It has inspired a great deal of work towards organ procurement practices and has successfully increased the number of BC's donors and transplants performed. For instance, the BC Transplant Society is known for being a leader in Canada with respect to procuring living donations. In 2006, they undertook a research project to study the practical and ethical implications of Living Anonymous Donation. This project is said to have been, "motivated by the critical shortage of kidneys for transplantation" (BC Transplant Society, 2006, para.5). To date, six anonymous transplants have been successfully performed in the province as a result of this project, the first of their kind in Canada (ibid). In 2006, the Society also launched the Paired Kidney Exchange Program. This program provides an alternate option for patients who have living donors that have been tested and found to be 'blood type incompatible.' "This program makes it possible for one incompatible couple to 'swap' donors with another couple in the same situation, therefore enabling two kidney patients to receive a transplant" (BC Transplant Society, 2006, para.2). Approximately 30% of those who are tested to be living donors are found to be incompatible (ibid) and so this program facilitates a number of transplants that would not otherwise be possible.

In 2006, the BC Branch of the Kidney Foundation and the BC Transplant Society jointly developed and launched the Living Organ Donor Expense Reimbursement (LODER) Program. This program is designed to encourage more living donors by reimbursing them for their accommodations, travel, loss of income, and other expenses related to their donation (ibid). This program was also the first of its kind in Canada. Since LODER's inception, all Canadian provinces have adopted programs to reimburse living organ donors for the eligible expenses related to their donation. In 2009, Ontario created a Transplant Patient Expense Reimbursement (TPER) Program that reimburses patients waiting on transplants for their relocation accommodation expenses. At this time, no such program exists in BC.

The nephrologist I spoke with discussed a couple of new ways that regional health authorities can increase the number of transplants. A notable example included procuring

organs from patients that are not brain dead, but in a permanent vegetative state. He told me:

R: I should tell you that there are different types of transplant donors coming up. We've talked about brain dead people as organ donors. You've heard of organ donation after death... Well, there's also [the case] where somebody is identified as a potential organ donor but he's on a ventilator and he's never going to be well enough to come off the ventilator, but he's not brain dead. So sometimes what they do now is if you can identify somebody like that, what happens is they... If they're never going to recover, if you can take them off a ventilator, wait until they arrest, and then basically rush them to the operating room, and take out the organs before they suffer too much injury.

I: I see.

R: So that is another area where organs can potentially be recovered. And it's something that is happening in BC.

I: I see.

R: It has to happen in very specialized centres where they have... where they can do it. And some people have been... Some potential donors have been transferred from the more rural and remote areas to bigger centres where something like that can happen. There have only been a handful of those kind of organ donations in the province, but they are happening. And it is something that will happen more in the future.

I: So another, sort of, means of procurement?

R: Yes. To help address the scarce organ resource [sic] (Anonymous, 2013).

He did not address the social or ethical issues that surround this approach to increasing donation rates. This quotation was quite surprising given the regulations set out in the BC Human Tissue Gift Act. The Act states that an individual must satisfy the brain death criteria before they are deemed suitable as a deceased donor, “[w]hen organ retrieval for the purpose of transplantation is being considered, the BC Human Tissue Gift Act requires that the diagnosis of brain death be made by two physicians independently, neither of whom is involved in the organ recovery or in the care of the potential organ recipient” (BC Transplant Society, 2013c). Regulations that ensure a patient is brain dead are designed, in part, to protect living patients from being viewed as potential sources of transplantable parts or as wasted medical resources. Even though this testimony came from an experienced renal care professional, there may be some important details missing from the story. If this practice is, indeed, becoming popularized, then a) there is very little

public discussion or debate about it<sup>19</sup> and b) the discourse of organ scarcity is so powerful that hastening someone's death so that they can become a donor is being justified in its name. This act serves as a strong caution against having scarcity dominate our ideas about renal disease and organ transplantation.

It appears that the donor awareness initiatives discussed above have successfully translated into an increased number of transplants performed. In 2013, the Transplant Society had a record breaking number (127) of living donor kidney transplants (BC Transplant Society, 2013b), having already set a new record high each of the previous two years. The province's median wait time for a cadaver kidney has also dropped by about 30% in the last couple of years; in 2012 it was 43.65 months – down from 62.2 months the previous year and 80.9 months in 2006 (ibid). In 2012, “BC's donors-per-million rate exceeded the national average, for both living donors (BC-19.6 donors per million, and Canada-16.3) and deceased donors (BC-15.2 donors per million, and Canada-13.6)” (BC Transplant Society 2013b). These statistics suggest that initiatives

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<sup>19</sup> Procuring organs from patients who are not brain dead is not discussed on the websites for the BCPRA, BC Transplant Society, the Transplant Research Foundation of British Columbia, or other relevant organizations. The guidelines for transplantation from a deceased donor state that brain death is mandatory. However, recent investigatory journalism has revealed that BC has been accepting organ donations from donors who have died of cardiac death, and are not brain dead, since 2012 (Sathya, 2014). The investigators claim that the majority of the debate around the criteria for determining death has taken place within the medical community and outside of the public eye (ibid). Provincial transplant organizations are not forthcoming about this practice in the content and educational resources that they provide to the public. Additionally, the amount of time required for determining cardiac death before retrieving organs varies substantially. The likelihood that the kidneys (and other organs) will be viable for transplant decreases quite quickly after life support is withdrawn. In Ontario, some hospitals require 5 minutes after the heart has stopped to declare death, whereas other hospitals in the same city wait for 10 minutes (*CBC News*, 2014). In Italy, physicians wait for 20 minutes to declare death and in some parts of the United States, a patient is declared dead after only 75 seconds (ibid). This is what one Canadian health lawyer refers to as “postal code death” (ibid), since “the standards for defining death in Canada vary so much that the hospital where a person is dying may affect when they are declared dead” (*CBC News*, 2014, para 1).

designed over the past few years to create awareness about and overcome kidney scarcity have been effective across the province.

One health professional in my study specifically credited the BC Transplant Society director for recent improvements in organ procurement:

“[t]hey also have a new director of the Transplant Society who is an intensivist. He works in an ICU. He’s not a nephrologist, he’s actually a surgeon.<sup>20</sup> And he is real gung ho about getting more organs for transplant. In other words, going out to smaller and larger hospital centres across BC and trying to get them to look at every potential donor to see what more could be done to be able to get more organs for transplant. Okay, so the new director of the Transplant Society is an intensivist who is working hard to get more organs for transplant – and they’ve almost doubled the number of transplants they’ve been doing” (Interview 11, 2013).

In sum, my findings suggest that across the province, a number of policies and practices have emerged in response to perceptions of kidney scarcity and the demands for more donors. It is predominantly clinical health professionals and charitable organizations driving these changes. While there is a lot of innovative work happening in renal care across the province, there are also a number of challenges for the regional renal system.<sup>21</sup> During the time of the study, the regional renal health program was undergoing an external review. Several of the participating health care professionals made note of this, saying that it may lead to some significant changes in practice. During my member checking with the head dialysis nurse, I was told that the review results had come in and that there was a several-year restructuring plan under way – the details of which are yet to be made public. In the following section, I explore some of the challenges in the regional system as well as the discourses used to describe them.

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<sup>20</sup> It is interesting to note that this individual is coming at the issue from a very clinical biomedical role. How connected is this surgeon to the needs of the patient population? Whose interests are being served by doubling the number of transplants performed? The implications of this are worthy of further consideration and are touched upon in the discussion section.

<sup>21</sup> It may be partly *because of* the BCPRA’s comprehensive data collection that those in charge are attuned to the problems in the system and these issues seem so apparent. Similar challenges may fly under the radar in other provinces and receive less discussion.

### **Regional policies, practices, and points of contention**

At the regional and community levels, there was little emphasis on transplant, though it is suggested to all eligible candidates. Participants were more concerned with ensuring that patients attend dialysis treatments and maintain their care plans. The scarcity discourses that manifested in these narratives had less to do with kidneys and more to do with the scarcity of human and health care resources, as well as the scarcity of patients' health and life-sustaining resources. Some of the regional issues identified in my interviews were: communication between health care professionals, making do with limited/transient staff and large case loads, the limitations of providing technology-mediated long-distance care, and the centralization of care in larger centres.

In its current state, the regional renal program struggles with establishing who is ultimately responsible for dialysis patients. Dialysis nurses tend to find themselves at the hub of renal care. They liaise with family doctors and other specialists, they do a lot of patient education and support, and they spend significantly more time with patients than any other health care provider. However, I was told that shifts in practice have limited the scope of what these nurses can do. Local nurses often have to get approval from an external nephrologist or refer a patient to a physician before they can make changes to a treatment plan. These referrals and consults can lead to a number of delays, confusions, and unnecessary changes. These challenges are explored further below.

#### *Challenges with staffing, workload, and communication*

At the community clinic level, the dialysis nurses are at the centre of renal care. Patients who attend clinic see them several days a week and come to know and trust them more than any of the other health professionals that they interact with. The clinic's nurses act as liaisons between the patient and the family doctor, the nephrologist, the social workers, dietitians, the pharmacist, the BCPRA, and other organizations. As is common in rural areas (Hanvey, 2005), the nurses adopt multiple care roles:

“[w]e've been so short-staffed that I've been trying to work full-time as a frontline worker and full-time as an administrator. And so it doesn't work. It just doesn't work... So actually this is the first time we've had enough staff... I'd far

rather be a nurse than an administrator... When I first started, there was no policy and no procedures. And so we just kind of made it up on our own. And not just on a whim, we would have rationales. And so now we've got a nurse educator. We've had her in [regional clinic] for about the last five years. So now she's coming out with standardized policy. Because even a year ago, what we did in [community unit] was not the same as what we did in [regional unit], was not the same as what they did in [other town in region]. So she's trying to standardize" (Interview 1, 2013)

Though standardization is beneficial for the system as a whole, it also has the capacity to restrict the professional autonomy of the nurses at the community clinic, which is unfortunate given that professional autonomy is regarded as one of the most satisfying elements of practicing nursing and/or medicine in a rural area (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002; Pathman, Williams, & Konrad, 1996). Since the full renal care team is located in the regional clinic town and patients see them so infrequently, the nurses in the community clinic end up taking on aspects of those roles as well. For instance, the community clinic nurses do a lot of patient education, advocacy, and counseling in addition to their clinical and administrative duties. One nurse identified some of the issues regarding communication between the community unit and the nephrologists at the regional unit:

R: "[Years ago] there was only one nephrologist. And then he stopped and then we had Dr. [nephrologist] come onboard. And that was probably almost 15 years ago. He's the only one that's ever, ever come out here... We now have three nephrologists who rotate call. So for two weeks, Dr. [nephrologist] will be on, and then he has four weeks off. And then we'll see him again in another two weeks. So Drs. [nephrologist] and [nephrologist] have never seen our patients. They might have seen them in [regional clinic] just if they were there or if they were on when our patients were there. So they've never actually seen our patients... And it's a very ineffective system because one nephrologist has one idea about how things are done. So the next guy comes along and says, "Well, I don't know why that nephrologist did that." So then they stop whatever medication, it's usually a medication, they stop that medication and give them something else. So our poor patients' heads are just spinning because they're getting sometimes... In six weeks, they can get three different prescriptions.

I: Oh, wow.

R: And so that... And I mean that's a lot of follow-up because we have to send the prescription to the pharmacy, and the pharmacy does all that work. ... And we do all that work too. I mean the work isn't a problem but it's very a) confusing for

the patient and b) it's not cost effective because the government is paying for a three month supply and, "Oh, guess what? We changed our mind." So I find that really, really frustrating" (Interview 1, 2013).

In addition to highlighting issues around coordination between health professionals, this quotation also reveals the challenges with servicing a satellite dialysis unit. When I asked about whether the dialysis nurses had to confer with the nephrologists when they want to make changes to a patient's treatment, I was told that the nurses' ability to make such changes has become increasingly limited. In years past, a nephrologist would provide consent over the phone for the community dialysis nurses to provide particular treatments, but now patients are encouraged to visit their family doctors first. For instance, if a patient came in with an infection, the community nurses used to be able to administer antibiotics. With the new rules, the nurses must now consult the nephrologist, who will then typically instruct them to refer the patient to his or her family doctor – who the nurses may or may not have a rapport with. This means the patients have to try to book an additional appointment with one of the limited number of doctors in the area and commute to that appointment, rather than receiving the antibiotics at their regular dialysis appointment. This is complicated for patients and for the health care professionals. The additional complexity also creates more opportunities for potential errors, omissions, or non-compliance. This is further complicated by the fact that some calls to family doctors go unanswered:

"But some of them just don't call back. They don't communicate well, you know. Like for whatever reason, I don't know. And so that is frustrating. And yet we can't make that change for [patients] to go to a different doctor. We do, especially if the patient is not satisfied, we do say, "you know, there are other doctors." Or we call the family and say, 'have you considered another doctor?'" (Interview 2, 2013).

Communication between all of the related care professionals is challenging, and patients do not necessarily relay all of their information to every member of their care team. The wide scope of a rural dialysis nurse's role can sometimes mean that they will end up taking on work that they could delegate to someone else in order to make the process

easier for the patient. Other times this scope can limit the care that they are able to provide.

Because of their large catchment area and limited/transient staff, members of the renal care team at the regional unit also take on a considerable amount of work. For instance, when discussing his visits to the community clinic, the nephrologist told me that he is unable to see all of the patients that are referred to him:

“I will also be seeing patients with chronic kidney disease. And I think there are about 85 patients who have been referred to see me. And I can see 75 or something like that. There are more than I can see. And when I’m there, I see patients from 8:00 in the morning until 6:00 at night, every 20 minutes, with no lunch or bathroom breaks” (Anonymous, 2013).

Similarly, a social worker at the regional clinic, Debbie,<sup>22</sup> informed me that her caseload consists of over 700 patients (Interview 15, 2013). Apparently, a social worker from Vancouver told Debbie that that is a sufficient amount for about four social workers there. Overworking the staff in mid-sized regions is not an effective or sustainable means for addressing the scarcity of health professionals in remote towns. Debbie receives assistance from another social worker, Claire, who works part time and remotely on dialysis cases at the community unit, and part time in another area of medicine at another hospital. Since she was relatively new to the job and working remotely, Claire had never met most of the community clinic’s dialysis patients in person. She told me that she relies on technology to reach these patients, “[w]e talk and e-mail. There are referrals done through [e-mail]. And oftentimes I just call them, you know, the patient and the family to see how they’re doing” (Interview 12, 2013).

Teleconferencing and videoconferencing have gained popularity as ways to manage the wide distribution of renal patients and connect with them. These conferences are also intended to compensate for the limited number of traveling physicians and specialists. One health care professional claimed that there are plans for the regional team to do more outreach in terms of video-conferencing in the future. However, though

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<sup>22</sup> All participant names used throughout are pseudonyms.

video-conferencing is a practical way to bridge long distances, discussing private health matters over technology is not appealing for many patients or practitioners:

“[w]e do video-conferencing with our stable chronic disease patients in [nearby town]... So with them, we can just... Like the pharmacist sees them, the dietician sees them, the nurse gets...she’s doing her assessment there. I don’t find that’s very helpful for the social work part because some of them are... Like sometimes you have to be screaming [to be heard over videoconferencing], right? And so people don’t want to be screaming their social issues over a TV” (Interview 15, 2013).

This may be especially true for older patients who do not always have access to or experience with computers, or low-income patients in rural and remote areas who may not have a computer or reliable Internet access. Experiences of illness are also highly personal. Not only in terms of confidentiality, but in terms of discussing changes in one’s body, sexual function, relationship strain, etc. Building a more intimate rapport with a social worker, for instance, is difficult to do without visual or bodily cues that are given in person. Given that they are not the most secure media, digital video or telephone conferences also have implications for patient confidentiality and privacy. Lastly, because they require less planning and travel, telephone and video meetings can be easier for staff and patients to forget or postpone. A home dialysis patient told me:

“I’m on home hemo. I have to do clinic. Well, for people that live in [major centre], they do clinic once a month. So you get to see a nutritionist, you see a psychologist, they see the main nephrologist, they see the resident nephrologist. Like they will see the entire team once a month. Whereas with me, they’re like, ‘Okay, well, you live so far away, we’ll see you every three months. But make sure you do your blood work.’ Right? So I do my blood work. And then they said, ‘Okay, we’re going to have phone conferences,’ just like you and me are right now. And so they say, ‘Okay, between this time and this time on this date, we will call you.’ I’ve been on dialysis, as I said, I got home in [just over a year prior], and I’ve had one actual phone conference with the doctors. Every other one they missed. They didn’t call me” (Interview 26, 2013).

In addition to being easy to overlook, these technology-mediated conferences introduce the potential for technical difficulties. With patchy phone reception and unreliable Internet connections in this remote area, these conversations can be broken into multiple calls or fail altogether. This was the case several times during my telephone interviews

for this study. Video and teleconferencing have large potential as methods for reaching remote patients, but there are a number of practical concerns that ought to be addressed before the practices become standard.

More broadly, many of the challenges discussed in this section result from the administration and specialists being centralized in the regional clinic and in larger cities. This centralization of care in urban centres is, “a practice that conforms to the management model that seeks cost efficiencies” (Fiske et al., 2012, p. 407) and is reflective of a broader trend in neo-liberal policy. This sentiment was reinforced when one health professional told me:

“I think on a broader scope, it’s going to be fiscal pressures [that act as barriers for patients]. I mean, we have a really good way of – because of the BCPRA data system, etc. the funding is secure – but on the other hand, the health authorities (and I’m sure this is true across Canada) all health authorities have to come in on budget. So, there’s a lot of fiscal pressure of “will that make a difference to patient care?” Well, it could make a difference if they look to, for example if they close a small unit that was not efficiently run, from a fiscal point of view, due to, you know. So, some of those pressures could, you know, potentially impact patients” (Interview 27, 2013).

This narrative and the others reflect the scarcity of human resources and health care funds in the region. In order to remedy this scarcity, there has been an increased reliance upon dialysis nurses to act as comprehensive care coordinators and/or administrators, upon traveling specialists, and upon technology-mediated consultations. Health care professionals at the community and regional clinics are working multiple roles and juggling numerous responsibilities. The division of labour is not well defined and this can lead to overlaps or omissions, as well as miscommunications between health care professionals. The awareness of the limited resources can itself be an added stress for these staff members.

#### *Moral distress and working with limited resources*

The renal care staff in the region is constantly reminded of the limited systemic resources that are available and have to make decisions accordingly. One nurse described this as a form of moral distress, “[m]oral distress being where you know what needs to be

done, but you don't have the tools to do it. And really, for the last few years, I really found that” (Interview 1, 2013). This type of distress seems to be common in remote health care provision (Kulig & Williams, 2011). Not only are the nurses aware of the limited funds and health care resources that they are working with, they are also acutely aware of the limited resources available to their patients. They recognize the high costs of transportation to dialysis, the expensive nature of the kidney-friendly diet, and the financial hardship that many of their patients face. In some situations, dialysis nurses feel that they have to advocate for their patients in a variety of inventive, and sometimes subversive, ways. For instance, the community clinic’s nursing team sometimes goes to great lengths to try and mitigate social issues from affecting patients’ care and treatment options. One nurse told me:

R: I got one of our patients into palliative care and got into so much trouble from [other health professionals]. And I just could not understand that.

I: And why was that?

R: Their biggest hang-up seems to be that the palliative program says, you know, if you kind of expect death in the next six months. But if you actually talk to the palliative people, which I did, I spent a lot of time talking, they say, “you know what? We don’t really care about the six months. We’ve actually had patients who have been in and out of this program for ten years. So don’t let that be a stumbling block.” But for whatever reason, [other health professionals] didn’t want to hear that. And the benefit to the patient is huge because their medication is all paid for.

I: It’s not otherwise?

R: The Renal Agency will pay for renal medications but in terms of any narcotics or that kind of stuff, they don’t pay. So we had one guy who needed [pain related drug and considerable heart care]... And so he was paying huge amounts of money. And when you’re on a very fixed income of \$900/month or something, you can’t afford it. So if you’re in the palliative program, they cover that.

I: I see.

R: And they also will give you resources. If you need bars in your bathroom or whatever. And they just kind of keep tabs on you (Interview 1, 2013).

Another health professional said that it feels as though she is always begging for resources for patients:

R: ...following up with the Ministry can be a struggle. So yeah, it would be nice if we could make everything much easier. And it’s just like you’re begging [on behalf of patients] all the time.

I: Is that how it often feels?

R: Oh, sometimes it feels that way. You know, even with the bands, you know, sometimes there's things that they don't...they're not able to provide. And then you have to really go through [regional health authority] benefits. And that's another thing you have to deal with and the patients have to deal with. You know, it's a real struggle sometimes (Interview 12, 2013).

In these cases, the discourses used by regional health care professionals did not resonate with the organ scarcity narrative in the provincial and national initiatives, nor with the majority of organ transfer literature. None of these participants suggested that getting all of their patients' kidney transplants would be a valuable solution to the challenges identified. Their concerns reflected a deeper understanding of the everyday challenges that renal patients face and their recommendations had to do with improving the effectiveness of the system in serving the needs of their patients.

## **Discussion**

### *Scarcity discourses: implications*

According to Foucault (1972), discourses are actively produced and promoted until they appear self-evident. This account treats discourse as more than simply a discursive phenomenon (what is and is not discussed and how), but also as an indicator and expression of the ideology, power, and politics that the discourse embodies. Foucault suggests that in order to unpack the power and politics, we ought to question who is speaking, "who, among the totality of speaking individuals, is accorded the right to use this sort of language? Who is qualified to do so? Who derives from it his own special quality, his prestige, and from whom, in return, does he receive if not the assurance then at least the presumption that what is says is true?" (ibid, p. 50). This is reminiscent of the quotation about the BC Transplant Society director, who is a transplant surgeon, going out to hospitals and spreading the message about organ scarcity. Foucault recommends querying the institutional sites from which an individual employs this discourse, where it gains its legitimacy, and where it is applied. He also claims that the discursive subject:

"...is situated at an optimal perceptual distance whose boundaries delimit the wheat of relevant information; he uses instrumental intermediaries that modify the scale of information, shift the subject in relation to the average or immediate

perceptual level, ensure his movement from a superficial to a deep level, make him circulate in the interior space of the body – from manifest symptoms to the organs, from the organs to the tissues, and finally, from the tissues to the cells” (p. 52).

In this analysis of clinical medical discourse, Foucault reveals the importance of identifying the speaker(s) behind the discourse (surgeons, nephrologists, health authorities, nurses, social workers, patients, family members), the content that is deemed relevant and legitimate, and the scope of the content that they discuss (ranging from clinical laboratory results to holistic health and well-being). This forces us to question “why this discourse and not others?” and examine the network of relations that make up the discourse.

Three different scarcity discourses have been identified in this chapter: the scarcity of transplantable kidneys, the scarcity of health care resources (primarily in terms of staff and funds), and the scarcity of health and life-sustaining resources for patients (primarily finances and access to relevant services and supports). The organizations’ documents, social media sources, and my interviews with renal care professionals suggest that organ scarcity is still the dominant discourse across the province.<sup>23</sup> Messages to the public are predominantly framed in terms of a shortage of kidneys and desperate patients in need of donors. This supports the claims about scarcity in the critical literature on organ transfer (Scheper-Hughes, 2006; Lock, 2002a).

The discourse that is used matters because in health care contexts, the language used to discuss treatment can serve as “active discourse” (Mykhalovskiy, 2001) and wind up not only reflecting what we do, but also directing it. For instance, concepts such as ‘efficiency’ or ‘cost-effectiveness’ that originally served as evaluative measurements have now become goals or outcomes in and of themselves in health services research (ibid). In my case study, the findings confirm that kidney scarcity has gone from being a descriptive concept that reflects our limited ability to perform transplants to a more

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<sup>23</sup> The scarcity of the funds and resources necessary for maintaining the dialysis population is embedded in the organ scarcity discourse as a rationale for procuring more kidneys.

prescriptive concept that drives and informs policy and practice in order to procure more donations. Though there are several scarcity discourses that surfaced, it is only the scarcity of kidneys that has received widespread public attention and generated large changes to policy and practice. Pervasive messages about kidney scarcity have led to a more accessible online donor registration, increased rates of donation and transplantation, social media promotion, the Living Organ Donor Expense Reimbursement Program, the Paired Kidney Exchange Program, organ retrieval from patients in a permanent vegetative state, and living anonymous donation.

On a slightly smaller scale, the discourse regarding the scarcity of health care resources and rural staff members has also translated into some action. Academic research on rural health has taken up some of these issues (Sutherns & Haworth-Brockman, 2012; Rourke, 1993, 2005). Academics have also taken up the issue of increasing reliance upon charitable organizations (i.e. the Kidney Foundation or BC Transplant), rather than the state, to provide support for rural residents at times of heightened vulnerability and dependency (Skinner & Joseph, 2007). The external review of the regional system and the subsequent implementation of a restructuring plan suggest that local health authorities are also taking notice of this discourse and the issues that it reflects. However, these issues receive substantially less public discussion than kidney scarcity. The scarcity of patients' health and life-sustaining resources receives even less attention. This may be due to the fact that addressing the social determinants of health is quite overtly political, whereas the politics surrounding the other discourses are more insidious. For instance, it is less politically controversial to ask people to register as organ donors than it is to suggest the implementation of a living wage. However, one can argue that choosing to remain inactive regarding the social determinants of health is equally as political as becoming vocal about them (Brassolotto, Raphael, & Baldeo, 2013). As Tesh (1988) notes, "this is not an unwarranted intrusion of politics into science. There is no science un-influenced by politics. This is a plea to get the politics out of hiding" (p. 177).

As noted in the previous chapter, the biomedical perspective of health claims objectivity and neutrality and treats illness as located in particular parts of the body. A

broader understanding of health recognizes that even though there are a number of lifestyle and therapeutic benefits to kidney transplant,<sup>24</sup> replacing a single part of someone who is living in poverty with several comorbidities can only do so much. It also does very little to prevent more people from experiencing kidney failure. Though BC's kidney donor registrations and transplant rates have increased over the past ten years, the number of British Columbians affected by kidney disease has increased by 60 percent (BC Transplant Society, 2013d). This suggests an increasing demand for kidneys that our current procurement methods could never satisfy. According to the critical literature (Koch, 2002; Scheper-Hughes, 2006), it is in this type of perceived crisis scenario that previously unacceptable forms of organ procurement are tabled for consideration.

In a relatively recent article for the *American Journal of Kidney Disease* (Gill et al., 2014), a collection of authors— including the executive director of the BCPRA — discuss financial incentives for organ donation in Canada. They argue that it would be premature to consider a regulated market for organ sales, but that there are a number of financial incentives that ought to be considered for compensating both donors and the hospitals that procure these donors. At one point, the authors say, “[p]otential deceased donors should be recognized as a potential health resource, and dedicated financial investments should be made to maximize attainment of this resource” (2014, p. 5). This article reveals that, despite the controversy surrounding paying donors, those in policy-making positions are seriously contemplating the benefits of financial compensation for organ donation. It also reveals a utilitarian understanding of potential donors' bodies and their parts that prioritizes the needs of potential recipients.

Many of the health care professionals I spoke with noted that despite the widespread messages about the Canadian kidney shortage, their numbers of dialysis patients had gone down, and the number of kidney transplants had gone up. So, most of them claimed that they did not feel an acute sense of a kidney crisis or desperate

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<sup>24</sup> Most of the transplant recipients I spoke with said that they were very glad that they had received a transplant and would do it again — and some of them will have to. Two of the four participants who received transplants are back on various forms of dialysis.

shortage.<sup>25</sup> In my, albeit limited, case study, the desperation for transplantable kidneys came more from clinical health professionals and charitable organizations than it did from dialysis patients and their families or nursing staff. This has interesting implications for questions of who benefits from current discourses, policies, and practices. Those closely affiliated with kidney transplantation (surgeons, nephrologists, donors, recipients, and those working for charities that support transplants or kidney health) continue to push for increasing donations and improving donor registration numbers. This is understandable given their professional, economic, and personal investments in the practice. Those who work more closely with renal patients appeared to be more concerned with providing accessible and effective renal treatment and improving patients' quality of life and health.

A feminist political economy analysis was central in bringing these findings to light. When considering the macro health system context, a feminist political economy lens reveals the centralization of health care services in larger urban centres as part of a trend in cost-cutting, neo-liberal policy. It connects the macro level policies with activities and experiences at the regional and community levels. It drove me to ask 'who benefits from this arrangement?' and 'which discourses are revealed and which are concealed?' Feminist political economy also highlights the impact that fiscal pressures resulting from limited resources have on renal care policies and practices. That said, members of the organizations discussed above are not only concerned with cost saving; from a health system perspective, kidney transplantation does have many therapeutic benefits. Transplant recipients have a longer life expectancy than those on dialysis, tend to have more energy, and can have a more flexible diet and a "more normal" life (Kidney

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<sup>25</sup> Perhaps it is *because of* all of the action in response to the kidney crisis discourse that the situation has improved. There are also several initiatives underway to prevent kidney failure and the need for transplant in the first place. My study, however, does not adequately capture the increasing efforts at screening and early detection. This is likely due to the fact that those I spoke with are already experiencing renal failure or are professionals that treat patients who are already undergoing renal treatment. Much of the primary prevention work is seen as within the purview of the Chronic Disease Prevention groups and not the renal or transplant organizations.

Foundation of Canada, 2006). There is nothing inherently wrong with encouraging organ donation and transplantation. What my analysis reveals are the risks associated with the organ scarcity discourse, its manifestations in this case study, and its limitations in terms of improving the lives of patients and their care providers.

### *Looking towards prevention*

As the National Executive Director of The Kidney Foundation of Canada noted, public knowledge about the leading causes of kidney disease and kidney failure is notably lacking. Innovation and public education regarding CKD prevention and management have yet to match those related to renal replacement therapies. Additionally, my findings suggest that kidneys are not the most urgently needed resource at the site of study. While improving education and awareness about organ donation is an important component of the renal health care approach, it appears that the organizations discussed above are well positioned to play a greater role in education surrounding diabetes, obesity, vascular disease, hepatitis, poverty, and the social determinants of health.

One might argue, ‘education about diabetes, vascular disease or the social determinants of health is outside of the scope of organizations that deal with kidney disease and organ transplantation. Their services ought to focus on treatment and support for those who already have failing kidneys. Let the people working for diabetes organizations or poverty networks concern themselves with that content.’ The problem with this perspective is that addressing treatment in isolation from prevention means overlooking the conditions in which individuals become ill and denying any obligation that we have as a society to provide healthful living conditions to all of our citizens. Information about these determinants can be empowering for patients and the general public as well as informative for those drafting policy.

With all of this said, organizations such as the BCPRA do an admirable job of collecting data and implementing new and innovative systems in the province. Similarly, the staff at the regional and community units work tremendously hard to provide high quality care for their patients. Many of the problems that I have identified are systemic

and structural barriers beyond the scope of what the BCPRA and other renal care organizations can do on their own, which makes eliminating renal health inequities in the region challenging. However, this does not mean that any of these organizations ought to abandon their mission to make high quality care accessible to every patient. Rather, they have to continue to be inventive and responsive to local needs as they move forward in their work. There is also a need for them to engage in collaboration with other sectors and organizations within the community that are better situated to address some of the social issues. There is a tremendous amount of agency and effort that goes into improving the lives of those with renal failure. However, these efforts are constrained by broader policies and systems of governance that generally advocate for minimal social spending and a reduction in public service provision (Fiske et al., 2012). These concepts are explored further in the following chapters. Chapter 4 focuses on the intersections of geographical isolation and social location and the impact these have on renal health and health care.

## Chapter 4: Health & Place

Building on the previous chapter's outline of the systemic context, this chapter focuses on the impact of the site's geographical location. The policies, practices, and discourses addressed in the previous chapter manifest in nuanced ways in this specific rural locale. Over the last 30 years, health geography has gained popularity as a discipline (Kearns & Moon, 2002). Unlike medical geography, which has traditionally been quantitative and biomedical in its focus, health geography concerns itself with qualitative research, relationships between people and place(s), and employs critical social theories in its analyses. Health geographers have expressed interest in how neo-liberal policy shifts affect the content that they study, but also their field itself:

“‘Scientific’ explanations have tended to be discursively coded by funders as objective, truthful and hard, while narrative and interpretative approaches in health geography are (often at least implicitly) coded as subjective, untruthful and soft. These discursive codings have, we argue, led to a situation in which an empirical health variations project, for instance, is more ‘sellable’ than an investigation of therapeutic landscapes (Kearns & Moon, 2002, p. 618).

This reveals a disciplinary debate in regards to how research is conducted and what is deemed worthy of investigation. The methods and theoretical frameworks employed by health geographers often align with those of feminist political economists, who also see location as central. Feminist geographers (Dyck, 2005; McDowell, 1999) have demonstrated these similarities through their attention to the value of ‘everyday’ geographies, of examining the physical places and social spaces that men and women occupy, and of the experiences amongst and between women and men across the globe. In recent years, rural health has become of increasing interest to health geographers. Canadian health geographers have been concerned with understanding rural health primarily in relation to gender (Leipert, Leach, & Thurston, 2012; Sutherns & Haworth-Brockman, 2012), aging (Skinner, Hanlon, & Halseth, 2014; Keating, Swindle, & Fletcher, 2011), caregiving (Williams & Kulig, 2011; Crosato & Leipert, 2006), and Aboriginal health (Illauq, 2012; Varcoe & Dick, 2008; Furniss, 1999). These thinkers typically situate their findings within larger health and social policy contexts and

recommend addressing rural health inequities through changes to policy and programming.

There is no consensus regarding a universal definition of “rural.” The term is often used by Canadian academics to encompass socio-cultural aspects of these regions, descriptions of the land, elements of northern living, and remoteness in regards to isolation (Williams & Cutchin, 2002). Acknowledging the complexity of rurality, I use the term “rural” in this chapter – and throughout – to address a combination of these elements. I do not intend to make broad generalizations about the experiences of rural living in Canada. Depending on the definition of “rural” being used, between 19 -30% of Canadians are formally defined as living in rural Canada (Kulig & Williams, 2011, p. 2) and there will undoubtedly be variation in their environments and their experiences. My participants’ stories and perspectives were not homogenous. That said, amidst the diversity, those who reside in rural regions face a number of similar and consistent structural challenges and/or environmental barriers and these challenges merit discussion.

### *Geographic isolation*

Bourke et al. (2012) argue that understanding health issues in a rural and remote context requires first understanding geographical isolation. “Geographical isolation embraces location by virtue of where a particular place is relative to others without homogenising or assuming sameness” (ibid, p. 499). By this account, geographic isolation itself has implications for health, but so do the nuances of specific rural locales. Framing the discussion in terms of geography illuminates the impact that spatial isolation has on local health needs and the health care system’s responses to these needs. In this sense, “rural and remote health are much more than merely the practice of health in another location” (ibid, p. 499) and as a result, discussions of renal treatment and care cannot simply be transplanted from urban to rural contexts.

The geographic isolation of my site of study contributed to both the scarcity of health care and human resources, as well as the scarcity of health and life-sustaining resources. This meant that dialysis clinics, nurses, doctors, nephrologists, and other

specialists were limited or difficult to access, as was safe, reliable, and affordable transportation. There were also challenges associated with the scarcity of affordable and accessible supports for healthy active living (diet and fitness related), reliable/adequate income, formal support for unpaid family care providers, funds (for patients and for the health care system), and workplaces that can accommodate and support dialysis and/or transplant patients and their donors. As indicated in Chapter 1, the allocation of scarce resources is a matter of equity and distributive justice; if not everyone can live [well], then we must ask who will do so and who will not? I found that participants who experienced various forms of socioeconomic disadvantage struggled with accessing the resources necessary to minimize the challenges associated with geographic isolation. This intersection of social and geographic locations is explored throughout this chapter.

While scarcity is certainly a prevalent concept in rural and remote regions, it is not *necessarily* a defining one. There may be a dearth of services and resources that are more plentiful in urban areas, but these shortages only tell part of the story. My participants implicitly and explicitly identified a number of benefits to living in a rural and remote location. These benefits include: an intimate sense of community, opportunities to connect with nature and enjoy the outdoors, the beautiful landscape, peace and quiet, some distance from rampant consumerism, a slower pace of life, a sense of pride and/or adventure that comes from ‘roughing it’ in the elements, preserving particular cultures and traditions, and more. In these ways and others, rural places are dynamic. They are distinct from urban areas and that is why health issues such as kidney dialysis and transplantation require discussions specific to these contexts.

This chapter begins with a brief overview of literature related to rural and remote demographics, population health risks, and gender norms and family structures. I then outline my place-related findings with a focus on geographic isolation as it relates to access to dialysis and transplant services, compliance with treatments, and travel and transportation. In the first section outlining my findings, I address the challenges faced by patients and their family care providers. The following section addresses challenges faced by health care professionals in terms of providing care and arranging transplants.

In the discussion section, I interpret these findings and identify some of the political and economic issues surrounding this location and the ways in which its isolation impacts the everyday lives of my participants. I argue that a de-contextualized focus on achieving good health via renal replacement treatments is often at odds with the ability to live one's life. In other words, the extensive labour involved with pursuing dialysis and/or transplant in a rural and remote region can compromise the quality of patients' everyday lives. Special attention is paid to the monetary costs associated with obtaining care and accessing services. Paired with current social, political, economic, and health systems, geographic isolation is a determinant of my participants' health and health care options. The intersection of their social and geographic locations provides the conditions in which they live and work.

### **Understanding rural health: health equity and demographic context**

According to the Canada Health Act (1984), health care in Canada ought to be universal, publicly funded, comprehensive, portable, and accessible regardless of where one resides in the country. However, there are challenges that arise when people live in remote destinations that require substantial travel for basic services and care. For instance, authors of one study noted that, “[a]mong people with chronic kidney disease, remote dwellers [of Alberta, Canada] were less likely to receive specialist care, recommended laboratory testing, and appropriate medications, and were more likely to die or be hospitalized compared with those living closer to a nephrologist” (Rucker et al., 2011). The distance from renal specialists poses difficulties in terms of chronic kidney disease prevention, early detection and management, timely treatments, and maintenance of treatment plans. This can translate into access-related health inequities in rural regions. Given the limited funds of the provincial health care system, it would be ineffective and inefficient to have clinics with specialists conveniently located throughout sparsely populated, large rural regions. An arrangement of this nature could also be considered inequitable, as the costs associated with providing more clinics would require funds to be taken from other services. The challenge then becomes developing effective ways to

understand and improve the health of rural and remote residents. This may involve changes to primary care, but could also include intersectoral collaboration, grassroots community organizations, and greater application of the determinants of health framework in the regional health authority's planning and practice. In the following two sections, I draw from rural health geography literature to identify particular characteristics of rural communities, associated population health risks, as well as gender norms and family structures in these regions. Feminist political economists frequently ask, "whom – that is, which people – are affected by the conditions in question?" Given the confidentiality regarding the specifics of my site of study, this section offers some broad insight into the demographics of rural and remote regions.

#### *Rural demographics and population health*

Though there is diversity within and between rural regions, geographic isolation has notable implications for a population's demographics. Compared to Canadian cities, rural areas have "fewer immigrants and visible minority populations, higher proportions of First Nations groups, and unique religious groups such as the Mennonites, Hutterites, Amish, and other Anabaptists" (Kulig & Williams, 2011, p.2). Those living in rural areas tend to have larger families and higher numbers of dependents – both children and older adults (ibid). This has implications for living and working arrangements, as well as family care work. Residents of rural Canada also tend to have lower levels of literacy and formal education (ibid).

In addition, rural areas also have higher mortality rates and lower life expectancies than do urban areas (Halseth & Ryser, 2010). This is said to be due, in part, to higher levels of high blood pressure and obesity, higher levels of arthritis/rheumatism and depression, and lower levels of self-reported functional health, self-assessed health status, and health-promoting behaviours (Coward et al., 2005). For instance, alcohol and tobacco use are higher in rural Canada and deaths related to the use of these substances are statistically higher in remote areas (Anonymous citation, 2011). There are higher rates of workplace and vehicular accidents, suicide, and disability experienced in rural

populations (Coward et al., 2005) and rural residents also tend to have a number of comorbidities – that is, multiple health conditions. Comorbidities can be particularly challenging for dialysis patients because the dialysis process can clean other medications out from the blood. These comorbidities can also delay wait list candidacy for a kidney transplant, as a nephrologist will not request a transplant until the patient’s cancer or heart condition is adequately under control.

These demographic characteristics “play a large role in the comparative vulnerability that rural Canadians experience across a number of population health determinants” (Kulig & Williams, 2011, p. 2). Because of the complexity of living in a rural place, Wanless et al. (2010) recommend that ‘rural residence’ specifically be integrated as a unique dimension within the determinants of health framework. This reinforces why discussions of kidney health and treatment in urban areas do not always readily apply in this context.

#### *Gender and geographic isolation*

Geographic isolation has different implications for women and men. For starters, there are distinctive social and economic characteristics that affect rural women’s health and well-being (Leipert, Landry, & Leach, 2012). While families in rural and remote regions are diverse, they generally tend to be gender and hetero normative – that is, heterosexual marriages and domestic partnerships with traditional gender roles regarding masculine men and feminine women tend to be the norm. Following ‘traditional’ gender roles, rural women typically marry earlier, bear more children, and live in larger families (Coward et al., 2005). Women in rural areas have less formal education than urban women, and earn about 50% less than rural men, whereas urban women earn about 34% less than urban men (ibid). Finding employment can also be difficult for women in these areas, given that the leading industries are male-dominated. Additionally, large families and plentiful unpaid household work makes having a dual-earning household extra challenging. Women may refrain from participating in paid employment because of the limited availability, or lack, of childcare. Poverty rates are higher in rural areas and

households headed by women are more likely to be poor than any other family arrangement (Halseth & Ryser, 2010). Of all women in Canada, the health status of rural women is the poorest (Sutherns, McPhedran, & Haworth-Brockman, 2003).

Particular psychosocial issues also affect women in rural areas. For instance, despite strong community and familial connections, rural women are more likely to feel invisible and adjunct to their husbands, children, and other relatives, “[t]hese women are often hesitant to seek support through formal networks because the nature of many small towns and rural communities negates anonymity” (Coward et al., 2005, p. 4).

Unpredictable income resulting from the boom and bust nature of farming and resource-related work also creates stress on the family household and, perhaps related to this, rural women are more likely than urban ones to be victims of domestic violence (Dyck, Stickle, & Hardy, 2012).

These are several of the factors that can influence rural women’s health and well-being. They contextualize rural women’s health issues and also demonstrate the intersections of gender, employment, living conditions, income, education, and other determinants that shape the opportunities for a healthy life in rural and remote regions. The structures of work and culture in these regions are not only problematic for women; they are also harmful for men. Strenuous physical labour and the traditional role of breadwinner/provider create a number of challenges for rural men. These considerations are discussed at greater length in Chapter 5. Men living in the region of my study die earlier than women of virtually all causes and do not live as long as men in urban regions of the province (Anonymous citation, 2011). Men in this area also have lower high school completion rates, the highest rates in the province for alcohol-related fatalities and hospitalizations, greater numbers of workplace injuries, and they work more hours than men and women elsewhere in the province (ibid). Men in rural areas tend to use health services less than women do and as a result, services to do with sexual and reproductive health have been geared towards women, leaving many men ill-informed about sexually transmitted infections and other related health risks (ibid).

There are also limited social and health supports tailored to the diverse needs of women and men in rural and remote areas; for instance, services for those with physical and intellectual disabilities, those with mental health issues, those who are LGBTQ+ (lesbian, gay, bisexual, transgendered, questioning, intersexed, asexual, queer, two-spirited, and others), single parents, Aboriginal peoples, or those from various cultural backgrounds. The absence of appropriate local services and a reluctance to seek support from outside of the community can lead to gender-based inequities in a rural locale reproducing themselves over time (Bourke et al., 2012). Policy makers must be cognizant of the fact that “women and men experience health and health policy differently and that an effective gender-based analysis necessarily includes a place analysis, particularly in a country as diverse (geographically and otherwise) as Canada” (Haworth-Brockman et al., 2012, p.59). Similarly, because of the extent to which gender serves as a determinant of health in rural and remote areas, an analysis of place also requires consideration of sex and gender. In the following section, I discuss the renal care challenges faced jointly and separately by the men and women who reside in the region of study.

### **Findings regarding patients and family care providers**

#### *The road(s) to recovery: Travel and transportation for dialysis*

Travel and transportation were the most significant barriers and challenges discussed by patients and health professionals. Figuratively, my participants’ road to recovery is filled with hurdles posed by their social location(s) and geographic isolation. More literally, the driving in the community and regional dialysis unit areas can be perilous and stressful and the lengthy commutes can be costly. At the time of my study, only 2 of 10 patients receiving dialysis at the community clinic lived in the same town as the clinic. This meant that most of the patients had a minimum 200 kilometre round trip each time that they came in for treatment. These commutes involve long and winding stretches of road, little to no lighting (there are no streetlights between towns), a great deal of wildlife and/or snow and ice, and other drivers who are in a rush to get to their destinations and are well aware that there are no police around to catch them for

speeding. There are also many transport trucks on these roads. These trucks can be intimidating to have following you at high speeds and often kick up gravel at smaller vehicles when they pass. One has to be especially alert when driving on these roads, which makes it extra nerve-wracking and tiresome to do these drives early in the morning or in the evening when it is dark. This is challenging for tired patients and their drivers who have to get up very early in the morning three to four times a week in order to make it to treatment on time. One family care provider told me about how time consuming and costly the drive was for her and her husband:

R: Like today, there was a snowstorm. So, that means we just stay in town.

I: So you said you had to get up at 4am or so to be here for 8:30?

R: Yes, 4:15. Because it's just right across here...

I: And how long is the drive?

R: 2.5 hours from the farm to here.

I: Each way.

R: Yes.

I: So you were saying that tonight you'll stay overnight?

R: Yes.

I: And is any of that covered or is that something that has to be paid out of pocket?

R: No, we pay for it ourselves (Interview 10, 2013).

When the driving conditions are particularly bad, a number of people opt to spend the night in the town that they are receiving care in. Though staying overnight in hotels, motels, and with family friends may offer a nice alternative to driving home on treacherous roads, it also means that patients and their companions have to spend unanticipated or unpredictable amounts of their own money on accommodations and food in order to attend dialysis treatments. This also means a number of nights without one's own bed, kitchen, supplies, and elements of home that provide structure, routine, and comfort. If a dialysis patient is providing care for a child or parent, spending the night in town may also have implications for care work arrangements. One patient and her husband added:

R: I think [dialysis] should be available all over the place. People can't afford this running around. It's hard on their life [sic], period.

R2: There was one couple from here, they ended up moving down south. They lost everything they had here.

R: They lost everything. And we're headed that way (Interview 4, 2013).

Both patients and health care professionals told me that the commute and the related costs are the leading reasons that people skip dialysis treatments. One of the nurses told me:

R: They are allowed a certain amount [of money] per year [from the renal agency]. So if they haven't used that, yes, they can utilize that. But once that's exhausted then... I mean the social workers try to find any little things, pockets of money that they can find. And they're really good at that. Like we have a social worker in [regional town] and she's so good. Like she will try to find... You know, if the patients are saying, "I can't afford even coming to dialysis because I'm driving from [neighbouring town] up here, and it's costing me this money, and I don't have it" then she'll...there's often things that they can do for them.

I: Oh, that's good to know.

R: Yes. But there are times when they have to say, "I'm sorry, there's no more," you know?

I: And what tends to happen then? Do they come less often?

R: Yes. We had one fellow where he just said, "I can't come more than twice a week" and he really needed the three times, but he couldn't afford it.

I: And that was for his gas or...?

R: Because of gas. And it was just coming to the end of the month where, you know, the next influx hadn't come yet. So you know, it didn't happen for him every...like on a regular basis but by the time the end of the month was coming close, when money got tighter, then he would just say, "I just can't come" (Interview 2, 2013).

As indicated in Chapter 3, the coverage provided by the regional health agency and the Kidney Foundation does not alleviate all of the financial strain that patients and their families face as a result of attending dialysis treatments. This highlights the relationship between residents' socioeconomic status and their access to health care services.

The burden of the commute cannot be overstated in terms of patients' everyday experiences of dialysis. The long, harsh winters in the region can mean up to seven months of dark days and intense winter driving conditions. Passing or being passed by other vehicles on a two-lane highway with snowy roads and poor visibility can be quite anxiety inducing. During the winter of 2013, there were between 10-15 fatal crashes in the region (Anonymous citation, 2014). Skinner, Yantzi, & Rosenberg (2009) suggest that "relatively little attention... has been directed toward the description and critical analysis of how everyday weather events and conditions affect the delivery of health

services” (p. 682). This perspective draws on the work of feminist geographers who highlight the value of examining routine, everyday activities and their connection to broader, systemic changes (ibid). The authors argue that the implications of severe weather are complex and rarely accounted for in health policies. Concerns about road safety were particularly pressing given that the majority of the dialysis patients at the clinic during this time were seniors who felt uneasy about sharing the roads with the local resource workers and transport trucks. A couple of participants spoke about this:

R: The biggest issue is they’ve got a beautiful dialysis wing in [community clinic town]. They have not got a thing in [neighbouring town]. And we’re required to drive up there for a four-hour session of dialysis, four times a week. In the summer, it’s not too bad. But in the winter, it’s horrific. It really is.

I: Yes. And that road along there too, there’s that gravel stretch there that gets really bad in the winter.

R: It’s bad all the time because there are [resource industry] people on it. They’re all full of workers on it now. And they don’t care. They’re not worried about someone in the car who’s elderly, taking it easy to get there safely (Interview 16, 2013).

An older couple echoed this frustration with the resource workers and told me about how the time required for driving cautiously in these conditions means devoting full days to dialysis treatment:

R: The roads...

R2: We’re on the third bumper on our car.

I: Really?

R2: And it’s only a 2010.

I: Wow. From deer?

R: One deer.

R2: One deer, yeah. A big chunk of ice fell off a truck or a grader or something.

R: Ice falls off on these little cars.

R2: And that was it. You can’t stop because it’s just going too...you know?

I: Yeah. And you’re in the middle of the highway. Right.

R: It’s a tragic road in the wintertime. It’s really bad. Especially with the [resource industry].

R2: It’s like they’re all in a hurry.

R: They’re all in a hurry, and you’re sitting there... We have to leave home about 6:40am in the wintertime in the morning.

I: That’s an early start.

R: To get here. And we leave and we come in and we do our thing, and then we go home... So we went home and it was 8:30 at night when we got home because of the roads.

I: So there's a whole day.

R: Yes, it's a whole day (Interviews 4&5, 2013).

In this couple's case, four of seven days of the week are mostly devoted to attending dialysis. Those in an urban setting will require a similar amount of dialysis, but the time spent getting to and from treatment may take less time given that there is likely shorter distance to travel, the roads are better maintained and plowed, and family members/companions are not as likely to have to spend hours waiting with minimal services or amenities nearby.<sup>26</sup> Additionally, urban residents will not usually require overnight accommodations when attending treatment. In short, attending dialysis is very costly in terms of time and funds for rural and remote residents.

For those who cannot drive, there is very minimal public transit available in the region. There is a Greyhound bus and a regional health bus that both have limited service hours and routes. This means that unless a patient lives a few minutes away in the community clinic town, he or she is dependent upon a driver. For the drivers, this means spending the requisite three to four hours in town while the patient is dialyzing – meaning their whole day is also consumed by the trip.

There is a man who lives in a neighbouring town and acted as a volunteer carpool driver for dialysis patients for over 10 years. Some patients said that they paid him approximately \$50/week toward gas and car maintenance and a number of them spoke about him as a major support for the community. When he decided to 'retire,' this had huge implications for dialysis patients in his town. The regional health authority and local nursing staff have had to come up with ways to replace his service:

R: [Regional health authority] did kick in [and provide transportation], but it was not... Like we always had to continue to say to the patients, "you need to be looking for different drivers." And at the last minute, [regional health authority] would kick in again.

I: But they waited until it was sort of dire?

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<sup>26</sup> However, urban residents may have to contend with considerable traffic.

R: Yes. Like we would be telling the patients, “well, as of this date, you will no longer have a ride with [regional health authority], and you have to have...” Well, then the last day, you know, they’d get a call, the patients would get a call and they’d say, “we’re coming to pick you up again.” They have accepted [the patient]... And sometimes we haven’t even heard about it (Interview 2, 2013).

The absence of a secure, sustainable transportation system reveals one of the risks associated with relying upon volunteers to provide access to health care services.

Transportation to regular dialysis appointments seems challenging for patients, and on top of that, they are also instructed to attend monthly renal care appointments at the regional unit – a notably farther (~400 kilometres from the community clinic) and more costly trip. This visit allows the patient to see the nephrologist and the full renal care team, if necessary, and receive testing and updates about their condition. Some participants are so weary of these trips that they simply refuse to go. One patient told me that she does not visit the regional unit unless there is “a real reason.” She said:

“Oh, they want to take tests and whatnot. Like they wanted to do CT scans and whatnot. You go down there, you spend two nights there for [an appointment that lasts] 15 minutes. Okay? Because that’s the only way they could set it up, was at such and such a time. Well, you’re sitting there two nights, all the food, the roads, motels... So I phoned them and I said, ‘look, no.’ So, I went to my [family] doctor “(Interview 4, 2013).

In some cases a family physician might be able to provide service(s) recommended by the regional clinic, but in a number of cases, general practitioners in remote areas will not have the equipment or training required to provide specialized renal care. The distance to the regional centre and the costs associated with making the trip thus prevent some patients from obtaining the tests recommended for monitoring their conditions.

Dialysis patients who travel for their care can claim the Medical Expense Tax Credit or the Disability Tax Credit when they file their taxes each year (Kidney Foundation of Canada, 2013a). For patients to be reimbursed for some of their care-related costs, the Foundation offers simplified and detailed methods. The simplified method involves claiming vehicle expenses by multiplying the number of kilometres by the cents/per km specified by the Canada Revenue Agency for the province from which the travel begins (\$0.49.5/km in BC). For meal expenses, patients may claim a flat rate of

\$17/meal to a maximum of \$51 per day per person, without receipts – though they may still be asked to provide some documentation to support this claim (Kidney Foundation of Canada, 2013a).

The detailed method involves keeping receipts and records for vehicle expenses paid for the 12-month period for medical reasons (ibid). Patients are instructed to keep track of the total number of kilometres they drove specifically for medical reasons and save all of the appropriate meal receipts. This amount of organization and administrative work can be challenging for patients and family members who are overwhelmed with managing their everyday care tasks and are often feeling unwell. For some, language barriers and limited literacy can pose additional challenges to the process.

For those who can and do save all of the appropriate documentation, patients told me that these tax refunds were of minimal assistance, “[y]ou only get \$500 for it... and the paperwork, oh my god!... But you’ve got to dig to find [these services]. Nobody tells you about these things” (Interview 5, 2013). I was told that the trips and meals were difficult to keep track of, the refunds were of negligible benefit to their financial situation, and that since they are still required to put out the money up front, patients did not rely on the refund to help them throughout the year. One participant told me, “[t]hey’re not going to give [much refund] to you anyway. So you just forget about it. That’s probably what they’re counting on” (Interview 5, 2013). In other words, the tax reimbursement is important for acknowledging the costs associated with renal care and providing some compensatory assistance, but it is not enough to meaningfully offset the financial hardships incurred by having a chronic condition or make dialysis patients feel supported by the system. Geographic isolation means that patients often have to travel for their basic renal/health services, and face a number of challenges in terms of seeing nephrologists and receiving additional testing. Trips that would be tedious in an urban setting become exponentially so in a remote rural location. When one introduces the prospect of a kidney transplant, a number of additional issues arise. These include multiple trips to Vancouver, the related expenses, time off from work, and childcare arrangements.

*“I’m not getting back on that f-ing bus”: Geographic isolation and barriers to kidney transplantation*

There is a medical bus provided by the regional health authority, but there are some notable problems with its service. The fee is \$20, which seems fairly reasonable, but a \$40 round trip can be quite costly for those living on a limited income. If the patient is older or has never been to the regional unit before, they may want to bring a companion, but may not be able to afford to. Additionally, the bus schedule does not work well for most patients. It requires them to leave at strange times and they often have to stay overnight because the last bus has already left when they are done dialyzing. The bus only makes designated stops and does not take patients door-to-door. Several of the health care providers spoke about the challenges associated with using the regional health bus. One said:

R: We used to have...the [regional health] bus would come in on the Monday, and the Greyhound bus Wednesday, Friday. They would go right into [town]. And then they shut down the Friday run. They would drop patients off at the [town] junction, which is about an hour, an hour and a half out of [town], at a gas station, that was closed, at 2:00 in the morning. And a cab would have to come out from [town] and drive them back in. And so it was a safety issue. The bus driver was good and he’d actually wait for the cab a couple of times. But we can’t be dropping our people off in -40 [degrees Celsius]!

I: Right.

R: At a gas station! Yeah. So it’s those kinds of things are just really, really frustrating (Interview, 15, 2013).

I: And are their accommodations covered if they have to stay overnight?

R: Depending on what their funding is. If they’re welfare, definitely. If they’re Canada Pension Plan or Disability, no. And again, it’s based on their income. So, often I can get Kidney Foundation to cover the cost of accommodation. But again, if they make... if it’s a couple, they have to make under \$1,800 [per month] combined... So I mean they have to be very low income to qualify. And our Easter Seals house has just shut down. So yeah, we don’t even have an Easter Seals house anymore (Interview 15, 2013).

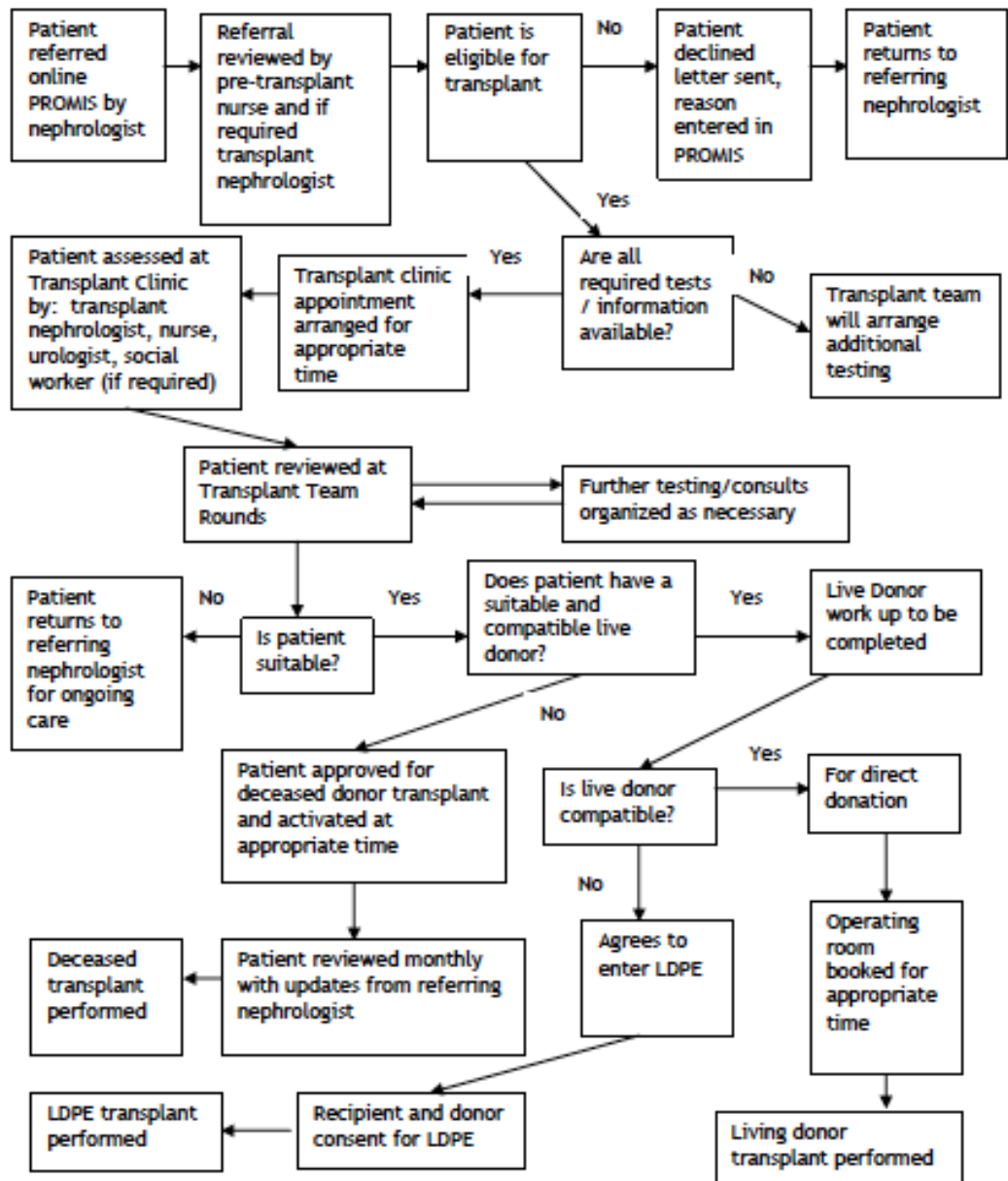
So, when patients are told that there is a bus that can take them to their appointments at the regional clinic or in Vancouver, it is really much more complex, challenging, and costly than it sounds.

I was not surprised to find that geographic isolation also creates barriers to kidney transplantation. Transplant can appear as a tempting alternative to life on dialysis for rural residents. It offers freedom from the regular commute and related dialysis care-related costs. It also means physical freedom from being tied to the dialysis machine and a greater ability to work or travel. However, orchestrating a successful transplant comes with its own set of challenges. Below is the BC Transplant Program's flow chart<sup>27</sup> tracking the processes of referral and assessment for kidney transplant:

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<sup>27</sup> I obtained written permission to use this chart.

**Figure 1. Kidney Transplant Program Referral/Assessment**



This chart demonstrates how many stages and requirements there are in the transplant work up process. Below are some excerpts from my conversations with three health professionals (a social worker, a nephrologist, and a transplant coordinator – not necessarily in that order) that highlight the difficulties involved with preparing rural patients for transplant:

R: “[w]ell, I think distance is still a barrier. It’s a barrier that people have to go to Vancouver to get a kidney transplant. We have some people who, for instance, have working wives. The kidney patients don’t work for some reason. Or they’ve got too many health problems, they can’t work. So they help take care of kids. So we’ve got some who turn down opportunities to get a kidney transplant because they don’t think they can be away for six weeks. So distance is still a barrier. The necessity to be away from home for six weeks to get a transplant has been a barrier for some of our patients. The other part of the barrier is that we’ve had some people where it’s been hard to get them to Vancouver quickly enough to get an organ transplant” (Interview 11, 2013).

I: What do you see as some of the biggest issues that your patients are facing?

R: I think the biggest one is just the travel issue. A lot of our patients are low income or, you know, welfare or have a job but are just struggling to make ends meet. And you know, having to take two days, even if it’s just two days every three or four months, out of their work schedule or whatever, and then having to pay for travel, it’s hard for them. And I do think there are some patients that put off having a transplant because of that, because they know they’re going to have to be out of work for a couple of months. And it’s not just the two to three months they may be in Vancouver; they can’t go back to work right away when they come back. They have to take it easy for, you know, another couple of months. And I think that’s a big deterrent.

I: Right. Have you had people explicitly say, “I don’t want a transplant” for that reason?

R: Yes (Interview 6, 2013).

I: Do you have anyone who has refused a transplant simply because of the distance to go down and live in Vancouver for a while?

R: Yeah, actually yeah, we’ve had a couple people. And again, one of our other fellows is just being re-worked up. But he’s the primary caregiver for his disabled son. And he said, “For me to go to Vancouver for three months, who will look after my son? My wife works full-time. We can’t afford her to quit her job while I’m down there.” So I mean that was a huge barrier for him. One of our other fellows, I mean he’s passed away now, but he was from [remote town]. So he got on the Greyhound bus after an appointment, he got to [remote town] at 2:00 in the

morning. The surgeon called him at 3:00 in the morning and said, “We need you back in [regional unit]. We’ve got a kidney for you.” And he absolutely refused, “I’m not getting back on that f-ing bus.” I’m trying to phone him. Like I can totally make arrangements. We’ll get the air ambulance to get you up here. Whatever we need to do. And he absolutely refused just because it was...

I: It was just exhausting?

R: It was another three hour drive back to [regional unit], and another trip, depending on... Yeah. So unfortunately he passed away. And, like, he was a very young man (Interview 15, 2013).

What these quotations demonstrate is that, according to these participants, it is not geography alone that acts as a barrier to transplant, but often it is geography *paired with structures of work and family care*. These structures are explored in greater depth in Chapters 5 and 6, but it is worth now noting their relationship to geographic location and to transplant options and opportunities. The physical geography means that patients sometimes cannot get to Vancouver in time to receive a kidney that has become available for transplant. The structure and deficiencies of the regional transit system have led patients to refuse potential life-saving transplants because of the associated labour and expenses. The shortage of affordable accommodations in Vancouver makes it very challenging for rural patients to spend several months away from home. However, all of these barriers are exacerbated by the fact that most patients cannot afford to take the time off from paid work or from work associated with family care. The ability to go to Vancouver for two to three months for transplant is a privilege afforded to those with means, or with secure employment. One of the nurses told me about how a wealthy dialysis patient from their clinic grew impatient with dialysis and the associated travel and actually decided to circumvent the system:

“...we did have one guy. He lived in [town] which is, I think, four to six hours up the highway. He had a lot of money. He used to fly down three times a week for dialysis. And he did have a living donor but he didn’t want to wait. So he took his living donor down to the Mayo Clinic in the States and for \$250,000 he got his transplant and all of that done. And he had to fly down there a couple more times just, you know, for follow-up” (Interview 1, 2013).

This example reveals that patients with higher socioeconomic status have more resources and/or opportunities for overcoming the barriers posed by geographic isolation.<sup>28</sup> The nephrologist I spoke with informed me that the majority of kidney transplants that happen for people in this region come from donations made by living relatives or friends. This is likely because patients are informed about the long wait time for a cadaver donor, but also because a living donation does not require an immediate and unscheduled surgery in the city – meaning work arrangements and child care needs can be sorted out in advance. Living donation means that the [presumably] rural donor also has to temporarily take time off and relocate for major surgery and recovery, making the process all the more complex.

Since most patients wait for years before receiving a transplant, there is a long period of time during which they need to be physically, mentally, and financially ready to go at a moment's notice when a kidney becomes available. Being at a great distance from the transplant team and the nephrologist, while grappling with the challenges of rural living, makes it all the more difficult for patients to maintain this level of preparedness. In the discussion section, I discuss the ways in which this state of affairs often pits the pursuit of good health and the pursuit of a good life at odds with one another.

Unfortunately, post-transplant care is not necessarily less burdensome than dialysis care. Though transplant is intended to restore health, it can also be at odds with living daily life. Depending on where one lives in the province, post-transplant travel may be just as tedious because the patient will still have to attend the regional unit for regular clinic follow-ups. This is reminiscent of Lock's (2002a) discussion of the man who was "married to the transplant unit" after his surgery. However, it seems that this marriage begins months or even years before the transplant itself. When one considers adding the large number of appointments and follow-ups required in the preparation for a kidney transplant to the already overwhelming weekly schedule required for dialysis and monthly meetings with the nephrologist, it becomes clear that the process can becoming

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<sup>28</sup> It also confirms the concerns expressed in the critical organ transfer literature that wealthy people may feel entitled to a transplant and may be willing to participate in transplant tourism in order to receive one.

overwhelming and unappealing for patients quite easily. So, while remote residents are certainly not excluded from transplant consideration, there are a number of factors that make it challenging for them to actually receive a new kidney. As Koch (2002) notes:

“[d]istributive justice results in the dissemination of a good or service to people specifically located within a bounded space. A study of justice or injustice of a distributive system therefore must consider the relative location and resulting relations between buyers and suppliers, between claimants who are denied and those whose petition is answered” (p. 46).

In other words, in response to the questions, ‘who receives these scarce ‘resources?’ or ‘who benefits from the existing transplant arrangements?’ it appears that there are ways in which rural and remote residents are, indeed, at a disadvantage.

### **Findings related to health care professionals**

#### *Recruiting and retaining rural health care professionals*

There are a number of ways in which rural and remote Canada is associated with Canadian identity.<sup>29</sup> Despite this, a dominant urban culture has tended to stereotype rural areas as, “backward, in the ‘middle of nowhere,’ homogenous, and politically conservative” (Bourke et al., 2012, p. 501).<sup>30</sup> As a result of negative perceptions and a lack of various amenities, rural or remote regions are often seen as undesirable places to live, particularly for professionals and those with higher levels of formal education. For instance, physicians in rural BC often experience isolation and burnout, and have difficulty socializing in non-professional settings in their small communities (Hunter, 2003). It is also challenging to recruit nurses to work in rural and remote areas where there is a greater amount of casual/part-time work (Hanvey, 2005) and frequent closures of health institutions. These are not new findings; the scarcity of rural physicians has dominated rural health literature over the last 20 years (Sutherns & Haworth-Brockman,

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<sup>29</sup> This is reflected in Gordon Lightfoot and Anne Murray’s popular songs about life in rural Canada (Kulig & Williams, 2012) and in the iconic nature of Canadian wildlife, winter sports, and “the great outdoors.”

<sup>30</sup> My experience living in a remote location before and during this study both challenged and reinforced these stereotypes for me.

2012; Rourke, 1993, 2005; Drummond & Drummond, 2000). This shortage and related challenges were confirmed in my study when participants spoke about recruiting and retaining renal care professionals in their region. This applied to both physicians and nurses. One health professional told me:

R: It's very difficult to retain nurses. It's a) hard to attract them, and b) it's hard to retain them. We've got eight doctors that are leaving in the next two months.

I: Really?

R: Yeah. And it's... I don't think it's anything too personal to [community dialysis town] but a lot of our doctors come from [country overseas]... So they come and, you know, they do a lovely job, but they don't really want to settle in [community town]. They want their foot in the door. So there's a lot of exiting. And because [community town] is very transient, we're a very young community. I think the average age is...

I: Twenty-seven, I saw.

R: Yes. So there's a lot of people coming and going. So that makes retention very difficult. Because you might have someone who's working in the [resource industry], he's got a wife, and then they decide, "nah, I don't want to live here anymore," and then they're gone.

I: Right. Do you see that a lot?

R: Yes. Yes, yes, yes. I know we're losing a couple of good nurses, not in dialysis but in the hospital, because their spouses are moving. Which is too bad. So there's always a tension between the staffing and resources (Interview 1, 2013).

Another health care professional made a similar statement:

"It's hard to get people to go somewhere remote to live and work. And it's not just in medicine. I have a physician colleague who went to live and work in [remote town nearby]. And he went there and a few weeks later, his wife left him. And they never got back together. You know, she just couldn't see living [there]. For him, as a foreign medical graduate, it was one of his, I guess, best looking options. So there are challenges" (Interview 11, 2013).

It appears that despite the widespread discussion of the scarcity of rural nurses and physicians and the initiatives and incentives to increase their numbers, the shortage of rural health professionals continues to be a problem at my site of study. Additionally, the quotations above reveal that gender dynamics and family and/or marital living arrangements also influence the retention of rural health care professionals in the region. This concept is addressed further in the discussion section.

Current initiatives to increase the number of rural physicians and nurses (Government of British Columbia, 2013; Bilbey & Lalani, 2011; British Columbia Medical Association, 2012; Cowan, 2014) appear to presume that finances are the most effective incentive. However, once physicians and nurses are in rural areas, these individuals have minimal social and professional supports (British Columbia Medical Association, 2012). They may require some of the same supports that their patients do; they too are affected by the isolation of rural and remote living.<sup>31</sup> Existing incentive programs also reinforce the popular notion that primary care physicians are “the gold standard of health care” (Leipert et al., 2012, p. 9). Canadian scholars (Leipert & George, 2008; Leach, 1999; Sutherns et al., 2012; Haworth-Brockman et al., 2012; and others) are increasingly identifying the need for a more inclusive and broader multidisciplinary approach to primary health care in order to effectively address rural men and women’s health and reduce health inequities.

The community dialysis unit was adequately staffed with nurses at the time of the study, but the quotations above reveal that they still faced challenges related to staffing the regional health care system. As noted in Chapter 3, the nephrologists, social workers, and other health professionals at the regional dialysis unit are notably overworked due to the large size of their catchment area and the limited resources available to them. Patients are aware of physicians’ reluctance to work or continue working in the region and, in a couple of my interviews with patients, it became clear that this has the potential to create a sense of distrust. One patient said:

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<sup>31</sup> The University of Northern British Columbia (UNBC) offers a Northern Medical Program as part of UBC’s Faculty of Medicine. This program aims at recruiting and training medical students (including students of rural origin and/or Aboriginal status) to practice medical in Northern, rural, and remote communities. Experience in rural and remote contexts is an important component of candidacy for the program and preference is given to residents of BC, but applicants must still have competitive grades and extracurricular involvement. Though this is an excellent and important strategy for retaining rural health professionals, students of rural origin continue to be underrepresented in medical and nursing programs across the country (Society of Rural Physicians of Canada, 2004; Hanvey, 2005).

“[y]ou see, here in [this region], they don’t stay very long. Not too many of them. So I’ve got one doctor who’s been here since I’ve been here. So I’ve been pretty lucky, but you talk to other people and their doctor is [here] two months, three months, and then they’re gone. They get their training. We’re like guinea pigs up here. That’s the way to put it” (Interview 8, 2013).

Given that the family doctor is the primary point of contact in the health care system and the gatekeeper to specialists, distrust or unease on the part of patients can be problematic and potentially lead to delayed or missed care opportunities. One health care professional suggested that a strong relationship with a general practitioner is pretty well essential if a patient is to move forward for transplant:

“If I then hear back through letters that he has kidney failure, I can then advocate for my patient and say, you know, this young guy, previously entirely healthy, he’s been working in the petroleum gas exploration business, you know, he’s got a young family, with a kidney transplant, he will be well positioned to live, be with us, work, do the right stuff with his family. So GPs who can identify, refer, advocate for their patients, do the right stuff, keep them healthy through thick and thin, that’s number one priority. I mean if you don’t have that, not much else is going to happen right [sic]” (Interview 11, 2013).

In sum, my findings reveal that the scarcity of health professionals in rural regions continues to pose challenges for staff and for patients. In lieu of unpredictable staffing, there are broader concerns about the sustainability of particular clinics and/or services. Unfortunately, this can create somewhat of a catch-22 when continual hospital and clinic closures threaten job security and deter nurses from working in these areas (Hanvey, 2005). In the following section, I address the ways in which geographic isolation and the wide distribution of patients creates challenges for health care service provision.

### *Challenges with providing services to a widely dispersed population*

In addition to posing challenges for patients, I found that geographic isolation also creates barriers for health professionals who are trying to provide care. The distance from specialists, professional development opportunities, and other health services and associations can make holistic health care provision challenging. Family physicians are not always in contact with the dialysis nurses and the regional nephrology team. So, when patients visit one provider instead of another, it can lead to missed communications and

miscommunications regarding patient care (Government of British Columbia, 1999).

Health care professionals in this region must also work at keeping tabs on their widely dispersed patient population. One of them told me:

“Probably the biggest [challenge] is just trying to deal with the patients that are so far away. Not all of them are reliable by phone and a lot of them do have a lot of changes. You know, we want more frequent blood work or their blood work isn’t good so they need medication changes. And especially the ones that are low income and the First Nations people, they move around a lot. So trying to get a hold of them and pass on information, and try and get information from them, I think is probably the biggest barrier that we deal with daily” (Interview 6, 2013).

This quotation highlights how social location, such as Aboriginal status or low income, plays a role in long distance health care management. Unfortunately, the amount of work that is involved with accessing and obtaining care can condemn vulnerable individuals to non-compliance with their treatment plans. The entire travel process and ongoing engagement with the system can be so overwhelming that, despite health professionals’ best efforts, patients sometimes decline treatment altogether. Some might be inclined to ask, “Why don’t the patients just move closer to their health care provider(s)?” The following quotations from health professionals highlight some of the reasons why patients – particularly Aboriginal<sup>32</sup> patients – opt not to relocate:

R: Again, Greyhound has cut service to a lot of our [remote] communities. Our First Nations people, First Nations and Inuit Health will only fund for three months and then they expect them to relocate.

I: Really?

R: Yes. Well, for a lot of our elders... I mean we’ve got [older people] that are pillars of their community. I mean to ask them to uproot and move to [regional unit town] from a little reserve. It’s just not feasible (Interview 12, 2013).

R: We have some First Nations patients living in tiny, tiny little reserves where they’re not exposed to any outside influences really. So then we start bringing them into [regional unit town] and try and give them all of this information, and telling them about [all of the required trips, appointments, paperwork]... Like I’ve had one young fellow, he literally said, “Like, I just can’t do this. I just want to go out to the bush and die” (Interview 15, 2013)

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<sup>32</sup> Though most of the health care professionals use the term “First Nations,” I use “Aboriginal” because it is inclusive of First Nations, Inuit, and Métis peoples of Canada.

R: Well, we have several patients that should come [for dialysis] three times a week, but they only come twice a week just because transportation is a huge issue. We have a gal that's coming down now from [town ~375km away], again, needing dialysis three times a week, but that's unreasonable... And a lot of our patients are older and they don't want to leave their communities. We've got a couple people now who as of the end of [month] have no transportation. So I feel like I'm going around and around in circles with one because he says, "Well, I'm not going to move. I've been here 25 years. I don't see why I have to move." And basically then, he's making the decision to stay home and die, because he needs dialysis. And to him, the security of staying home is more important than living (Interview 1, 2013).

In the second and third quotations, patients expressed a preference for death – or perhaps, for living out their lives on their own terms – over undertaking the labour involved with attending treatment. On one hand, these choices can be viewed as a testament to the value of home and community, and a challenge to the notion that renal patients are so desperate that they will do anything in order to live. On the other hand, choosing death over relocation can also be read as indicative of the inadequacies of the system(s) in serving the needs of their most vulnerable patients. One health professional informed me about recent efforts to address these inequities:

“[t]he last time I went to Kidney Days, they had a meeting on transplantation in the First Nations community. And they were actually saying, you know, what we need is a period of affirmative action to get away from the issues of the past. And let's try and see how we can get every First Nations person who might be a transplant recipient transplanted as soon as possible. Let's find ways to break down these barriers. So that if a First Nations community person from [remote area] comes down to Vancouver for assessment as a potential donor, you know, if he's down there and he has some heart issue that has to be addressed, for God's sake, let's get it checked out while he's here; rather than let him go home and then realize that it might be we're going to have to move heaven and earth to get him lined up for the test again. So those are some kinds of things where, you know, we recognize that there are challenges in dealing with people living in rural and remote areas where we need to figure out how to do a better job” (Interview 11, 2013).

It appears that some systemic efforts are being made to address the transplant barriers faced by members of Aboriginal groups, but considerable work remains to be done in the realm of Aboriginal renal health more generally.

One of the biggest points of tension regarding dialysis care provision across the region is the fact that a number of residents from a particular neighbouring town (6 out of 10 of the patients attending the community clinic at the time of the study) have been fighting for a dialysis unit in their own town to avoid their lengthy, frequent commutes. This debate has been going on for several years and led to a regional consultation, news pieces in local papers, and discussions amongst and between patients and health care professionals. A number of patients discussed this issue with me. When discussing the issue with a health professional, I was told that building another clinic was not possible because of the unpredictable staffing and the widely dispersed patient population.

Interestingly, the discussion took on both practical and ethical tones:

“...[a]nd it was interesting, right, because – and we even met at [site with stakeholders]– and basically, when you tell them that you might build a dialysis unit or have the opportunity, they freak out because the nurses would rather work dialysis than Emerg. And then you say, “well that means that when your kids are in a car accident, your emergency room will be closed, but your dialysis unit will be open.” You know? So, is that really what you want? So none of the administrators or people in the hospital want that. Because there’s limited bodies. And you’ve got to consider the greatest good. When there are five of you on dialysis, you think the greatest good is about you” (Interview 28, 2013).

This utilitarian language of ‘the greatest good for the greatest number’ has been widely criticized in moral philosophy for its lack of recognition of the rights of individuals (Williams, 1973). While health care professionals need to provide the best services that they can for as many people as they can, the rights of those individuals are equal. A social justice or health equity approach does not favour the majority simply in virtue of their numbers – quite the opposite as special attention is paid to the rights and perspectives of groups facing bias such as women, people of colour, people with low incomes and other intersections of marginalization (Armstrong, 2001; Hankivsky & Cormier, 2009; Raphael, 2009). This is not to suggest that there is an ethical imperative to open additional dialysis units (the area’s patient population might drop, there are staffing and overhead costs that the system cannot sustain, etc.). Rather, I am identifying the tension between individual and collective health care needs and suggesting that the concerns of these dialysis patients warrant consideration and creative solutions. If the

discourse used to discuss the matter suggests a dismissal of patients' concerns by virtue of their low numbers, this could potentially lead to further marginalization or systemic distrust. The same participant also added:

“[y]eah and one of the things that we try to say to people is, you know, when you live in somewhere that is, you know, relatively devoid of the congestion of the city, and closer to this and closer to nature, and closer to this, this and the other thing. A simpler way of life, there's things that you give up. We all make choices. Right? And to think that, you know, you don't have to give up anything, all of us give up stuff – whether you live in the city or the country or rural or remote. I mean, those are choices. But when it comes to your health, sometimes you have to make decisions. You either move or you do other things. You know, I mean it's no fun driving 45 minutes in the city either” (Interview 28, 2013).

While there may be something compelling and/or understandable about this matter-of-fact response, the quotation is reminiscent of when Koch (2002) notes:

“[p]lanners may ask, ‘So what? There aren't enough people there to justify another transplant hospital. The price one pays for rural living is a diminishment of the services that must – for efficiency's sake – be located in the major cities' ... The problem is that when mapped, that argument makes a mockery of a *United States* and therefore of the laws promising equality to its citizens” (p. 187).

In other words, there may be very practical and operational considerations that prevent there from being more dialysis centres in large rural regions, but the resulting conditions can be at odds with a health equity agenda. The implications of these findings are discussed below.

## **Discussion**

### *Rural residence and the social determinants of health*

When it comes to renal care and accessing kidney transplants, geographical isolation places rural and remote residents at a disadvantage. However, this disadvantage is somewhat difficult to quantitatively confirm since so much of the kidney allocation process happens on a case-by-case basis at specific institutions and the data are not widely available (Canadian Blood Services, 2011; Madwar, 2011). In response to Tonelli et al.'s (2006) work suggesting that remote dwelling Canadians were not disadvantaged in terms of accessing a cadaver kidney, Zaltzman (2006) replied:

“[a]lthough Canadian guidelines have been established for assessing kidney transplant candidacy, transplant centres probably vary in their willingness to list patients with end-stage renal disease and increasing comorbidity. The true waiting list accrual rate is unknown. It is unknown whether the number of patients referred by primary nephrologists or accepted by the transplant physician and who live in more remote areas differs from the number of those living closer to the transplant centre” (p. 490).

This suggests that there is a gap in the understanding of the challenges that rural and remote residents face in terms of accessing cadaver kidneys. Given the social demographics, transportation barriers, and comorbidities of patients in rural and remote areas, physicians and nephrologists may be hesitant to recommend them for transplant in the first place. What can be taken away from Tonelli et al.’s (2006) work, though, is the notion that access to specialists, family physicians, regular dialysis treatment and care, and conditions for healthy living may be more significant determinants of receiving a cadaver kidney transplant than one’s proximity to the transplant unit.

It may not be cost effective or practical to open additional satellite dialysis units, but it is worth investigating the challenges that dialysis patients face and developing creative and effective ways to mitigate these challenges and improve care and health outcomes for rural renal patients. It is understandable that some health care professionals may feel exasperated with the regional health system or with trying to provide services to those who live so far away and who cannot always comply with treatment instructions, but perhaps the process requires collaboration with those outside of the health care system. The exasperation may stem, in part, from charitable organizations, social workers, and nursing staff trying to treat social, political, and economic problems within a clinical care setting where transplant surgeons and some nephrologists treat health and illness as isolated in the body.

While there are identifiable ways in which rural and remote places are distinct from dominant urban culture, they are also exposed to and shaped by it. The dynamic lives of the individuals who participated in my study are not divorced from broader Canadian culture. Their health is not solely produced within their remote region, but through, “a complex process of relations in specific rural places and in more urbanized,

social, cultural, political, economic and health arenas” (Bourke et al., 2012, p. 498). Those who live in urban areas do not experience the same place-based challenges experienced by my participants. A feminist political economy analysis of my findings highlights the intersection of spatial and social locations. It requires asking “who – which women and which men – are disadvantaged in light of current arrangements?”

My findings confirm that geographic isolation exacerbates inequities that result from other social determinants of health. Those who were most affected by the barriers posed by geographic isolation included women and men with: low incomes, Aboriginal status, multiple health conditions, low levels of education, and inadequate employment accommodations. Many of these people were seniors. In other words, it is my participants’ geographic isolation, in tandem with current social, political, economic, and health systems that prevents them from accessing various goods and services and provides the conditions in which they live and work. This highlights, once again, the tension between structure and agency.

This state of affairs may appear to some to be of my participants’ own choosing – deciding to live outside of a major centre, refusing to relocate, or declining alternative treatment arrangements. However, as indicated above, these decisions do not take place independent of the other elements that structure one’s life. For instance, it is not easy for an Aboriginal Canadian who lives on a reserve to simply relocate to a major urban city for renal care. Nor is it easy for an elderly patient whose family, church, and support system are in a remote town to uproot and live alone elsewhere – or for a labourer with a grade-eight education who has been in the resource extraction industry for 20+ years to navigate the many points of a complex care system and dramatically change his lifestyle. Furthermore, many residents of this region do not actively *decide* to spend their lives in the area. Many grew up in the region or moved there for work, not expecting to get married and raise a family there. So, yes, these individuals make choices about their lives and their health, but not always within conditions of their own choosing. By asking “which people?” and focusing on specific narratives via case study, the nuances of lived experiences come to light. Additionally, some of my participants’ narratives reflect a

preference for *living* over extending *life*. What I mean by this is the fact that the medical understanding of “life” is very clinical and measurable, whereas individual experiences of life are much more complex. Medical professionals may feel that it is unfortunate or irrational to decline treatment, but some patients may feel that they are choosing ‘living’ (work, family, care work, proximity to home, etc.) over extended or improved biological life. For those with very limited resources, there may be little choice at all.

Smith et al. (2008) nicely note that:

“[w]hile rural location plays a major role in determining the nature and level of access to and provision of health care services, it does not always translate into health disadvantage... Rurality per se does not necessarily lead to rural-urban disparities, but may exacerbate the effects of socio-economic disadvantage, ethnicity, poorer service availability, higher levels of personal risk and more hazardous environmental, occupational and transportation conditions... Focusing solely on ‘area-based’ explanations and responses to rural health problems may divert attention from more fundamental social and structural processes operating in the broader context to the detriment of rural health policy formation and remedial effort” (p. 56).

This quotation reinforces that the solution to the challenges faced by rural residents is not simply to suggest that they relocate to more convenient locations. Through analyzing the interview data, it became apparent that a variety of social categories acted as determinants of renal health and access to replacement therapies. As indicated in the quotation about the patient who flew in to dialysis and to the United States for a transplant, privileged and wealthy persons who live in remote areas do not experience the same challenges regarding access to health care or to health and life-sustaining resources. These individuals can more easily afford the time off, the travel and transportation, and the out-of-pocket expenses associated with obtaining treatment. This suggests that class and income were substantial determinants of renal health and access to treatment. The fact that access to and the number of health care options are so dependent upon individual circumstances reveals the extent to which health care has been individualized.

Gender also very much contributed to the challenges at this site. The high turnover of female nurses and physicians largely stems from the transient work of their male partners and spouses in the resource industry, and the prioritization of the male

partner's career. One participant mentioned that a male physician and his wife separated because there were not enough supports and amenities for her to build a life while he worked in the region. Rural gender roles, work, and family structures thus inform the decisions of health professionals to live and work in this region. This is also the case for patients in need of transplant. Paid employment and unpaid care work at home inform patients' ability to go to Vancouver for the time necessary to prepare for and recover from a kidney transplant. These issues are explored in greater depth in the following two chapters.

The scarcity of health professionals and the services that they provide is a matter of quasi-natural scarcity. That is, it is not only the case that there are a limited number of health care professionals available; it is also the case that the health professionals in the region choose not to stay there for very long. In other words, their scarcity is not solely a matter of the number of staff members. It is also a matter of the quality of life and of work for those practicing medicine and nursing in this region. This is a form of scarcity that can be remedied with changes in policy and practice. In the same way that a kidney transplant is not a cure-all for the health of an individual, transplanting more health care professionals from urban centres into rural areas will not resolve all of the broader issues regarding the challenges of life in a remote, rural region. A more nuanced understanding of these scarcities will yield a more nuanced response to them.

### *Conclusion*

Bourke et al. (2012) argue that rural health manifests in geographically isolated spaces, but is also the product of connections between actions in rural locales with macro level policies, funding, health systems, social determinants, and a range of broad processes. These systems and their physical and social boundaries are created by human actors and, as such, are amenable to change. So, though geographic isolation poses some very tangible barriers to renal treatment, the health care and political systems have the ability to modify their approaches to health education, care provision, and resource allocation in order to more effectively serve remote populations. Similarly, though there

are structural constraints that make renal health [care] complicated for remote residents, there are also opportunities for individual and/or group activism in order to improve or subvert these systems.

The geographic isolation of the site of study affects dialysis patients, transplant recipients, their families, and kidney care professionals. Throughout my participants' narratives, there was a tension between living life and pursuing good health. The health care professionals spoke to the tragedy of lives lost due to declined treatment or the inability/unwillingness to commute/relocate, but the patients spoke to the extent to which pursuing renal treatment in a rural and remote location can consume one's life. Frequent commutes, dangerous driving conditions, long winters, and limited public transit make it difficult for patients to access and maintain their dialysis treatments and renal care plans. Transplant preparation, surgery, and recovery require substantial travel arrangements on behalf of the patient, his or her family, and a potential donor, which is especially difficult given the low socioeconomic status of many patients in this region. Limited education in the region also poses challenges in terms of navigating the health care system and practicing health-promoting behaviours. Health professionals in this field can be left feeling as though the geographical barriers restrict them from providing care to the best of their abilities.<sup>33</sup> These findings are valuable for kidney transfer scholarship because rural and remote residents are disproportionately affected by particular social and physical conditions as a result of their location(s) and are also less likely to have their voices heard, their needs known about or met, or their health outcomes improved.

My findings confirm feminist political economy's claims about the significance of everyday places and of understanding people's health from where they are located. By examining my findings at the meso health care level and micro level of personal narratives, my feminist political economy analysis reveals some of the personal, practical, and political implications of living with chronic kidney disease in a geographically isolated area. This chapter also reveals two of the scarcity discourses identified in the previous chapter: the scarcity of health care and human resources and the scarcity of

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<sup>33</sup> Though it may allow health professionals to practice their full scope of practice.

health and life-sustaining resources.

Lastly, my findings are also complicated by the fact that the site of study is not only rural and remote; it is also a resource town.<sup>34</sup> Skinner et al. (2014) note that resource communities face unique health challenges because of the variable success of their local industries, the transient nature of their populations, and because these towns “were neither originally designed nor presently equipped to support older people” (p.2). These traits are said to distinguish these communities from experiences of aging in other rural areas (ibid). I would argue that these features also impact experiences of chronic illness, of aging *with* a chronic illness, and of aging while caring for someone who has a chronic illness in a resource town. In the following chapter, I explore this particular characteristic of the site by addressing the implications of gender, work, and health for those working in the resource industry and living in a resource town.

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<sup>34</sup> Not all of my participants live in the dialysis clinic’s town, but most of the patients and their families live in the surrounding area and also worked in resource industries.

## **Chapter 5: Work in the Resource Industries: A Feminist Political Economy Analysis**

Following the previous chapter's focus on health and place, this chapter focuses on place-related labour. Kidney transfer discourse very rarely includes explicit discussion of work. There are lengthy discussions about people and their parts, as well as the social and political systems in which they exist, but few researchers address the everyday labour that is performed by those who experience kidney failure or explore the ways in which working conditions contribute to an individual's kidney health. Discussions of how paid work intersects with gender are even more rare in this field. In this chapter and the next, I use a feminist political economy lens to address the intersections of work and gender and the ways in which these intersections inform experiences of kidney failure and renal replacement therapies.<sup>35</sup>

For participants in the region of my study, I found that the division of labour, the types of labour, and the health-seeking behaviours of workers were informed by gendered expectations. Rural places have a reputation for being gender normative (UN WomenWatch, 2012). They tend to be places where men and women perform traditional Western roles of masculinity and femininity. Though many people challenge these roles, and perceptions of gender are evolving, these norms remain across Canada (LaRose, 2011). During my interviews with dialysis patients and their care providers, I witnessed some harmful health effects of gender in this context. I also noted the ways in which these roles and participants' health outcomes were very much related to the work that they perform. According to Miller (2004), gender-specific work is actually an important aspect in the creation of gender differences. From this perspective, we not only prescribe certain work for women and men based on our perceptions of gender, we also form these perceptions because of the work that each gender performs. Examining this gender/work relationship is then critical in terms of identifying, addressing, and preventing gender-based health inequities. The Canadian Institute for Health Research (CIHR) explains the relationship between gender, work, and health in the following way:

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<sup>35</sup> Renal replacement therapies are treatments that replace renal function for individuals with chronic kidney disease and kidney failure. The term refers to hemodialysis, peritoneal dialysis, and kidney transplantation.

“[w]ork is an inextricable part of life—be it paid employment, or unpaid work such as caregiving. Gender and sex influence how we define jobs and divide work, whether worksites and equipment are physically suited to women and men’s bodies, and how risks such as occupational exposures affect workers who may vary by gender, sex or related characteristics such as body size, body fat levels, reproductive status or hormone levels” (Government of Canada, 2012).

All of the male dialysis and transplant patients I spoke with had worked in the resource extraction industries (oil and gas, logging, mining, etc.) at some point in their lives. This involves physical labour that is predominantly done by men. This work, and the culture surrounding it, is very much bound up with traditional notions of heterosexual masculinity (Anonymous citation, 2011a;<sup>36</sup> Anonymous citation, 2011b; Miller, 2004). A local colloquialism is that the local industry “turns boys into men” (Anonymous citation, 2011b). These men are taught to take risks, to ignore their physical ailments, tough it out, and work through the pain. They are often cast as the breadwinners for large families and feel as though they have no choice but to work, even when they feel unwell. Their gendered role of financial provider thus intersects with the needs of both the broader formal economy and their ‘familial economies of care’ (Fox, 2009). Similarly, most of the women I spoke with had husbands and/or sons in the resource industry. This very much shaped their family structures at home and the conditions for care work, which are discussed in the following chapter. None of the women I spoke with had worked in resource extraction themselves. In the discussion section of this chapter, I discuss how work in the industry may affect women.

In this chapter, I discuss work in the local resource industry, its impact on labourers and residents of the region, its relationship to gender and concepts of rural masculinity, and its political and economic significance. Special attention is paid to the demands of the everyday work itself and the physical, emotional, psychological, and financial challenges that workers face when undertaking these roles. I argue that an ethos of frontier living informs the ways in which local men perform their work and their

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<sup>36</sup> Under the advisement of my supervisory committee, I have anonymized the citations for articles and reports that could potentially identify the site of my study. There are three regional reports and one local news article that I draw from in this chapter.

gender. These performances have negative implications for the kidney health of these men, and the structure of their work poses barriers in terms of obtaining and maintaining effective renal treatments. Though this arrangement is harmful to the health of these men, it is not contested or adequately addressed by those in power due to the ideological underpinnings of the work and the industry itself. I suggest that the frontier discourse has been utilized to reinforce neo-liberal notions of individualism and to garner support for the privatization and leaning<sup>37</sup> of services. This is done by celebrating traditional masculinity, self-reliance, and individual responsibility for health while obscuring the ways in which this approach comes along with welfare state retrenchment and leaves these workers without adequate institutional supports and at heightened economic and social vulnerability. This is particularly worrisome in remote rural regions where isolation exacerbates the social determinants of health and residents are in need of a number of supports and services.

### **Historical context: BC's Gold Rush & the ethos of frontier living**

For historical context, it is important to acknowledge that British Columbia's provincial history is very much tied to resource extraction. In the 1850s-1890s, the province was deeply affected by the Gold Rush stampede, which spurred the emigration of tens of thousands of workers looking to strike it rich via gold mining (Berton, 2001). Many small rural towns throughout the province blossomed and boomed during this period, only to have their numbers drop dramatically once the Gold Rush had ended. A number of saloons were erected in these new towns and it is reported that there was a great deal of gambling and prostitution in these regions (ibid). Gender imbalances were pronounced in these rural areas, with women making up less than 20% of the population for some of the towns (Porsild, 1998, p.20). Though lots of wealth was extracted from the

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<sup>37</sup> In this context, the "leaning of services" refers to the diminishing role of the state in providing and funding public services and an increased reliance on individuals to produce their own good health. This trend also includes the application of market-based management techniques that seek to quantify and measure all possible aspects of service delivery and achieve maximum efficiency with minimal investment (Daly, 2012).

land, most of those who came to the region seeking fortunes ended up in poverty, “[i]t was also an era in which the rich grew richer and the poor poorer, when the ‘haves’ had almost everything and the have-nots’ almost nothing... when banks foreclosed and men quite literally died of hunger in the street” (Berton, 2001, p. 94). The influx of business to these regions also led to the displacement of many Aboriginal peoples (Porsild, 1998), as the development of British Columbia was treated as part of Western colonial expansion (ibid). These events have left a frontier legacy across Western Canada. Many of the themes and issues from this history were echoed in my participants’ present-day narratives.

In the interviews, many of my male participants drew upon what I refer to as an ‘ethos of frontier living.’ This ethos can be understood as a local ethical dialect that privileges family and community, self-reliance and independence from outsiders and larger systems, self-interest, survival skills, and tradition. Though rural places can be known for their communal living, this concept may only extend to those with community membership. Many of these rural ideologies of self-reliance have developed out of settlement and homesteading histories (Leipert & George, 2008), as well as out of building lives and communities for themselves in ‘untouched’ regions of the country. This ethos involves a commitment to ‘doing what has to be done’ and reflects various intersections of: working class labour, country-Western living, and preserving local traditions. These ideologies are important to residents given that many urban outsiders overlook or fail to acknowledge the resilience and resourcefulness of many rural communities (ibid). As such, community members remind themselves and one another of these traits and successes.

The ethos typically surfaced when participants discussed their work, their reluctance to complain about or voice their struggles, and their health-seeking behaviours. For instance, when I asked one participant if she and her husband received any assistance with paying for overnight accommodations related to dialysis care, she said, “No, we pay for it ourselves. And we never ask them to help us. So we don’t need any extra help from anybody” (Interview 10, 2013). She seemed to express pride in not

depending on anyone or any organization for assistance. As the conversation unfolded, it became very clear that this couple could, indeed, use a great deal of financial help. Later in the interview, the same participant said, “[s]o that’s how it is. We don’t ask for any help because it seems like you probably won’t get it anyway. So don’t bother asking” (Interview 10, 2013). This suggests that the ethos may also include elements of internalized social and/or cultural marginalization – that self-reliance is not only a choice, but also a necessity. The ethos was identified in individual decisions regarding health and wellness practices, the organization of care and care work in the region, and the local discourses around dialysis and transplant. Below are a few examples of how this ethos informs participants’ health seeking behaviours:

I: Is [medical tourism] the kind of thing that you’d ever think about?

R: No. I don’t trust nobody.

I: Okay. Fair enough. When other people talk about it -

R: Sometimes I don’t even trust the doctors here (Interview 8, 2013).

R: My family doctor? I don't know because I very seldom ever... I don't get sick so why should I go to the family doctor? This one I've got now, he's been here, I don't know, a few years, I guess... Yeah, it's very seldom that I'm sick so I don't have to go to the doctor. The only one I had to go to was when I was having that... Well, I was having a little heart trouble... That's cancer up there too, eh? I've had it cut out four times now (Interview 13, 2013).

R: When I got sick... I had very few sick days in my life and it worked against me. My wife gets mad at me because I don't... I won't take time off for an ache here or an ache there. But then they put me through this machine and it said my heart was... the main arteries in my heart was plugged up [sic] (Interview 24, 2013).

R: And I guess if I had went [sic] to the doctor a little sooner, possibly I could have avoided it. But when you start getting sick with dialysis, it's you don't know really if... There's not enough information out there that's telling people the symptoms that show up ahead of time. And I didn't know nothing about that [sic]. I knew there was something wrong with me but I was stubborn about going to a doctor and just about waited too long... I was just about dead (Interview 29, 2013).

Other examples of how the ethos manifested – and intersected with masculinity and work – are included in the following sections. As indicated above, health was spoken about by

most men as ‘the ability to work’ and work was often treated as a priority above their health. For instance, when one man was waiting on important results from his renal team, he told me, “I said it to them, I said, I’m trying to run a business up there. Do you think we could maybe get this boat in the water?” (Interview 20, 2013). Similarly, another man’s wife quit her full time job to perform dialysis on him at home so that he could continue to work on their ranch:

“I’m a diehard rancher. I come from a family of ranchers. We came here when I was 16... I’ve worked at other jobs too, because with a family ranch, you have to, but I’ve never left the ranch. I’ve lived on this place here that I have since 1969” (Interview 17, 2013).

This notion of health as the ability to work is reinforced in a report on the health of men in this region (Anonymous citation, 2011a) and in other academic sources (Leipert & George, 2008; Dabrowska & Wismer, 2012). In the following section, I address the work culture(s) and working conditions of many of the men living in this region.

### **Boom or bust: Challenges with work in the resource industry**

For those currently living in rural British Columbia, the resource industries provide employment opportunities that allow people with little formal education to make substantial salaries. Apart from generally low-paying retail or service positions, there is a limited selection of work opportunities in the region for non-professionals or non-farmers (Leach, 1999; Winson & Leach, 2002). The high pay from resource extraction work also dissuades some people from attaining higher education. A recent report noted that the average salary of young Canadian men (aged 17-24) working in the leading resource industry increased by 21% between 2001 and 2008 (CBC News, 2014). While salaries for men of this age rose, it appears that their school enrolment has declined (ibid). This is worrisome given that education is a determinant of health and lower levels of education are correlated with poorer health, increased stress, and less self-confidence (World Health Organization, 2014b).

The high salaries that these young men favour over education are also not particularly secure. The economy in this part of the province is based largely on resource

extraction, “which is subject to boom/bust cycles and vulnerable to the global economy” (Fiske et al., 2012, p. 405). This is particularly pressing in the community dialysis clinic’s town, given that this region is identified as having one of the least diversified regional economies in the province (Horne, 2009), making it highly vulnerable and dependent upon plentiful resource extraction. During times of economic decline, rural resource-based communities experience a loss of services most acutely (Fiske et al., 2012). This can lead to young men working numerous shifts of incredibly long hours early in their careers because of a lack of certainty about their future income and opportunities. This amount of work can be strenuous on their health and on their families.

Recently, the regional health authority put out a report focused on understanding the conditions of industrial camps in the province. Industrial camps are places where companies provide food and lodging for workers close to their work site. They are used to house transient workers for both short and long-term projects (Anonymous citation, 2012). At the time of the report, there were just under 2000 of these camps across the province. In the literature review and environmental scan, the researchers found that the majority of health related information and policies put forward by companies in this region focus almost entirely on workplace safety (ibid). However, the issues that were most pressing from a public health perspective were: the implications for health care infrastructure and use of services, mental health, overall well-being of workers and their families, problematic substance use and its impacts, public health and communicable diseases, and social and health impacts on host communities (ibid).

The increasing numbers of these camps make it difficult for regional health authorities to adequately track, monitor, and service them. The ongoing influx of workers also places added strain on the already limited rural health care professionals and service providers (ibid). The camps themselves are also reported to be hazardous. The atmosphere of some camps was said to be “prison-like” with little to do during down time and a culture of partying, heavy drinking, and drug use (ibid) – reminiscent of the excesses of Gold Rush towns. Workers do not leave these issues behind at the camps; they bring them home with them. For instance, the town where I conducted the study has

the highest number of workers on methadone in the region and the town's methadone clinic has a demand that exceeds its capacity (Anonymous citation, 2013). However, many workers are not at home all that often. They must leave their families for 12-18 hour workdays and often for shifts of 21 or more days in camp. This is difficult for them and for their family members who are left at home. It can be damaging to spousal and parental relationships since the workers – typically husbands and fathers – are absent for long periods of time.

The labour itself is stressful and dangerous. This creates added stress for workers about potentially becoming injured, unable to work, and financial hardship for them and their families (Anonymous citation, 2011a). Additionally, “men from the poorest communities still do the most dangerous jobs” (Doyal, 2001, p. 1062), which puts already vulnerable men at heightened risk. Shift work itself can impact and exacerbate all aspects of physical and mental health including: depression, anxiety, sleeping issues, injuries, and chronic conditions (Centre for Disease Control and Prevention, 2003). One study cited in the regional review found that the mobile workforce, paired with a culture of heavy drug and alcohol abuse, is related to increased rates of sexually transmitted infections and communicable diseases in the region of study (Anonymous citation, 2012). Once again, the negative health effects extend beyond the camps and affect neighbouring communities as well.

In light of all of this, the regulations for the industrial camps are being revisited. The authors of the regional review claim that it is unlikely that the companies running the camps will take on any further responsibilities regarding health promotion or general employee well-being (Anonymous citation, 2012). There is an industrial camp health plan being proposed by the regional health authority that addresses food, sewage, housing, and water issues on the sites. It asks for a procedure to address serious injuries and illnesses, and an additional statement is under consideration that asks employers to provide a balanced diet of sufficient quantity (ibid). It is good to see that the province is beginning to give these issues greater attention, but this plan is certainly not comprehensive. It is clear from the issues identified in the report that the regional health

authority's role in addressing the health of those in the industrial camps and their host communities extends well beyond the responsibilities outlined in the current regulations. In other words, the regional and provincial health care systems must compensate for the inadequacies in the housing and service provisions that these corporations offer their workers. This is troublesome given that the local health care system is chronically underfunded and the corporations that run these industrial camps generate billions of dollars each year.

In short, the natural resources located in this part of the country—paired with the region's isolation from other services and industries—have contributed to the particular living and working conditions that shape the health experiences of these residents. The industry's current regulations are inadequate for ensuring worker well-being and community health and these effects are tangible. This is evident in the reports and in the testimonies of my participants that follow.

#### *Men, masculinity, work, and rural identity*

As noted earlier, work in the resource industry is very gendered. “Extraction industries, especially in single-industry communities, exhibited some of the greatest job segregation” (Leipert et al., 2012, p. 13) with men engaged in most of the manual labour and women in support jobs such as administrative jobs or cooking and cleaning. This segregation exposes men and women to different health hazards. For instance, men are more likely to experience death or severe injury as the result of a workplace accident (Anonymous citation, 2011a; WorkSafe BC, 2012). The industry itself is considered masculine, “not only in the historical and contemporary demographic composition of its employees, but in its assumptions, values, and everyday practices” (Miller, 2004, p. 48). While the same can be said in a number of industries, these issues manifest in particular ways in this line of work and in a rural context.

Rural men typically engage in more physically demanding work than men in urban centres (Gregory, 2009). This work is also generally less safe since these men frequently work with heavy equipment in isolated areas or on their own. As a result, rural men are more likely to be under psychological stress than men in urban centres (ibid). In

rural places, it is less common for men to regard talking about their health as a ‘normal’ social practice and many men view visiting a doctor as a last resort (ibid; Anonymous citation, 2011b). This may be related to the ethos of frontier living and its discourse of self-reliance; however, concepts of rugged masculinity and ‘men’s work’ are also very much bound up with this ethos – perhaps inextricably. One man who participated in a community consultation said that he lived in a frontier town and that most men there learn to put on a tough exterior (Anonymous citation, 2011b). In Canada, the frontier is said to have originally represented hope, “[e]ven today, [it] often becomes an embodiment of hopes many thought they had long surrendered to the harsh reality of compromise and making do” (Conway, 1994, p.1). Today, it may represent the hope that hard work, risk-taking and perseverance will ensure financial success. For men tasked with the role of financial provider in a place where other resources and opportunities are often limited, the hope of substantial compensation and security from resource extraction work can be a driving force. In fact, this drive contributed to Jack’s transplant rejection:

“[I]ike, when I worked crazy stupid hours and was trying to get ahead in life, I’d work seven days a week, 12 to 14 hours a day in the oil patch. As a benefit to that, I never dwelled on the fact that I had a kidney transplant. I never dwelled on the fact that I had an illness. The drawback to that being you get carried away with work. Or with me, I’d get carried away with work, and I started to forget my pills, and I got lax... But I mean for me, I make really good money up here. Whereas like other people that even have transplants, they work 35 hours a week. You know, I work 35 hours in two days. And so it’s good because you don’t dwell on the fact that you’re sick. But when you’re sick, it’s a real pain” (Interview 26, 2013).

For this man, 35 hours over two days does not constitute “crazy stupid hours,” as he is no longer working seven days a week. Working this much certainly allows him to provide for his family of six, but it does not create conditions that allow for him to take good care of his kidneys and his general health. Being sick was spoken about as an inconvenience to his work schedule. Most of the male participants spoke in these terms.

The authors of a report related to men’s health noted that in the region of study, a man’s identity is “intricately interwoven” with his role of provider, and his ability to work trumps everything else (Anonymous citation, 2012). Rural men will often ignore

health issues that may interfere with their work, until the point where they do interfere –a time when the issue has usually become much worse and more challenging to treat (ibid). Similarly, the rural male identity also encompasses elements of risk-taking behaviours such as extreme outdoor sports, heavy substance use, driving in dangerous weather conditions, excessive alcohol use for recreation, and others (ibid).<sup>38</sup> Gendered social norms have excluded rural men from certain healthful practices. For instance, the perception that “real men don’t cook” has left many men unskilled in the kitchen and reliant on fast or processed/prepared food when forced to prepare meals for themselves (ibid). Also, as noted earlier, because men use health services less, public education and outreach efforts regarding sexual and reproductive health have been generally geared towards women (ibid). This has left many men in the region ill-informed about sexually transmitted infections and other related health risks.

Many of these concepts were confirmed in my study when my participants discussed their lifestyles, their families, and their kidney health. Almost all of the men spoke about being hard workers, not ‘complaining’, not seeking medical assistance until the circumstances are dire, and ‘doing what needs to be done’ in order to support their families. When telling me about the day that he discovered that his kidneys were failing, Peter really highlighted ‘the way life is’ for those in this line of work:

R: ...I was in pretty bad shape apparently. I didn’t seem to think so.

I: You didn’t feel anything?

R: No. I mean other than, you know, achy and sore. You know, don’t forget, I worked outside for 40 years.

I: Right. You’re used to being achy.

R: When you got up with a cold or an achy back, you went to work.

I: Right.

R: You know, you didn’t... you saw a doctor every 10 years, whether you needed to or not. That’s a man thing. But you’ve still got to feed those little mouths. So that’s just the way life is (Interview 20, 2013).

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<sup>38</sup> These qualities are not unique to rural men. Doyal (2001) argues that taking risks is a part of the development and maintenance of heterosexual male identity. Some of the risks that she mentions include dangerous paid work, high risk sports and hobbies, excessive drinking and smoking, and treating health care and health promotion as “women’s business” (ibid, p. 1062).

In this quotation, Peter refers to his behaviour as “a man thing.” He explicitly identifies a relationship between his gender role, his work, and his health seeking behaviours: one does not complain about one’s ailments because it would not be manly and because work has to be done, and said work cannot be passed up because one has the role of financial provider in the family unit. Regarding the “little mouths to feed,” research suggests that one reason that men in this region tend to keep quiet about their health issues is because they fear that others may think, “how well can you take care of your family if you can’t even take care of yourself?” (Anonymous citation, 2011b). A man’s kidney failure is then seen as his personal failure, a notion that is reinforced by the individualist, neo-liberal discourse commonly used to discuss health in North America – and in the resource extraction industries.

Jack told me more about how the demands of his job directly related to the rejection of his transplanted kidney:

R: So I got really lax about taking my meds, and ended up... I didn’t get blood work done for like five months.

I: And was that just because you were feeling pretty good and you weren’t worried about it?

R: I was feeling good, but the other thing was... I was working in the oil patch, and the oil patch, I don't know if you know much about it, but you leave at 5:00 in the morning and you get back at 9:00 at night. Well, you can’t get blood work done at night.

I: Right.

R: And you go to camp for months on end, and I’d be gone. Just the way it worked out... What do you do? And I was running my own company by that point. So I was pretty much obligated to work non-stop. I had to work. I had nobody... I couldn't afford to pay a driver other than myself. And I couldn't afford to take a day to go and get blood work done (Interview 26, 2013).

Forgetting anti-rejection pills, missing blood test appointments, and other results of such a demanding work schedule have forced this transplant recipient back onto home dialysis, which he now performs at night during his sleep. This young man’s story reveals the social determinants of his kidney failure. Changes to his work schedule and professional lifestyle might have prevented the need for a second transplant, but such changes are beyond the purview of the health care system and, as such, are often overlooked.

In the majority of narratives by these men, work was prioritized over health. Since not all of the men had extended health benefits, vacation time, paid sick days, or job security, there was a pressure for them to work while they were able to. Additionally, the minimal free time has the potential to place pressure on these workers to maximize their ‘fun’ during their off time, hence the binge drinking, heavy partying, extreme sporting, and other ‘hard-living’ activities. I spoke with one older man, Bill, who said that working people simply do not have the time to concern themselves with health:

R: Personally, I think we’re awful lucky [sic] in this country with the medical system we’ve got. When you fall off the rails, that’s when you find out... But yeah, for a working person who’s too busy working and trying to raise a family to worry too much about medical and anything like that [sic]. And it’s always been like this.

I: So you think that people are generally working so hard and so much that they don't have time to think about health things?

R: That’s right (Interview 24, 2013).

This view was consistent with what I heard from older male participants who had worked in the industry. Many of them had not been to a doctor in 10-40 years, and some appeared to say this with pride. However, despite their neglect for their bodies, these men were quite aware of how their work affected their health:

I: And what brought you [to the area]?

R: Work... We transferred for work, but I’ve always... You know, as I kid, I logged and then... I’ve always been in the oil patch sort of. Like I say, I’ve been working since I was 15. So I put a lot of years in, 40-odd years. And I worked hard. You know, I’d get out in the weather a lot, and every day. So that takes a toll on you (Interview 20, 2013).

“I worked in the oil patch for 50 years... you’re going all the time. And the oil rig, it’s a rougher part of your life. You’ve got work to be done and you don’t ask questions. You just tear right at it and you’d use up a lot of energy that way” (Interview 24, 2013).

Bill worked until he was over 75 years old. In addition to kidney failure, he has also had a stroke and a heart attack. When discussing the lifestyle that came with working in the industry, he told me:

R: [w]hen I was working on the rigs, oh, there were a lot of times you’d get called out and you didn’t have time to eat.

I: Right.

R: And I always packed a lot of chocolate bars and cans of pop to eat on the fly.

I: Quick snacks, right?

R: Quick snacks. And the other thing was the oil companies, when they were in trouble, they wanted you out there now... You'd just get into bed at night and the phone would ring. And I'd have to get out and drive all the way to [town], which is six hours of traveling... We were very hard on our systems. And there was no time for nothing else [sic].

I: You mean for anything outside of work? Is that what you mean? Like for family?

R: Well, the wife and I over the years have... We camped quite a bit when we'd get a chance. We liked camping and we liked traveling, but you couldn't think ahead too far. And all the boys in the patches are the same today. You make plans to go to a lake or something with your family, and get called to a rig way back in the bush. But you accept it as part of life. Either that or get out of it (Interview 24, 2013).

This notion of accepting this grueling work schedule and its precedence over health and family are not only issues related to the resource industry or concepts of masculinity, they are also reflective of working class life more generally. Men and women who do shift work in cities to support their families are also faced with similar 'choices' about balancing their health with their work and familial obligations (Mikkonen & Raphael, 2010). Though some workers in the resource industry may earn higher wages than those in many other working class professions, they rarely have the time, energy, or freedom to enjoy the fruits of their labour. This became apparent through the anecdotes about having to cancel family camping trips (Interview 24, 2013) or miss out on family reunions (Interview 5, 2013). The financial benefits that come with their handsome salaries are offset by precarious employment, hazardous working schedules and conditions, and the other social determinants of rural living.

In sum, these men perform work that is harmful or hazardous to them, they seldom speak up about these harms, and they have little work-life balance or time to tend to their basic health needs. It is difficult for many of them to abandon this work because of their roles as husbands and fathers and the link between these roles and the role of financial provider. The intersection of their gendered familial roles and their gendered workplace roles can have a negative impact on their health and on their kidneys. The

narrative of the younger man with the rejected kidney transplant captures the health impacts that this work can have earlier on in one's career; whereas the narratives of the older, retired men reveal its more long-term effects. This is not to essentialize or to say that there are not counter examples to these performances of rural masculinity. There are certainly workers and families whose experiences diverge from those I have discussed and there is ample room for things to change moving forward. However, my participants' narratives were quite consistent. The consistency and prevalence of these concerns suggest that these issues have not significantly improved as of yet.

### *Impact on host communities*

In addition to the impact that this labour has on the health of workers, participants also discussed the industry's impact on families and communities; the high cost of living in a resource town; the local environment; obligations that these companies may have to the communities; and implications of the ubiquitous presence of these companies' vehicles on the roads. The industry's transient workforce also influences the types of businesses and services that operate in the region. This determines what is available for those who reside in the region more long term and also leaves communities marked by a form of social transience (Fiske et al., 2012), where the frequent coming and going of friends, relatives, services, and workers can disturb the social networks established in the area.

Though a relationship to/with the resource industry can be identity constituting for many individuals and communities in the region, several people expressed criticisms and frustration with it. One participant asked me the following:

“[w]hy can't the [resource] companies put some money into funding a dialysis wing for the hospital in [our town]?... I mean they've taken enough out of us, out of the community. Why can't they give something back for a change?” (Interview 16, 2013).

This comment highlights a perception of the corporations' self-interest and lack of regard for the well-being of the community in which they operate. Some of these companies do occasionally contribute to the local community. For instance, one company made a

\$5,000 donation to the community dialysis unit. Another company provided some additional funds to support one of their employees (the son of a participant I spoke with) while he took time off to donate a kidney to his father. These are nice gestures, but I would hesitate to claim that they reflect altruism and a deep commitment to the community. Charitable donations can be beneficial for these companies in terms of tax deductions, marketing and public relations, and meeting corporate social responsibility obligations. Similarly, providing a token sum of money to support renal treatment is much less helpful than creating healthful workplaces, appropriate benefits and supports, and reasonable work schedules for employees.

In terms of environmental responsibility, Louis expressed his concern with how the industry affects those in the region:

I: Do you think there's anything else that we could be doing to improve the lives of people who are on dialysis?

R: Shut down all the factories. All the pollution that's getting in the air, that's what killing everybody.

I: The factories nearby?

R: Oh, yeah, they're bad. They say, 'oh, no, nothing is going to happen.' You know, they do it at the beginning and then the next thing you know... And then it all goes in the air... It's the same thing. You've got that plant down there, two plants down there. You've got one in town and one not very far out of town, maybe half a mile from town. Where does that go? That's why so many people are dying from pneumonia.

I: So you think that something that we could be doing is cleaning up the environment we live in?

R: They blame it on the people driving cars and that. Well, quit making them. It's as simple as that. They've got other ways [to power them] now... So what's their excuse? The oil companies don't want that. They've got oil to sell (Interview 8, 2013).

Louis was the only participant in the study to explicitly speak about environmental health hazards. His concern about air quality is well founded. The air pollution emissions from the local industries include toxins such as, "benzene and particulates, smog precursors, acid emissions and greenhouse gases, such as methane and carbon dioxide" (Environment Canada, 2013, para. 4). In 2006, Environment Canada published a report regarding the air pollutants from the oil and gas industry and these emissions are said to contribute, "17%

of the sulphur oxide, 21% of the nitrogen oxide, and 28% of the volatile organic compounds in Canada” (ibid). There have been minimal federal funds allocated to research on the health impacts of these practices, as well as a systematic silencing of those who speak out in demand of greater industry regulation (Klinkenborg, 2013). This is problematic for a number of social, ethical, and environmental reasons. The current federal government is doing very little to regulate the practices of these companies because the industries are a huge economic driver for the Western provinces and for the country as a whole. The industries in question generate *billions* of dollars annually. In the following section, I begin to unpack these political and economic concerns.

## **Discussion**

### *Commodifying labourers: Neo-liberalism and the “new” frontier*

The issues surrounding work in the resource extraction industries are very much tied to history, politics, and the broader economy. Despite the region’s isolation, wider Canadian culture, popular culture, national media, global information, and political discourses all influence the rural locale (Bourke et al., 2012). Broader historical, social, political, and economic structures manifest in rural BC that privilege capitalism, globalization, and Western culture. For instance, the province’s Gold Rush history and its present day role in the global resource economy inform work-related opportunities, culture, policies, and practices.

The conversations that I had with male dialysis patients and transplant recipients reminded me of Scheper-Hughes & Wacquant’s (2006) *Commodifying Bodies* and the various ways in which the bodies of vulnerable workers in an assortment of trades and professions (professional athletes, paid gestational surrogates, sex workers, and others) are treated as rentable, disposable, and/or reduced to commodities. Much of the organ transfer discourse focuses on the perks or perils of commodifying *kidneys*. Concerns are expressed about the ways in which donor bodies may be treated as reservoirs of spare parts for the elites (Joralemon, 2000; Cohen, 2002; Scheper Hughes, 2002), and I entered into this research attuned to this notion. Interestingly, my participants’ narratives reveal a

relationship between the commodified bodies of working class labourers and the failure of their kidneys, rather than simply a commodification of kidneys themselves.<sup>39</sup>

Marx's (1932) concept of alienation in the capitalist mode of production demonstrates the way in which workers lose the ability to determine their own lives or fully access the goods and services that result from their labour. Though workers are autonomous, those who own the means of production generally direct the workers' goals and activities – and also reap the rewards of the labourers' work (ibid). Similarly, Foucault (1978) discusses how state regulations of individual bodies are used to support power relations. Central to his work is the concept of 'biopower', which he claims was indispensable to the development of capitalism (ibid, p. 140-141). Biopower refers to the ways in which states “insert bodies into the machinery of production as objects of utility that need to be managed, and then exercise techniques of power at every level of the social body in order to ensure the social hierarchy and its internalization” (ibid, p. 141). When exercised effectively, biopower can create individual desires for particular social, professional, or gendered norms. Foucault (1977) argues that normalization is effective as a means of training and disciplining citizens because of its invisibility. Unlike codified laws enforced by authorities, norms are internalized and reinforced through self-surveillance and the judgments of peers (ibid). Feminists who draw upon Foucault's work often argue, “gender is constructed and maintained through discourse and everyday actions” (McDowell, 1999, p.22).

In the case of rural masculinity, the men in my study aim to build lives and identities for themselves that satisfy the needs of the state, systems, and structures in their lives, though they may not conceive of it this way. This is not to say that their actions do not also serve their own wants and needs, but rather, to point out how challenging it is to separate those from the wants and needs of the system(s). Their work provides good wages and the ability to provide for one's family. A man may feel very proud that he has worked hard in this difficult industry, even while knowing the toll it has taken on his

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<sup>39</sup> Though the discussion of kidneys as lifesaving medical resources in Chapter 4 suggests a commodification of kidneys as well.

body, his family, and his quality of life. As workers in the resource industry, their labour meets the needs of the capitalist system, but this work also puts them at odds with achieving the state's ideal of a healthy citizen. Once again, feminist political economy reveals a tension between structure and agency. The men in my study conduct their work within a frame of rural, working class, heterosexual masculinity. They exercise agency, but they do so within the confines of: capitalism, the health care system, the organization of industrial camps, the global resource economy, their families, and their prescribed gender role(s). As indicated above, their diets, their lifestyle 'choices,' their work schedules and duties, their renal care arrangements, and their time spent with their loved ones are all notably shaped by these external structures.

*Ethos of frontier living: Closing thoughts*

Resource extraction work and the ethos of frontier living are reminiscent of the notion of "the American dream" (Adams, 2001) in which 'freedom' includes having the opportunity for material success and upward social mobility. These are said to be achievable through determination and hard work. This discourse can be motivational and empowering for rural men, but it can also render them complicit with a system that often works to their disadvantage. Discourses are, after all, "marked by complexity and tensions; they compete for meaning and as they are taken up acquire new meanings that are often unintended and on the surface appear to be contradictory" (Fiske et al., 2012, p. 420). Indeed, there is a tension or contradiction between the rugged individualism of the frontier and the small town communalism that is present in these parts. The narratives of the men in my study suggest that the shaming or denial of dependency and vulnerability largely manifest in the workplace. The ethos is very much tied to resource extraction and the culture surrounding the industry in this part of the country. In the homes, churches, and communities of these men, there appears to be a stronger sense of interdependence and communal living. In other words, there may be competing values and ideologies at home and at the workplace. Once again, this reflects the tension between the demands of the broader economy and the demands of the familial economy of care.

The language of individual freedom, independence, and resilience all connote a sense of strength and capability – of not having to rely on anyone or anything beyond what you already have. However, as I have noted earlier, the frontier discourse obscures the ways in which the notion of individual responsibility for health comes alongside welfare state retrenchment and leaves rural residents increasingly without institutional supports and at heightened economic and social vulnerability. This stands in contrast to the dream of hard work leading to material success. When discussing the impact that ‘the myth of the frontier’ has for the Alberta oil industry, Miller (2004) notes:

“[s]elf-interest, competitiveness, power and toughness are characteristics of the frontier's enduring hero, the cowboy... Will Wright has argued convincingly that the cowboy hero is the American cultural icon representing individualism and independence, and that he is a ‘model for social action’ (Wright, 2001, p. 8). Wright suggests that the cowboy myth explains, in an engaging and understandable way, the theory of market individualism. It reflects both explicit theoretical concepts: ‘freedom, equality, rationality, autonomy, opportunity, private property’ (Wright, 2001, p. 1), and implicit factors: ‘the need for an open frontier, violence as a civil necessity, white male superiority, and an endlessly productive environment’ (Wright, 2001, p. 2)... Thus, the frontier and the cowboy create a specific present day consciousness reflected in the culture of the oil industry in Alberta” (p. 62).

It is not surprising, particularly given the province’s Gold Rush history, that similar themes surfaced in my exploration of British Columbia’s resource industry. The ethos of frontier living is further complicated and contradicted by the fact that the notion of British Columbia’s frontier is, itself, contested. Frontier discourse is used ubiquitously throughout the province<sup>40</sup> to promote rural identity and pride and yet, its historical narratives often mask colonialism, homogenize Aboriginal peoples, and dismiss land claims (Furniss, 1998). These stories dominate historical discourse in many BC towns and the “myth of the frontier” becomes, “a discourse that shapes how local residents understand the past, the present, and their relationships with one another” (Funiss, 1998, p. 12). In other words, the idea that these communities were built on untouched lands

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<sup>40</sup> In the following chapter, I cite examples of how the health care system employs this discourse.

without assistance from anyone is fictitious. Some variations of the frontier narrative recognize the self-reliance and survival skills of Aboriginal communities, but they tend to celebrate the resilience of these groups and generally downplay the impacts of colonialism (ibid). In considering the political and economic aspects of gender, work, and health, it is valuable to unpack the history of the region and its resonance in current practices and policies.

Discussions of kidney replacement policies and practices must not only include contextual elements regarding place and space or the structure of the related system(s), they must also look at the everyday lives of those experiencing kidney failure and the determinants of their health. For many years, my participants' everyday lives involved work in conditions and industries that were not conducive to good kidney health. Initiatives that are designed to treat failing kidneys or prevent chronic kidney disease often neglect work and the conditions in which patients spend the majority of their time. A feminist political economy perspective allows for the re-contextualization and re-politicization of rural men's kidney failure and recognizes the broader determinants of their health.

In this chapter, I advocate for greater consideration of "work" in kidney transfer discourse. I used a feminist political economy lens to address the intersections of work and gender and the ways in which these intersections inform everyday experiences of kidney failure and renal replacement. I found that the division of labour, the types of labour, and the health-seeking behaviours of workers were highly gendered. I argue that an ethos of frontier living informs the ways in which local men perform their work and their gender. This ethos informs the attitudes and behaviours of men who work in the resource industry and typically works against those who espouse it because it often requires a denial or shaming of dependency and vulnerability. The ethos may also involve an internalization of one's spatial and/or social marginalization in ways that can be empowering and/or oppressive. Within this context, gender and work have direct implications for the health of men's kidneys, their ability to screen for illnesses, the time

they have available to follow up about diagnoses, compliance with treatment plans, their ability to maintain a healthy transplant, and more.

I do not intend to ignore the work of women in the resource extraction industries. Though the major local industry is still largely male-dominated, there are certainly women working in this field. They too face a host of gender-specific work and health issues that merit exploration. However, none of the women that I spoke with had worked in these industries themselves, so my data did not capture this experience. Miller (2004) has taken up research of this nature in Alberta, Canada. She claims that women in Alberta's oil industry: are still underrepresented in number, they frequently experience "everyday paternalism and condescending chivalry" (p. 49), are excluded from informal work-related networks and activities, face a contrast of "women's roles" and "normal roles" (p. 65) in the workplace, and often feel pressured to adopt more aggressive approaches for interacting with Alberta's 'tough' country-Western men. Given the industry and demographic-related similarities between the provinces, there is reason to suspect that one might find similar results in rural BC. This type of project is a valuable avenue for future research.

The issues surrounding men, masculinity, and work are not divorced from the issues that confront women and the work that they perform. In the next chapter, I examine the gendered nature of unpaid care work, what it means for familial economies of care and the broader economy, and the implications of offloading care from health institutions onto individuals and their families. This offers further insight into the tension between individualism and interdependence.

## **Chapter 6: A Feminist Political Economy Analysis of Care Work for Renal Patients**

The previous chapter addressed gender, work, and health with a focus on the paid work of men in my study, the health impacts of rural masculinity, and the ethos of frontier living. This chapter focuses on women, unpaid health care work, and changes in health policy. In addition to all of the hard work and committed care provided by the nurses at the community clinic, a great deal of a dialysis patient's care takes place in his or her home. This chapter addresses the work that goes into caring for renal patients beyond the formal health care system. In the community dialysis unit and surrounding communities, there is certainly no scarcity of caring. In fact, the system heavily relies upon unpaid care work. It is estimated that, "upwards of 70% of all care provided for ill or dying individuals in Canada is provided by family caregivers" (Williams et al., 2010) and most of this care is provided by women (Armstrong, 2012). However, my participants' narratives suggest that resources and supports for those who provide unpaid care are quite scarce. When I spoke with my key contact during member checking, she noted that over her career she has come to realize that it is, indeed, the unpaid care workers<sup>41</sup> who bear the bulk of the work for dialysis patients with minimal recognition for it.

In this chapter, I discuss family care workers and the various types of care that these individuals provide for dialysis patients and transplant recipients. Many of the women I spoke with held paid positions at various points in their lives, but primarily assumed 'caregiving' roles within their homes. This work often goes unacknowledged or inadequately supported because it has traditionally been seen as an extension of women's 'natural' caregiving duties and their roles as nurturers (Coltrane & Galt, 2000). This unpaid health care work often comes with negative consequences for women's health

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<sup>41</sup> The term "caregiver" is contested in care work literature (Harrington Meyer, Herd, & Michel, 2000) because it presumes that family members, particularly women, will "willingly provide care regardless of personal consequences... that the care is given freely at no cost, or at a cost that the giver is willing and able to shoulder" (p. 2). In short, the term implies a choice to provide care that most care workers do not experience. For this reason, I have used the terms "care worker" or "family care provider" wherever possible.

and/or their economic security (National Coordinating Group on Health Care Reform and Women, 2002). I identify the interesting ways in which families are structured and restructured in order to support unpaid care work. For instance, some older dialysis patients will move in with their children and then provide care for their grandchildren, separated spouses may decide to cohabit again to accommodate care needs, some relatives will donate one of their kidneys, and some couples will separate because of the heavy workload that the care demands.

Drawing from two of the most compelling narratives, I address some of the challenges that unpaid care workers face in their daily lives. Many of the care workers I spoke with were consumed by caring duties, concerned about neglecting their own health, and worried about the implications for their families and their finances if they too were to become chronically ill. A number of them expressed some sadness that they were not able to enjoy their retirement and some disappointment about being unable to travel. None of the familial care workers held remunerated jobs. For some this was because the high demands of care work required them to leave the workforce, and for others it was because they were retired.

Using a feminist political economy lens, I examine the gendered nature of work in this context, what it means for familial economies of care, and the implications of offloading care from health institutions onto families and individuals. I argue that the shift towards home-based renal care reflects the domestication of health care (Childerhose & MacDonald, 2013) as well as a shift towards smaller government. It can be seen as part of the domestication of health care insofar as it allows patients to perform medical interventions themselves in their homes. This liberates them from the lengthy commutes to the clinic and permits them the flexibility to dialyze at times and for durations that are best suited to their needs. It also encourages them to be active in, and informed about, their care and their conditions. However, a consequence of shifting treatment from the clinic to the home is that a substantial amount of work and responsibility is transferred from institutions to patients and their families. This type of systemic reform shifts away from publicly funded care towards privatization and cost

cutting. Behind these transitions is an assumption that family members, usually women, are best suited to perform care work and that they will willingly do so without personal expense.

Caring for relatives who live in close proximity is common for those living in rural areas, as they tend to have larger families and higher proportions of dependents, both children and older adults (Coward et al., 2005; Crosato & Leipert, 2006). Care for renal patients is provided and expressed in multiple forms. For instance, care work can include being a full-time/live-in care provider, providing emotional support, running errands for dialysis patients, driving them to treatment, managing their medications, administering their home hemodialysis, changing their PD bags, paying their bills, or even donating a kidney. On top of all of this, those providing care must also attend to their own needs and maintain a household. Two of the family care providers I spoke with performed home dialysis. Home dialysis treatments can be beneficial for patients, but there are also practical challenges associated with it. For instance, administering hemodialysis and maintaining the machines is a lot of responsibility for patients and their family members, the equipment takes up a large amount of space in the home, and there is no trained professional present to help out if and when things go wrong. Home dialysis can also be isolating, as there is little to no social element to it.

With an aging population, increased rates of diabetes and kidney disease, and the province's push for more home dialysis and PD, the numbers of relatives assisting renal patients at home can be expected to increase in the coming years. It is important to examine the effects that this has on those providing the care, as well as the conditions for care work. According to a study by Belasco et al. (2006), the quality of life for those caring for hemodialysis and PD patients is generally lower than average, “[a]nxiety, fatigue, deterioration in family relationships, social isolation, and stress can occur when caregivers take charge of home dialysis for either adult patients or children” (ibid, p 955). Similar findings were confirmed in my study and are outlined in the sections below.

### **Context(s) for caring**

### *Gender and work inform decisions about renal care*

Care work has historically been considered within the realm of women's work (Fiske et al., 2012; Kittay, 1999; Herington Meyer, Herd, & Michel, 2000). Kittay (1999) suggests that gender equality still eludes many women largely because social institutions fail to take into account the dependency<sup>42</sup> that is experienced during childhood, illness, disability and old age, nor do they adequately support those who provide care for dependents. As noted earlier, scholarship in feminist political economy has largely contributed to the increased recognition of the domestic sphere as being of cultural, political, and economic significance. The family economy (in terms of finances) and the familial economy of care (in terms of the division of labour and care provision) can both inform and/or reproduce broader systems (Coltrane, 2004). In other words, institutions can mimic the structure and dynamics of households in terms of gender roles; the distribution of power, resources, and responsibility; and the organization of work. Similarly, workplace dynamics and structures can be recreated in the home. The private and public spheres do not exist in isolation from one another.

Feminist political economists conceptualize care work in a number of ways, as “multi-dimensional practices, as unpaid domestic and voluntary labour, paid labour, a burden, a sacrifice, and as women's work” (Fiske et al., 2012, p. 419). My findings align with these conceptions of caring and include financial care provision, family restructuring, and kidney donation as care work. Care work has traditionally been invisible from a systems perspective. A feminist political economy perspective makes this work visible, highlights the gender-specific challenges that women face when adopting caring roles, and identifies the ways in which these roles interact with other components of the system(s).

Both gender and work are very much related to decisions about renal care provision. For instance, one care worker I spoke with, Lois, had to quit her job in a major urban city to return to the farm to provide full time care for her husband because his

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<sup>42</sup> By “dependency” Kittay means our reliance upon others to provide us with care and assistance.

home business was their major financial support. It appeared that their living apart had been for work-related reasons rather than a separation. She told me that they had struggled with making the trips to the regional dialysis clinic and so home hemodialysis provided by her was their best option, “[y]our main breadwinner, a lot of times, is the one that’s on dialysis and you just don’t have the money [to make those trips]” (Interview 17, 2013). For Lois and her husband, work and economics very much shaped their treatment decisions as well as their care work arrangements. Lois’ husband was not a transplant candidate. In situations where the primary income provider is ill, spouses have the option to donate a kidney in order to secure the breadwinner’s ongoing employment and survival.<sup>43</sup>

Lois’ story reveals that the household economy and factors such as the higher income of many men can impact donor willingness and treatment decisions. This finding is supported in existing research (Zimmerman et al., 2000; Jindal et al. 2005). For instance, results from a Canadian study suggest that the gender disparity among living kidney donors can be largely attributed to “an overwhelming predominance of wives among spousal donors” (Zimmerman et al., 2000, p.534). Of spouses in this study, 36% of wives and 6.5% of husbands who were deemed eligible donors went on to donate a kidney (ibid). More generally, women become organ donors much more often than do men (Lock & Nguyen, 2010) and yet, women are less likely to receive transplants (Biller-Andorno, 2002). As noted in Chapter 1, research from Mexico reveals that it is often mothers who are expected to donate kidneys, “their sacrifice is part of their prime role as nurturer of the household, and ultimately their bodies are thought of as more expendable than those of working men” (Lock & Nguyen, 2010, p. 249). Similarly, in my study, Jack’s wife and mother of his four children, offered him her kidney in spite of their failing marriage (Interview 26, 2013). Three wives I spoke with left the workforce to care for their husbands.

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<sup>43</sup> In the event that the spouse is not a blood type compatible donor, the couple can register for the Paired Donor Exchange program.

These findings reinforce the relationship between gender, [care] work, and [donor and recipient] health. However, these trends are not necessarily predictive and there are cases that challenge them. For instance, Jack declined his mother's offer to donate a kidney, despite the benefit to him and his career, because of his family's concern for her well-being (Interview 26, 2013). Another transplant recipient I spoke with – Ruth, a woman in her 50s – received a kidney from her son who was still very involved in the workforce (Interview 21, 2013). Additionally, after Frank's wife left, he cared for his daughter on his own (Interview 16, 2013). There are many complex factors that informed the treatment choices and caring labour of the participants in my study and these examples illustrate that the care provided for loved ones is not *solely* determined by gendered expectations or finances. That said, these social constraints shape the treatment choices that are available.

*“Good Health Begins at Home”: A systemic shift towards home care*

In my document analysis and interviews with health care professionals, I found that emphasis is placed on different treatment options at different levels of the system. As noted earlier, at the federal/provincial levels, kidney transplant is most strongly encouraged. This is evident in the prominent awareness-raising and donor recruitment campaigns and initiatives led by the organizations documented in Chapter 3. At the provincial/regional level, the push is for home hemodialysis or PD. At the community clinic level, efforts are primarily targeted toward compliance with dialysis attendance and care plans. This varying emphasis reflects different needs and goals at each level of care, as well as varying proximity to renal care patients and their daily lives.

Home dialysis and/or PD are encouraged by several provincial organizations and are popular in documents regarding renal care in BC. For instance, the BCPRA (2013) put out a brochure titled *Dialysis Options in BC: A guide to making the treatment choice*

*that is right for you*<sup>44</sup> in which there is a notable emphasis on home-based treatments. On the second page of the brochure, there is a large header reading, “Good Health Begins at Home” and the following four pages outline the benefits of home dialysis and the benefits of having patients manage their dialysis care on their own (ibid). Though they acknowledge in-centre dialysis as an option, they do not provide a detailed outline of its benefits. There is also a series of questions and a lifestyle chart to help guide patients’ dialysis decisions. The brochure highlights the lower cost of home dialysis. It states that while there may be increased costs regarding water, sewer, and power usage, “the cost of traveling to the dialysis unit three times per week (gas or HandyDART, parking, and meals) are most likely higher” (ibid, p. 7). In this instance, home hemo is presented as saving costs to the patient, rather than to the system.

The emphasis in the BC Renal brochure is that patients ought to guide their own care. The brochure notes that regardless of the treatment method selected, “[y]our kidney care team will support you with being as active as possible in your care” (ibid). Research suggests that home dialysis *is* an excellent option for many people since more dialysis is better and patients have more control over their lifestyles (BCPRA, 2013). Home dialysis also has benefits in terms of improving the ease of work and travel. Bringing dialysis to the patients’ homes is an effective way to reduce high costs for the system, reduce the travel that is so challenging for patients, and provide high quality care to patients in remote regions. However, it is also important to identify the political and economic incentives for encouraging home-based care, as well as its implications for those at home.

The impetus toward home therapies at the provincial and regional levels is not surprising given that home dialysis saves the government a great deal of money. There is a one-time set up fee, but there are no staffing or overhead costs. I was informally told that the BC Renal Agency has recently set a goal of getting 33% of their renal care patients onto peritoneal dialysis at home (Personal communication, 2014). This goal will only be achievable if PD ends up being an effective treatment for a third of BC’s dialysis

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<sup>44</sup> On the agency’s website, there are 21 pages of documents for patients to access and this brochure is listed first, as the most popular document accessed. This speaks to the wide reach of its message.

patients – something my key contact seemed uncertain about. At the community clinic, three people I spoke with were ‘failed PD’ patients. The practice of changing fluid bags from one’s abdomen four to six times per day and maintaining a clean and sterile catheter entry area is not feasible or realistic for everyone. Most of these participants experienced infections. Additionally, one health care professional told me that, “some people come in on PD and you cannot understand why that choice was made, given their body [sic]” (Interview 1, 2014). In other words, not everyone will be a suitable candidate for PD or home dialysis. One dialysis patient I spoke with told me about his reluctance to use home hemo:

I: You mentioned that there are some horror stories you heard about home dialysis. Can you tell me about some of those?

R: Well, there was one guy here, a big guy, 6’4”, you know. And he worked construction all his life. Had a bunch of Cats and a bunch of track hoes. And then of course he probably had the same thing happen to him as me, he had to go to work, you know. And if you don’t go to the doctor, once every 10 years... And I guess he was hooked up at home, and something happened and that was the end of him. And he wasn’t doing it at home for very long. He was doing it in here on the same days I was actually. You know, just things like that. What would happen if we had a crisis at home? Could my wife handle it?

I: Right.

R: And not to blame her in any way but...

I: But that’s a lot of responsibility?

R: Well, yeah. And I don’t like that. Plus, you have to have a lot of storage for all the stuff. You know, we have a couple of little dogs. Everything has to be sterile. Oh, we couldn’t do that. I’d have to add a whole room onto the house (Interview 20, 2013).

One of the family care providers, Wendy,<sup>45</sup> told me that issues regarding her health were the primary reason why her husband received dialysis at the clinic rather than at home:

I: I see. And generally would [husband] be a candidate for home dialysis?

R: I don’t think so. No, I think we’ve got far too much on our plate right now.

I: Yes, I’m sure that would add...

R: Because I’ve got my own issues too... And the more work I get, the more I’m going to likely not be able to handle it. Right now I seem to be handling it very well with what we’re doing. But you know, if you put any more on the plate, I’m not so sure.

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<sup>45</sup> Once again, all participant names are pseudonyms.

I: Right. Yes, because that's extra work at home as well.

R: Yes. So I get all his medication and stuff, and then I've got to remember, "did I take my own?" (Interview 24, 2013).

In short, though PD or home hemo have a number of clinical and economic benefits, they do not necessarily suit the lifestyles and living conditions of all renal patients.

As noted above and in Chapter 3, for those at the community clinic level, there was primarily a push for compliance with care plans. Those who are closest to the patients are well aware of the daily challenges that they face and recognize how difficult it is for these individuals to regularly attend dialysis and comply with the kidney diet, roster of medications, and any sort of exercise regimen. At different levels of the system, there are different needs, goals, and priorities. Those in administrative positions will always have slightly different concerns than frontline workers – and this is the case in many areas of medicine or business. Those at a distance from the rural patient-experience may recognize that home-based therapies and transplant are cost effective and efficient alternatives to life on dialysis, but they are not always attuned to the local challenges associated with these treatment options.

### **Family restructuring and kidney donation as care work**

Accommodating the care needs of a renal patient often involves restructuring elements of family life. This can mean restructuring the home to include a dialysis room, reorganizing work and life routines, rearranging family living configurations to meet the required care needs, and redistributing kidneys between family members. Six of the dialysis patients and one transplant recipient said that they were currently living with their children or their parents and one dialysis patient was staying with women from her church group. Two of the four transplant recipients had received kidneys from immediate family members.

For some families, the dialysis patient would move in with his or her child for support, and then provide some care for his or her grandchildren in exchange. This sometimes took the form of watching the young ones after school or preparing meals for

the family to create an intergenerational system of caring. For those with large families, multi-generational living arrangements can be difficult to manage, as there are so many different peoples' needs, preferences, schedules, and abilities at play. Conversely, having a larger family with multiple children can also be an asset as it provides several options in terms of who to reside with or receive care from – or a sharing of duties amongst the descendants. One of the participants said:

R: [Our daughter and son-in-law] say we have to move, which we know. But we've got to sell our place. And of course it's going downhill because we can't do the work on it anymore. So we want to get enough to cover any bills so we're clear of bills. That's our priority. Just sell it to pay the bills. Well, they've got a bedroom suite in the basement of the house and they can't make up their mind whether they want family there or not. And I can see their point. So the other day we went and looked at apartments catering to seniors... But when we told them we were looking at these apartments, well, "You can't afford that. You can't afford that." Now they're really getting working on the suite. You know, they had some bad renters in there. And then his family says, sort of, "no because it's family." [Daughter] says, "I always wanted you to live where we can keep care of you." So what do you think? He's sitting there, and all we can do is say, "Well, we looked at another apartment," to get them moving again... And the other daughter, if we run short, which we often do, about \$100 before the end of the month, she's always there to lend and to help (Interview 4, 2013).

Several dialysis patients mentioned having their children help them with housing or its associated costs. Financial provision is also very much a form of care work. This type of care requires a reorganization of finances and/or living arrangements for one or more households. The work involved in caring for a dialysis patient has sizable implications for the lives of multiple family members or friends and a single person's care presents significant changes in a number of people's lives. Those with little to no family to care for them are especially vulnerable. Because care work is such a large undertaking, some relatives consider kidney donation less burdensome than relocating or giving up paid employment.

In several participants' narratives, kidney donation was implicitly discussed as a form of care provision. These narratives reflect a restructuring of family members and are discussed below. In an early study on gender disparity in kidney donation, it was found that compared with men, women were more likely to perceive donation as an extension

of their obligation to their family (Simmons & Klein, 1977). Though donating a kidney may be seen by some as an extension of ‘caregiving’ or as the ethical imperative for a loved one (Lock, 2002a), these exchanges do not happen independently of the existing and often complicated relationships between donors and recipients. Though the BCPRA and the provincial health care system strongly encourage living related donations, the rearrangement of bodies and redistribution of kidneys between family members can present a number of challenges. For instance, Jack told me about the complex family politics surrounding kidney donation in his family:

I: Does it make a difference to you if it’s coming from someone that you know or a stranger? Like does it feel easier to digest as an idea if it’s someone you know? Or does it not make a difference?

R: That is actually a very touchy subject for me, because my dad gave me my first transplant, right? Well, a few years ago, me and him [sic] started having family problems and he actually told me he regretted ever giving me my kidney. So for years and years and years, I swore that if I ever lost my kidney, I would never accept a person I knew to give me it [sic]. I didn’t want to know them so that it could never be thrown in my face, it could never be used against me.

I: Right.

R: Well, I lost my transplant. My mom and my ex both went for testing. They were both matches. I didn’t want to take my mom’s even though she was older and the doctors wanted me to take hers in case in I lost a second transplant in the future. Because I had my siblings tell me basically that if anything happened to mom, they’d never forgive me. So...I was going to take my ex’s kidney – and she wasn’t my ex at the time. The long and the short of the story was the only reason why she was giving me a kidney was so that she could leave me and I’d be healthy (Interview 26, 2013).

Jack’s story reveals that the willingness to provide care via kidney donation can change along with changes in the relationship. This is important to recognize given the dominant biomedical view of kidney transfer as a technical medical procedure and an exchange of abiographical material (Brodwin, 2000). Care provision can require substantial changes not only to the households and/or finances of patients’ loved ones, but also to their bodies. The sacrifices of those who provide such care are often understated. Jack’s wife offered her kidney so that he would be well in her absence – and perhaps also so that he could continue to provide financial support for their children. This mode of care

provision was not unique to their case. Another transplant recipient, Charles, and I had the following exchange about transplant and his family politics:

I: I was just curious about that conversation with your sister in terms of did she bring it up, had you asked her about [donating a kidney]?

R: No, I brought it up. I actually brought it up with the whole family. I think it was at my dad's funeral actually that I brought it up with the whole family. And she was the only one who was willing to do it.

I: I see.

R: Because my one sister ended up with cancer. My brother has a condition but they can't figure out what it is. Every once in a while, it's almost like he has a heart attack but they can't figure out why. I can't remember why the other two wouldn't do anything. But then [sister]'s got a family that she's raising on her own so...it's complicated (Interview 22, 2013).

I also spoke with Ruth whose sons were both busy working in the resource industry and were unable to provide her with daily care or drive her to her dialysis appointments. As a result, one of them decided to give her a kidney. She said that he did this so that she would have an improved quality of life and be relieved of the regular clinical obligations associated with dialysis (Interview 21, 2013). In the following section, I note that Margaret says that caring for someone means giving yourself to his or her needs (Interview 10, 2013). While I am quite sure she was not referring to physically giving a particular part of yourself, her comment is relevant for this son who gave himself – via his kidney – to his mother's needs. In this instance and in Jack and Charles', families were *anatomically* restructured in order to provide care for the renal patient.

In the cases that follow, I describe the restructuring of two particular families. I discuss how Margaret moved back in with John to care for him after they had been separated and how Frank's wife left him to care for Alice alone. Given the number of participants who told me that they were living with their parents or with their children for temporary or indefinite support, it became apparent that the care required for a patient with renal failure is so demanding that most rural families cannot continue to function with their previous arrangements. Families are re-arranged spatially, financially, emotionally, professionally, and even anatomically in order to care for a renal patient. When considering recommendations for changes in policy and/or practice, it is important

for those in power to understand that though it may appear that family members can readily provide care outside of the health care system, this amount of care work often requires patients, care providers, and other family members to dismantle and/or rearrange their living and working arrangements in order for this to be possible.

### **Cases of Caring: Margaret and John**

In this section and the next, I draw from the narratives of two specific informal care providers. I use these narratives as points of entry into the issues. The narratives, as expressed by the participants in their own words, really highlight the extent that care work can dominate one's life and the challenges associated with providing medical care at home. These stories really ground the themes (being consumed by caring duties, concern about neglecting their own health, financial worries, sadness about not being able to enjoy retirement or travel, and the strain of having care offloaded from institutions to families) and provide a solid experiential foundation for the discussion. The nuances reveal the complexity of care work in action and illuminate areas worthy of greater attention in policy and service provision.

The first narrative comes from a woman named Margaret who provides care for her husband John. She drives him to and from hemodialysis at the clinic several days a week, manages his meals and medications, and provides him with full time care at home. Margaret and John were separated for a couple of years before this arrangement took place. While they were separated, Margaret was told that John was about to die. She went to the hospital to be with him and, over some time, he recovered and asked her to move back in and care for him since he was no longer able to live on his own:

“...and so that's when he asked me if I would come and look after him. And he said, 'Because if you don't, I'm going to die.' I said to him, I said, 'I'll be honest with you, this is a big thing you're asking me. You know that. Because before I left, you made...' When he was going through all that, he made life so miserable for me that he basically chased me away. He chased me away from there. He was so mean and miserable. I would talk to him and he wouldn't answer me for days on end, only if he wanted something real bad [sic]. I would talk to him and he wouldn't answer me and I would cook something and he would throw it in the garbage, and stuff like that. Just rude and so mean. (Interview 10, 2013).

Given their difficult history, returning to live with him was a hugely emotional decision for Margaret. It was also an economic decision. The move required her to quit her paid job in order to provide John with full time care. The two of them now live off of his Long Term Disability income. Margaret said that things had improved between them since she had returned home, but that there was still room for further improvement.

*“Loving, thinking, and doing”: the full demands of care work*

When speaking about the sacrifice that Margaret has made, she told me, “[y]ou really have to care for the person, really love them a lot, in order to give yourself to their needs. You know?” (ibid). Providing such extensive care does not come without physical, emotional, and psychological tolls on the care provider. Like most of the unpaid care workers I spoke with, Margaret expressed concerns about her own well-being. With the amount of care work that John requires, she has little time to tend to her own needs or pursue anything for herself. She told me that caring for John means constantly thinking for two people. The mental labour involved in doing this was absolutely draining for her:

“[d]on’t ask me to do something while I’m in the middle of doing something already because if I get messed up here, then this doesn’t get done properly’... It’s frustrating for me because I’m thinking all the time. And I said, ‘it’s hard for thinking for two people. Because that’s what I’m doing right now, thinking for two people. Thinking what’s best for you and what’s best for me’ ... I said, ‘remember me too, because if my health starts going, you and I are in trouble’... Because, for my own health, my own well-being... if I don’t look after myself, who is going to look after me? I said, “you can’t. You can’t look after me” (Interview 10, 2013).

Margaret’s comments are reminiscent of Leira’s (1994) notion of caring as “loving, thinking, and doing.” It is love that Margaret says fuels her care work, but the labour involves constantly performing the physical, intellectual, and emotional work this is required. In the above quotation, Margaret also reveals how isolating the work can be. She provides for herself and for John, but does not experience a sense of security regarding her own needs. Who cares for her? She speaks to the emotional toll of the choice to care for him, but also emphasizes that it was performing the everyday tasks

such as “the driving and the hard work of caring for a home” (Interview 10, 2013) that made the care work most challenging.

Margaret and John live several hours from the dialysis clinic and so the travel was very burdensome for them. It is at least an hour’s drive into *any* town from their home, so grocery shopping and errand running are quite inconvenient as well. If they run out of over-the-counter painkillers, for instance, they either have to invest a couple of hours into the trip to get more, or wait until the next time that they plan to be in town and cope with the discomfort in the meantime. Given the driving conditions discussed in Chapter 4, it is easy to understand how any outing – planned or unplanned – can become burdensome for them. John was not a candidate for home dialysis or PD. Margaret said that he was on a transplant wait list at one point, but that they have never heard any follow up about that. Given how much of herself she has already given to him, I did not consider it appropriate to inquire about her being a potential donor, and she did not address this in our discussion. We did, however, discuss her concerns about her own physical and mental health. These are addressed below.

#### *Concern for care provider health and wellness*

Many unpaid care workers worry about, and often neglect, their own needs because of the focus on the dialysis patient. A number of the individuals providing care experienced various injuries and illnesses themselves. Some of the care provider health issues that came up in conversations were: an injured shoulder, injured knee, diabetes, a stroke, heart trouble, arthritis, early stage kidney problems, depression, fatigue, and more. Margaret expressed concern about who would care for her if her health were to decline in the future, and added that she was already managing injuries:

“[a]nd I said, ‘I can’t do the physical work that I once did. And you know that. And if you expect me to look after you, then you’ll have to try and make things easier for me.’ And so that’s where things are right now. Because it’s too hard. It’s too hard on the farm... I hurt my leg real bad too because of all the strenuous work I had to do packing those great big blue [water] jugs. I hurt my knee and... So it’s been a real struggle all around” (Interview 10, 2013).

John receives his dialysis from the nurses at the community clinic. After hearing the stories of these care workers, it is easier to understand why they would be willing to drive all that way, despite the burden, rather than dialyze their loved one at home: a few hours of dialysis at the clinic offers the only break that these women get from their care work. When we spoke about things that might make life easier for those caring for dialysis patients, Margaret echoed this sentiment and indicated that she could use the most help at home:

I: And are there any services that might help make things easier?

R: Yeah, that's one of the things. Because I don't have no support that way [sic]. I don't have nobody [sic] to come and take my place for a few hours or a day or so or whatever... And what would help me the most, if somebody would sit with him for maybe a day or a few hours so I can go and do what I need to do. You know, stuff like that.<sup>46</sup>

I: More at home, then?

R: Yes. Because you get to the point where... Like this morning, I felt like I was going to break down and just bawl because everything... I have to do everything. Everything. Lots of times you have to dress them up because they can't do it themselves. And make sure they have their food and their medication. And drive them... Make sure they don't slip and fall. All kinds of stuff (Interview 10, 2013).

It is the daily tasks associated with care work, the constant planning, cleaning, monitoring, and vigilance that make life so challenging for Margaret and the other care workers. These tasks place a tremendous strain on their mental health. In spite of this, discourses surrounding home care are generally framed in terms of empowering patients and keeping them in their communities (Anonymous citation 5). Little public recognition is given to the impact that home care has for the health and well-being of the person(s) providing the care.

After expressing that it felt good to sit and discuss her situation with me, I asked Margaret about supports that might be available to her. She expressed interest in speaking

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<sup>46</sup> The regional health authority offers some home support services and respite care, but these come with a fee. The fees may be subsidized based on income. Accessing these services requires referral, application, and assessment by a case manager. None of the unpaid care providers I spoke with mentioned hearing about or applying for these services and only Lois mentioned seeing a home care coordinator. None of the other care providers spoke about receiving any systemic supports for their care work.

with a counselor at the community clinic, but they do not have one on site. Her suggestion makes a great deal of sense, as she has to be there for roughly 12 hours per week with little to do while John dialyzes. Adding an additional trip to the regional centre to speak with their social worker would likely be too much for her already overwhelming schedule. Telephone or video-conferencing would not likely have served her well. She did not have Internet at home and she may not be comfortable discussing these issues over the phone, without necessarily seeing the person she was opening up to and with John being in the house and within earshot. As John indicated, he would likely die without Margaret's assistance. Keeping him alive requires tremendous work and great sacrifice on her part.

In sum, Margaret's story confirms that families undergo major organizational transformations in order to support dialysis patients. Her story also illuminates several issues regarding care work: its financial impact on families when the patient is too sick to work and the caregiving needs are so demanding that the care worker cannot continue with paid work; the work's complete and unrelenting nature; the challenges and demands that this work poses in terms of everyday tasks; the ways in which these challenges are exacerbated by geographic isolation; and the financial, emotional, and health-related vulnerability that care workers experience.

### **Cases of caring: Frank and Alice**

This narrative comes from an older gentleman named Frank. He is the primary care provider for his adult daughter Alice. Alice has an intellectual disability and lives with Frank several days per week. Alice received a kidney transplant over 20 years ago, but a few years back, after some other health complications, her kidney began to shut down and she started on home dialysis. Since that time, Frank's wife has left them and moved out of the country. I include this narrative not only because it illuminates how complex the conditions for care work can be, but also because this case challenges gendered assumptions about care work. This narrative serves as a reminder that gender based analyses can sometimes generalize and omit outlier cases, and that such stories also

merit discussion and consideration. Additionally, Frank's story illustrates some of the challenges that come with performing dialysis at home.

When Frank was learning to perform dialysis, he had to attend training sessions at a dialysis clinic for several weeks. He noted how unappealing that regular commute would be long term and why home dialysis was preferable:

“[s]o you travel up there for an hour to an hour and a half. You go to the hospital, get [her] hooked up on dialysis, and then you've got three or four hours to kill. So you go and wander around town and go to Tim Horton's for coffee, maybe, if you can afford it, or look around the stores. But you can only do that so many times a week without getting bored stiff” (Interview 16, 2013).

Similar to Margaret's comment that a counselor at the clinic would be helpful, Frank's comment reinforces the fact that there are minimal resources available for caregivers who spend up to 12 hours per week at the dialysis unit. Home dialysis may be more convenient for Frank and Alice, but that does not mean that it is easier.

#### *Challenges with dialysis at home*

For all of the care providers I spoke with, care work left little time for much else. Dialysis dictates the majority of their everyday and long-term life choices. For instance, Frank's week was dominated by Alice's dialysis schedule:

“I dialyze [Alice] Sunday, Monday, Wednesday and Friday. My day starts at 6:00 in the morning when I get up. I have a shave and a shower. I start racing the dialyzing equipment up around 7:00. And then I get her hooked up by about 8:00 in the morning. So she's off it by about 11:30 and then I have the machine to clean up when she's finished obviously. That's for four days a week. And Saturday, there's a deep clean on the chemical side on the machine that has to be done, and the filters have to be changed in the water processing system. So really I'm tied into it at least five days a week” (Interview 16, 2013).

Margaret did not frame her struggles as being the result of flaws in the health care, political, or economic systems, but rather, as issues related to her own family system and its economy of care. Unlike Margaret, Frank discussed his experiences with references to broader health and political systems. He said that despite saving the health care system money, he felt as though he and Alice went without any support in return:

“[i]f my daughter was in hospital on hemodialysis, or if she’s going to [community clinic] three times a week, four times a week, it would cost taxpayers a whole lot of money, a heck of a bunch of money. But because I’m doing it at home, it’s just costing the same in supplies, nothing more... But the biggest problem I find is although we’re doing this service for free, there’s no government grants or whatever to assist you in any way shape or form with any extra stuff I need... Not a thing. Not a cent” (Interview 16, 2013).

“[s]ome support from the government would be nice. That would help an awful lot, especially in terms of dietary problems. And my personal life is my own business, I suppose, but it’s difficult dialyzing her, making sure her bags are okay on her tummy, doing the laundry, which I’ve got to do this afternoon, and cooking meals. They’re all burdens that have been placed on me because I’ve taken on this task. And it’s not a burden that I regret, don’t misunderstand me” (Interview 16, 2013).

Frank rejected the individualist notion that he alone ought to bear the burden of care. He expressed disappointment and frustration with the lack of institutionalized support. Performing dialysis at home adds a host of responsibilities to his existing housework and caring duties and these tasks are draining for him. He did not say whether he has always done housework such as laundry, cooking, and cleaning or if these duties fell upon him once his wife left. It is unclear if gendered expectations about what constitute work are relevant here. Additionally, Frank struggles with the challenges of providing care for a loved one with an intellectual disability. This contributes to his daughter’s level of dependency and the tasks that he is required to perform for her. Overall, Frank was quite candid about the sacrifices that are involved with this work:

“I’m in an apartment. So give us a two-bedroom apartment and convert one bedroom into a medical room [sic]. I had to rip the apartment apart inside because I had to put in water softener equipment, water drainage, everything that’s needed. The biggest thing I have a problem with is changing the filters on the machine, the equipment, and the incoming water supply. They’re difficult, they’re heavy, and they’re clumsy. But they have to be done every month. It’s still an expense for supplies... And I’m not complaining, I’m not moaning about it, and I’m not dishing about it at all. I’m just stating it as a fact. There’s a lot you have to give up when you go on dialyzing someone at home” (Interview 16, 2013).

Frank's love for and commitment to his daughter were unmistakable. He repeatedly emphasized that he would do anything for her, but was also very honest about the personal and financial tolls that this work took:

“[w]ell, [when Alice's kidney was failing and we had to travel] we had no health benefits because [Alice] is on welfare. All they would pay for was one trip to Vancouver and that was it. So they gave me an allowance of one trip to take her to Vancouver basically. And they argued about that, but however, that's what they did. But from then on it was on our own. We used what savings we had up, and I went into debt big time” (Interview 16, 2013).

The costs associated with providing care for a chronically ill rural patient can be enormous and those with low or limited incomes feel them most deeply. The limited systemic supports leave families to bear this burden on their own. Despite having universal health coverage, Alice's care put their family into debt. With a heavy debt load and several days of the week committed to dialysis treatments, home care really restricts Frank's ability to travel or get away for periods of time.

*“It does take your life”: The confining nature of home dialysis*

Providing care for a dialysis patient, particularly if it includes home dialysis, means that there is little leisure time for care providers, but also that any travel is significantly limited. The inability to travel was a notable theme in the interviews. It can leave care providers feeling trapped in their care work. Frank told me:

“[w]hen you're retired and getting older, like I am, sometimes it would be nice to put your feet up and say ‘to heck with it, I want to watch hockey or golf’... I have a motor home I bought for my retirement. I can't use that. I haven't used it for three and a half years because I'm unable to because she can't go anywhere. We can't leave town, you see” (Interview 16, 2013).

Two other care providers also mentioned their unused motor homes, their inability to get away, and the extent to which dialysis governs most of their life decisions. Reinforcing Frank's testimony, one of them told me:

“[i]t pretty well... It does take your life. You don't go anywhere because every second day, you have to dialyze him. So you're pretty well... We bought a motor home. If we want to go someplace ...he dialyzes for a couple of days in a row and then we can maybe go for two days and that's it. Then he has to be back to

dialyze again... Both of our lives are totally controlled by dialysis. And you want to go someplace to do something, and you can't. You know, there's family reunions. You can't go because he can't dialyze" (Interview 17, 2013).

Dialysis patients looking to travel can book sessions in advance at clinics in other cities and provinces. However, these clinics are not always close to the travel destinations and a couple of patients expressed hesitation about being dialyzed by unfamiliar nurses. In a rural and remote location where travel is already so time, energy, and cost consuming, patients and care workers are less likely to do more of it when they are saddled with so much work at home. With the travel already required for renal care, many families will not have the resources to travel for pleasure. This is particularly the case when the family care worker is also experiencing health issues.

Like other unpaid care providers, Frank expressed concern about his own health and his ability to care for Alice as he ages:

"I'm a little concerned because I'm getting older myself now. I'm 80 next year. So I've got to keep my wits about me and make sure nothing happens to me because if I do [sic], [Alice]'s got to find someone to drive her..." (Interview 16, 2013).

While the prospect of 'losing one's wits' is frightening enough, Frank feels added pressure to keep sharp for Alice's sake. Similar to Margaret, Frank does not have someone to care for him – or his loved one – should his health decline. The laundry, cooking, and other household chores are tedious and tiresome for him, but they did not seem to induce anxiety or concern. It was the need to perform these dialysis-related interventions that he seemed to feel somewhat uneasy about. For instance, when speaking about the challenges that come with having a non-expert performing medical tasks at home, he said:

"[o]n a Sunday when I'm on my own here with Alice, and she does dialyze on Sunday because her body needs it, if anything goes wrong, I've got to deal with it myself because there's no one else I can get hold of on a Sunday, which is understandable. So you're on kind of... You're walking a tight rope, if you like, is the best I can explain it. Hoping you're not going to fall on either side, to keep things in a steady balance" (Interview 16, 2013).

Interestingly, Frank never attributed his challenges to being a single parent. Instead, he discussed his frustration with a social system that does not provide adequate support for people at times of vulnerability and dependency. Unlike the other care providers, he acknowledges the politics of performing dialysis at home. Though he saves the system a considerable amount of money by dialyzing Alice at home, he is left feeling precarious about their situation. Overall, Frank's narrative reinforces Margaret's concerns about the unrelenting nature of care work and about care worker health and well-being. It also reveals that dialyzing someone at home requires substantial sacrifice in terms of time, space, and finances. His home has become a medicalized site of care provision and he has taken on the task of administering medical treatment in addition to his everyday caring responsibilities. This concept of lay medical expertise is explored below.

#### *Lay expertise and dialysis at home*

Family members who administer home dialysis receive six weeks of training at the regional clinic. This is important and beneficial, but it is not akin to years of nursing education and experience. A patient on PD, Layla, told me about the difference it made to have the trained nurses administer her care when she used to dialyze at the clinic:

R: The dialysis nurses in [community unit], they're amazing...they saved my life at one time too.

I: How did they do that?

R: Well, my fistula opened<sup>47</sup> and [dialysis nurse] held it, I think, for two hours. She held it shut. So there was a lot of pressure. And she tried to hold it shut. Like it kept squirting. And she worked... I think she said she was sore for two weeks after that. From holding so much pressure back.

I: Wow.

R: Yeah. So I was very... At that time, I was very, very happy that I was doing it in a unit and not at home. So, yeah. And we've discussed it there with the other

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<sup>47</sup> A fistula is a permanent access site where tubes from the dialysis machine are inserted into the patient. It is colloquially known as the dialysis patient's "lifeline" (American Association of Kidney Patients, 2013). This access site allows blood to be pumped from the body, cleaned by the machine, and then returned to the patient's body. Because of the amount of blood being filtered during dialysis treatment and the high pressure at which it is pumped, a burst fistula can lead to a patient losing a great deal of blood quite quickly.

dialysis patients. It's not just the dialysis, you always get... somehow you get a little counseling being together there and talking to each other and to the nurses (Interview 19, 2013).

Family members cannot always provide the same level or quality of support at home that patients would receive in clinic. Also, just because family care workers have been trained to administer home dialysis does not mean that they are confident about doing so – or good at it. Lois reinforced Frank's concerns and identified the increasing extent to which family care providers are required to perform medical interventions:

“[I]ike I have a full list of pills, and I am now giving him insulin in the morning and at night, and taking his blood sugars three times a day. So I actually have myself a writing pad, and I make out everything. And he gets eye drops as well. So I've got everything that I have to do when he gets up in the morning wrote down [sic]. And I put the time I do it. And then he has his breakfast and then a little later, a snack. And then it's lunchtime and then it's time for needles and stuff again. So it's actually... It is actually basically pretty much a full time job. We do get a couple of hours to ourselves on the days he doesn't have dialysis because we get all his morning stuff done and then we can carry what needs to be done between that and the supper hour. And as well with the oxygen and everything else, we can take off for a couple of hours and go somewhere. And then you've got to be back for the whole routine starting early supper again. So it's basically a full time job... It would be nice if we get set up in town to have somebody come once or twice a week just to see that we're getting everything done properly” (Interview 17, 2013).

Even with Lois' dutiful note taking and routinized care schedule, she expresses concern about whether everything is being done properly. Her story captures both the sheer volume of medical tasks that she performs and the unease that can come with this level of responsibility for the care of a loved one.

In short, family care providers in this region face concern for their own physical and mental health and anxiety about providing proper medical care for their loved ones. Many lack the ability to enjoy retirement because of caring responsibilities later in life and experience the fatigue that comes with never getting a break from their caring duties. Care providers also contend with the expenses associated with traveling for treatments and/or leaving the workforce, the large amount of driving required to get to clinic, few available/accessible supports for them, losing a full room in their homes to home dialysis

machines, and many more everyday tasks. This work is constant and often goes without much recognition or support. It generally requires family care workers to sacrifice their personal wants and needs in order to serve those of a loved one. With the shift towards increasing home-based care, these conditions require significant consideration.

## **Discussion: Political and economic implications of care at home**

### *Conclusions about gender*

The participants' quotations about the daily tasks and challenges associated with providing care work reinforce Smith's (1987) notion of the everyday world as problematic. They also confirm Armstrong's (2012) claim that unpaid health care work is "a gender issue, an equity issue, and a human rights issue" (p. 6). By examining care work from these micro, lived perspectives, this form of labour and the equity issues associated with it can be made more visible and can eventually be integrated into broader discussions of health and social policy. A deeper understanding of informal care systems can generate appropriate accommodations in the formal health care system and in society more generally. Traditionally:

“[w]omen in all environments play a fundamental role in caring for others, and in doing so face a number of gender-specific stresses and challenges as they take on multiple roles in their families and communities. The care that women provide for friends and family must be recognized and integrated into workforce planning and in meeting the needs of rural and remote women...” (Haworth-Brockman et al., 2012, p. 52).

As noted in earlier chapters, the workforce in the region of study is largely male dominated. This left a number of the women that I spoke with and their families very vulnerable when their financial providers became ill. All of the women I spoke with had adult children, but it would be interesting to speak to members of the “sandwich generation” (Miller, 1981) – adults who simultaneously provide care for their young children and for their parents – and see how caring for a dialysis patient may contribute to that work/family dynamic. Given the focus on dialysis care, my study did not capture other caring roles that participants might have within their communities, churches, bands, or extended circles of family and friends, but those are also worthy of consideration.

Two of the five unpaid care providers I spoke with were men. This is significant because the performance of care work by men is “socially constructed and variable” (Coltrane & Galt, 2000). The care work that men perform – or avoid – is informed by broader social and economic systems. Coltrane and Galt (2000) argue:

“including men in our theories and empirical studies about caring can help us understand the complex social, economic, and psychological processes that make care work gendered. By documenting the shifting historical and cultural conditions shaping family work for both men and women, we can better understand how the social organization of care work supports gender inequality, and perhaps better predict how changes in social and economic conditions might produce more equal gender relations in the future” (p. 16).

Several health care professionals mentioned that they knew of a number of husbands caring for their wives on dialysis. So, while care work has historically been (and largely continues to be) women’s work, it is important to acknowledge the ways in which people’s lives diverge from these norms and traditions. Sex and gender-specific policies and practices that support ‘caregivers’ ought to be designed to the benefit of both women and men, particularly if we want to see a more equal distribution of care work between the sexes. If supports for caring are only targeted towards women, male care providers risk slipping through the cracks, becoming marginalized, or having their needs overlooked. I found it interesting that Frank was the only family care worker to discuss his experience in relation to broader systems, and to express dissatisfaction with the government’s level of support for unpaid caring. This may have to do with gendered expectations about care work, but it may also reflect a worldview that sees the state as having a role in caring for its citizens.

### *The role of the state in caring*

Feminist political economists generally turn to the state to explain the current context of health care (Fiske et al., 2012) and in this case, care work and the provisions for caring are understood differently depending on the welfare state and the society. “Advanced welfare states like those in Scandinavia are often identified as ‘caring states’ which offer citizens not only security against the pitfalls of the market, but also promise

of high quality care for the very dependent” (Leira, 1994, p. 185).<sup>48</sup> In these states, the government is seen as having a substantial role in mitigating the inequities that are exacerbated by unpaid care work:

“[t]hinking about caring in terms of work is perhaps an idea that more immediately suggests itself in Scandinavia because the discussion is set within the context of well developed, institutional welfare states in which the public provision of care for very dependent people is commonly accepted and anticipated and the commitment to women’s formal employment is strong” (ibid, p. 186).

This stands in contrast with the United States where family-based care and for-profit care are more common (Esping-Andersen, 1990). Despite Canada’s universal health care system, our approach to care provision is increasingly becoming more like the neo-liberal, American system (Armstrong & Armstrong, 2001). This transition is evident in the discourses used to discuss care provision and in the changes to related policies and practices. Recent reforms in rural BC reveal, “a rationalization of health budgets that has shifted from publicly funded institutions to family and community; and centralization of government services in distant urban centres” (Fiske et al., 2012, p. 415). The concentration of services in the regional centre and major urban transplant centres can inadvertently leave rural and remote residents out of renal care decision-making, consultation, and the shaping of local health care priorities. Broadly speaking, these reforms have included movements away from institutional care and towards privatization and cost-cutting (Sutherns & Haworth-Brockman, 2012; Armstrong & Armstrong, 2001). Behind these transitions is the assumption that family members are best suited to perform care work and that they will do so well, willingly, and without personal consequence (Harrington Meyer, Herd, & Michel, 2000).

In their work in rural British Columbia, Fiske et al. (2012) found that “[t]hrough framing social policy in neo-liberal discourses, care giving is depoliticized and citizens’

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<sup>48</sup> However, recent work on Scandinavia (Peterson & Hjelmar, 2013) suggests that that there are increased pressures towards the marketization and reduction of welfare and caring services.

right to health care is marginalized” (Fiske et al., 2012, p. 403). This is not surprising given that neo-liberal states rely on unpaid work to provide for those in need (via charity, philanthropy, religious groups, volunteers, and family members) in order to justify reductions in spending and tax cuts. Also focusing on British Columbia, Skinner et al. (2014) claim that resource frontier communities in particular have experienced “decades of government service devolution, divestment, and downloading” (p. 4) and increasingly rely on voluntary organizations and unpaid volunteers to support older people as they age. The same can be argued for those in a resource community who age with chronic conditions or while caring for someone with a chronic condition. Once again, this reliance presupposes that unpaid workers will be willing and able to provide the necessary services – and that these services will be sustainable and of adequate quality.

With informal and unpaid care workers in Canada providing an estimated \$26 billion of unpaid work annually, the Canadian healthcare system relies on informal care work to support our aging population (Vuksan, Williams, & Crook, 2011) and to alleviate costs to the health care system. By shifting treatment from the clinic to the home, a substantial amount of work and responsibility is offloaded onto patients and their relatives and care providers. “Conceptualizing care, even childcare, as *work* [emphasis added] underlines the meaning that caring is not something that arises naturally but is something that requires skills that have to be acquired or learned” (Leria, 1994, p. 189). Family care providers must develop the practical, intellectual, and emotional skills that are necessary for managing someone else’s everyday needs alongside their own.

### *The domestication of health and the offloading of care*

My data reveal the presence and the implications of neo-liberal discourses about care provision that are at work in the rural renal care context. One of the most prominent implications that surfaced was the domestication of health care. Childerhose & MacDonald (2013) use the term “domestication” to describe the movement of diagnostic devices into homes for use by consumers. They argue that the use of domesticated biomedical devices, goods, and services ought to be conceived of as *work* that is

performed by consumers (ibid). They describe this work as “a form of tool use that allows non-experts to produce diagnostic knowledge about their own bodies and health; and as the ongoing biopolitical work that is expected of citizens to produce healthy bodies” (Childerhose & MacDonald, 2013, p.1). Dialyzing at home can be empowering for patients as it can enable and encourage them to become well-informed about the nuances of their condition(s) and render them less dependent on medical experts for their care. However, home care and self-regulation also have implications for how we understand risk, responsibility, liability, and blame (Hogle, 2002). From this perspective, the shift towards home-based renal care reflects both the domestication of health care and a broader shift towards individual responsibility for health and well-being.

In the case of home hemodialysis, a room in the patient’s house or apartment must be dedicated to dialysis equipment and kept sterile. For most of my participants, this involved re-plumbing, new wiring being put in, and the installation of a water softener. As Frank pointed out, there are also regular cleaning and maintenance responsibilities involved. In addition to the medicalization of their home space, patients and their family members also take on the duties of performing medical interventions and diagnoses. Such responsibility can be stressful, particularly if the care workers are seniors or have low levels of education. This stress was evident when Lois expressed her desire for someone to come by once or twice a week to ensure that she was doing everything properly. When called upon to provide this type of work, “family caregivers must often learn complex medical care and specific technical vocabularies” (Crooks, et al. 2007, p. 2; Williams & Crooks, 2008). For home dialysis and PD, they must also become familiar with the related equipment and technology.

Unfortunately, there are very few supports available to assist rural residents when they do struggle with providing home care. There is a hotline that they can call when there are technical problems with the dialysis machines, and they can call nurses and social workers at the regional unit, but in an acute emergency, these people are often hours away. Consider, for instance, what this could mean in situations similar to when Layla’s fistula burst. She claimed that having a trained nurse present saved her life. With

the wide distribution of rural and remote residents, the shift towards decentralizing care and bringing it to the homes of dialysis patients appears to make a great deal of sense. The regional health agency's website claims that they know that people in the area want to maintain as much control as possible over their lives. As a result, they provide a range of health services that promote "independence, choice, and dignity" (Anonymous citation, 2014). They add that most residents of the region are "by nature, resilient, self-reliant, and independent" and that they want to help them stay that way (ibid). The use of individualist, neo-liberal, and frontier discourses are apparent here.

On one hand, many rural and remote residents use these discourses themselves and do desire independence. On the other hand, framing care in this way can be understood as yet another method for placing the responsibility for health and wellness onto individuals and lessening the onus on the state to provide the conditions for care.

Additionally:

"[t]he discourses of consumer choice and empowerment – central features of contemporary health consumption in North America – obscure the work involved in the selection and use of biomedical goods and services at home... and [obscure] the social determinants that shape health consumption decisions" (Childerhose & MacDonald, 2013, p.2-6).

In other words, the language of choice and self-reliance is meant to make home dialysis patients and their care providers feel free, competent, and capable, but it masks how much labour and sacrifice are involved in such a large and high stakes undertaking. Skinner & Joseph's (2007) work reveals that demands for unpaid and volunteer-based care provision are increasingly placed upon rural communities without consideration of their local demographics, socioeconomic limitations, and their actual capacity and ability to provide such care. They claim that this is particularly the case in rural communities:

"...where self-reliance and the capacity to cope through volunteer based initiatives has often been over-estimated. The divergence between ideologically based assumptions and empirical reality suggests that the voluntary sector is a contested setting in which the implications of restructuring are being actively and even aggressively mediated" (Skinner & Joseph, 2007, p. 123).

The discourses of self-reliance also silence any discussion about how issues of race, class, gender, disability, income, employment status, Aboriginal status, and other social issues might further complicate dialysis-at-home decisions and practices. For instance, one man receiving dialysis at the clinic who was not well enough to participate in the study was of Aboriginal heritage and lived on a reserve several hours away from the clinic. An unpaid care provider told me that home dialysis was not an option for this man because he did not have running water in his home. Living on a First Nations reserve, and with all of the health determinants associated with it, very much influenced this man's care options. Lois and Frank also expressed concern about their abilities to perform dialysis as they age into potential physical and intellectual disabilities, respectively. In this sense, care work can change throughout the life cycle and older care providers may face age-specific care work challenges. Lastly, as indicated in earlier chapters, most of the families in this study had relatively low socioeconomic status or limited incomes. Dialysis and transplant treatments caused several of these families to go into debt. Harrington-Meyer, Herd, & Michel (2000) argue that, "locating dependency within individual families serves as yet another method that sustains, and even magnifies, socioeconomic inequalities" (p. 3). This makes sense given that people of lower socioeconomic status generally lack the resources necessary for accessing supports such as respite care, paid companions, or privatized care services.

## **Conclusion**

The neo-liberal discourse surrounding care is similar to discourses about scarcity; it identifies a limited availability of health care resources and looks to individuals and their families to provide the treatments necessary for producing healthy citizens. Neo-liberal care discourses overlook the social determinants of health and treat health concerns with a limited behavioural and biomedical approach. Despite a strong focus on the individual, this discourse does not focus on the complexities or experiences of individual dialysis patients and care providers. In this case, care work is de-contextualized and de-politicized. My data reveal that care work is political, it is *work*, it

is gendered, and it is classed. The organization of care work reflects how we distribute the burden of dependency in our society. The unpaid care workers I spoke with struggle with their own health issues, their lives are [re]structured and consumed by caring duties, and they experience physical, emotional, and financial costs as part of caring for a loved one. They are often required to sacrifice their personal wants, needs, plans, and kidneys, but receive very little recognition or support in return.

Given the amount of care that dialysis patients and transplant recipients require, it is surprising how little the topic surfaces in organ transfer discourse. My case study reveals the extent of this unpaid labour and makes the scarcity of ‘caregiver resources’ and institutional supports for care work more visible. Discussions about care work necessarily involve acknowledging and addressing dependency and vulnerability, but these concepts can be challenging to unpack in a rural frontier context where independence is so privileged and strongly encouraged. For those who require assistance, there may be feelings of guilt, frustration, or blame around their newfound need for assistance and support. In order for the shifting of care (from health care institutions to the home, family, and community) to be beneficial for patients and their care providers, adequate and culturally appropriate supports must be provided. This means that not only do the services need to exist, but they also need to be reasonably available, affordable, and accessible to those who require them. When such supports are made available, those who are able and choose to perform care work can do so with less of a personal toll, and those who are unable or do not wish to perform care work will have the option not to. In the following chapter, I discuss some of the implications of these policy changes, as well as my conclusions and recommendations.

## **Chapter 7: Conclusions & recommendations**

In this dissertation, I used a feminist political economy framework to investigate kidney scarcity in rural and remote British Columbia. In keeping with this methodology, I performed a case study using critical ethnography and document analysis. This was done in order to determine if and how the issues identified in the critical organ transfer literature were of concern in a particular Canadian setting and to better understand lived experiences of scarcity.

My research confirmed some of my expectations and also produced some unanticipated findings. I had rightly expected that transportation would be an issue, that gender would have implications for work and treatment options, and that those who were most economically vulnerable would face additional challenges with managing their treatment and their care. I had not anticipated the extent to which the town's history would resonate in current narratives. I was surprised that the concept of the frontier was so embedded in the local culture. I was also surprised by how significant men's health issues were. I had anticipated inequities regarding rural and remote women's health (and these were confirmed), but I had not realized how severely gender affected men at this site of study. Organ transfer literature speaks at length about the commodification of kidneys and so I had been curious to see how that process might operate in my case study. However, instead of observing discourses and practices that commodified kidneys, I witnessed a commodification of labourers in the local resource industry – something that largely contributed to the kidney health of these men.

After exploring the critical, theoretical organ transfer literature and outlining my research methods, the chapters of the dissertation were organized based on the concepts that emerged from the data. Among the themes explored were the manifestations of scarcity in the provincial and regional systems, the impacts of place and geographic isolation, the experience of working in the local resource industry and its construction of rural masculinity, the ethos of frontier living, the complexities of performing unpaid care work, and the implications of providing care at home. This research contributes to

scholarship in several areas of study and also provides data that can be used by health care professionals and policymakers.

### **Contributions to organ transfer discourse**

#### *Treatment priorities at different levels of the system*

This research began rooted in the critical organ transfer literature, with a focus on scarcity. As a result, my findings and analyses offer several contributions to this scholarship. In Chapter 1, I identified several gaps in this literature. These gaps include: minimal qualitative Canadian content, little attention explicitly paid to sex and gender, how these issues might manifest in a rural and remote context, the roles of waged labour and unpaid care work, experience of life on dialysis, and how ‘scarcity’ can function as an “active discourse” (Mykhalovskiy, 2001) in the public arena(s). My case study provides qualitative Canadian content that speaks to each of these under-researched aspects of organ transfer.

A core contribution of my findings is the identification of different treatment foci at different levels of care. At the national/provincial level, renal care and transplant organizations push for kidney transplant as the primary renal replacement therapy. This is encouraged because of the therapeutic benefits of transplant, but also because of the considerable cost-savings that it provides for the health care system. At the provincial/regional level, the health care system is increasingly encouraging home hemodialysis or PD. The system is largely in favour of patients performing their own dialysis because it is more flexible, reduces travel to dialysis clinics, and – importantly – is less costly. At the community level, health care professionals push for renal patients to attend dialysis and maintain their care plans. This is because local health care professionals are aware of the barriers that their patients face in terms of accessing renal replacement therapies. These barriers largely result from patients’ health status, social location, and geographic isolation. This finding is an important contribution because this variation in treatment focus reveals differing systemic priorities and concerns. It also reveals the impact of the increasingly limited capacity of the public health care system to

support those with renal failure. Additionally, it highlights the significance of proximity to rural and remote patients' daily realities.

*The three scarcity discourses*

*i. The scarcity of transplantable kidneys*

My work contributes to our understanding of how scarcity functions as active discourse. Across these levels of care, I have identified three distinct scarcity discourses at work. This is another core contribution of this dissertation. At the national/provincial level, the *scarcity of transplantable kidneys* is the dominant discourse. I have demonstrated that the ways in which renal care and transplant organizations frame their message matters because these messages shape opinions, priorities, and practices. This discourse is used to frame the majority of public discussions about renal failure and it confirms many of the concerns identified in the critical organ transfer literature. For instance, my data reveal that the kidney scarcity discourse has been influential in changing policies and practices in British Columbia. Hospitals have received additional encouragement to consider all potential donors, transplant awareness raising initiatives and campaigns have increased in size and numbers, online donor registries have been established, financial incentives for donors are being considered, and procuring kidneys from deceased patients who are not brain dead is taking place in some locations across the province. In light of all of this, the narrative of kidney scarcity is rarely unpacked. My findings contribute to its unpacking.

The notion of an “organs shortage” or “organs crisis” has become the accepted way of thinking about organ transfer and fuels the drive for the procurement of more and more kidneys for transplantation. I argue that this is concerning, not only because kidney scarcity is somewhat artificial, but also because the perception of a crisis scenario opens up the possibility for previously unacceptable forms of organ procurement to be permitted. This is worrisome given that those who are most vulnerable in our society are most likely to be providers of organs and are least likely to receive transplants. I suggest that despite the therapeutic benefits of kidney transplantation, the kidney scarcity

discourse is too limited. It ignores the complex, nuanced dimensions of health and treats health in a very micro, individualized way. Increased kidney donation and donor registration do little to prevent chronic kidney disease, diabetes, and/or high blood pressure; nor do they provide the public with the education and resources necessary for avoiding the conditions that can lead to renal failure. Koch (2002) claims, “[t]he scarcity that presumably rules in these and other venues is rarely independent of antecedent decisions made within a complex system of social organization” (p. 8). I argue that by focusing primarily on the deficiencies in donor willingness and the allocation of ‘scarce’ kidneys, attention is diverted away from broader questions of how other resources are distributed in our society, who benefits from current arrangements, and who is harmed by them.

*ii. The scarcity of health care and human resources*

The second scarcity discourse I have identified has to do with the *scarcity of health care and human resources*. This meso level discourse reflects the geographic isolation of the site of study and the limited services and supports available for patients and health care professionals. The site’s isolation means that dialysis clinics, nurses, doctors, nephrologists, and other specialists are limited and/or difficult to access. Safe, reliable, and affordable transportation are also limited. The scarcity of health care and human resources discourse reveals the burnout and moral distress of local health care professionals and the transient nature of a resource frontier community. It also highlights the centralization of services in urban centres and the prioritization of cost-efficiencies that result in under-served and vulnerable rural and remote areas.

Just as the kidney scarcity discourse is used to support the push for increasing transplants, the scarcity of health care and human resources is used to justify the shift toward home hemodialysis and PD. This shift has gained traction largely in response to travel issues, a limited number of dialysis clinics, limited staffing, and budgets that cannot comfortably support a large population of patients receiving dialysis in clinics. My findings confirm that shifting care work from health institutions to homes has

negative effects on the health and well-being of those providing unpaid care. Remedying this type of scarcity at the health care system level would yield a number of benefits for the participants of my study, but the discourse is still somewhat limited because it does not address the causes or the determinants of renal failure. In the same way that procuring more kidneys for transplant will not cure people's kidney disease, transplanting more doctors, health care dollars, or dialysis clinics into rural and remote areas will not address systemic inequities and the broader determinants of the population's health. Similarly, addressing this scarcity by popularizing home dialysis may lead to benefits for dialysis patients and the health care system, but these benefits often come at the expense of family care providers.

*iii. The scarcity of health and life-sustaining resources*

The third scarcity discourse that I have identified is the *scarcity of health and life-sustaining resources*. This includes the scarcity of affordable and accessible supports for healthy active living (diet and fitness related), affordable housing, formal support for unpaid family care providers, and workplaces that can accommodate and support dialysis and/or transplant patients and their donors. This discourse takes a macro perspective and looks at the social determinants of health. It surfaced in discussions about participants' finances, work, and everyday lives. Of the three scarcity discourses, the scarcity of health and life-sustaining resources was largely absent from the documents that I analyzed and from public discussion of kidney failure. This is likely due to the fact that remedying this type of scarcity is often seen as outside of the purview of the health care system and would require larger social and political change.

My participants' experiences of scarcity appeared to have more to do with forms of social and/or material scarcity than they did with the scarcity of transplantable kidneys. This finding challenges the popular image of dialysis patients desperately waiting for kidney transplants and directs attention towards the distribution of other resources.

Given that many of the dialysis patients I interviewed were older adults, most were not interested in being put on a transplant waiting list. However, these participants

and their spouses often struggled with finances, housing, care work, and transportation. A limited focus on kidney scarcity conceals the challenges experienced by older adults who live with renal disease and by those who care for them. As a result, my findings reveal a need for further discussion surrounding the needs of older renal patients and care providers in rural and remote locations.

Throughout this dissertation, I have argued that the kidney scarcity discourse has contributed to the de-contextualization and de-politicization of organ transfer and has obscured the social, political, and economic conditions that can contribute to or exacerbate kidney failure. This de-contextualization is problematic because it can enable health inequities. It does so by ignoring the effects of race, class, gender, age, disability, colonialism, geographic isolation, employment, working conditions, care work, and other social and historical factors. Lock & Nguyen (2010) argue that diabetes and vascular disease – the leading causes of kidney failure in Canada – are “diseases associated with poverty and social inequality, many of which could be prevented” (2010, p. 235). Additionally, a third of all dialysis patients in Canada are living in poverty (Kidney Foundation of Canada, 2014). De-contextualization provides a façade of objectivity, neutrality, and normativity, while often abstracting the practice from these realities of lived experience. De-politicization can be harmful for the same reasons. Public activism towards addressing kidney disease currently includes encouraging donor registration, wearing awareness-raising paraphernalia, indicating one’s donor status on Facebook or social media, and other efforts to address the donor shortage without really doing much to prevent or understand kidney failure at individual, social, or structural levels. De-politicizing these issues may be useful in terms of gaining acceptance into public conversation, but ignoring the related politics does not make them go away.

In short, my work contributes to organ transfer discourse by re-contextualizing and re-politicizing kidney scarcity. It reveals the implications of pursuing kidney donations without addressing the conditions in which individuals experience kidney failure. I have identified three scarcity discourses and the ways in which they have or have not informed policies and practices in rural and remote British Columbia. My work

shifts the discussion from limited kidneys and limited health care resources, to one of the social and economic realities of individuals living with kidney failure.

### **Contribution to rural health geography**

#### *Rural and remote residence as a determinant of renal health*

The third main contribution of my dissertation is the recognition of rural and remote residence as a determinant of kidney health. There has been very little research on hemodialysis and kidney transplantation in rural Canadian communities and my case study offers insight into the related issues and experiences. My research contributes to the burgeoning body of Canadian rural health literature that identifies rural residence as an important determinant of health. The isolation of my site of study had considerable implications for dialysis patients, their families, and a variety of health care professionals. It made dialysis attendance, kidney transplant, and care provision extremely challenging. My findings also confirm that geographic isolation can exacerbate inequities that result from other determinants of health such as poverty or Aboriginal status. Those who had limited financial resources felt the effects of isolation most deeply. They were less likely to attend dialysis or renal care appointments and less equipped to manage the burden of providing care at home. Rural and remote residence has been spoken about as a barrier to accessing kidney transplants and other health care services, but until now it has not been discussed as a determinant of renal health itself.

#### *The ethos of frontier living*

Another contribution of my dissertation is the ethos of frontier living concept and the insight that it provides into the intersection of gender, work in the resource extraction industry, and renal health. This concept embodies the intersections of rural and remote living, rural masculinity, and the culture of resource extraction work. It values and celebrates self-reliance, hard work, toughness, and dominion over the land. It also reveals the ways in which the site's frontier history is invoked to support current neo-liberal policies that encourage independence and individual responsibility for health. Skinner et

al. (2014) point out that Canada's "resource frontier" has been under-researched. There has certainly not been any discussion to date of kidney dialysis and transplantation in our resource frontier communities. The unique needs of these communities, and the conditions that they provide for renal health and treatment, have been relatively unknown. By focusing on the resource industry and the site's frontier history, I was able to capture a richer, more complex picture of why the men in my study experienced kidney troubles or had challenges with their renal treatments. This surfaced in the narrative of Jack, the young man whose transplant was rejected after his grueling work schedule kept him from getting blood work done and from maintaining a proper schedule for his medications. It also surfaced in the stories of older men who ignored the early symptoms of renal disease because they were used to being in physical pain from their work or could not take time off to visit a doctor.

Some of these experiences could be understood through gender or class-based analyses, but these are not just any male labourers. Their specific social and geographical locations are central to their experiences. I have revealed that at this site of study, gender, work, and place intersect to inform health, treatment options, and the success of these treatments. This work reinforces social health geography's ability to capture richness and complexity that could be overlooked in a quantitative analysis or mapping of the same site of study.

### **Contribution to feminist political economy**

Feminist political economy was central to all aspects of this research. It informed my choice to use a theoretically grounded case study and to analyze scarcity at macro, meso, and micro levels. It also drew my attention to constructions of gender, their varied meanings, and the intersection of gender with other forms of marginalization. My findings confirm feminist political economy theory and have extended its application to the field of kidney dialysis and transplant. By applying feminist political economy to a new content area, my work offers original insight into the specific material conditions in which rural and remote kidney care is accessed, provided, and denied.

### *Care work*

Feminist political economy led me to explore unpaid household labour, family structures, and familial economies of care. My findings contribute to our understanding of the gendered and complex ways that care work is performed. These findings support the concerns in the unpaid health care work literature regarding the negative health effects that care work has on the health of women. All three of the female care providers I spoke with had left the workforce in order to provide full time care for their husbands. On top of caring for their partners, these women struggled with managing their own physical, mental, and emotional health. Their stories reveal that even though these care providers work extremely hard, they do not always feel as though the care that they provide is sustainable or of adequate quality. This work contributes to feminist political economy scholarship that addresses the shifting of care from health care institutions to individuals and their families. It confirms the negative effects that these broad neo-liberal policy trends have on unpaid care providers and their care recipients. My findings also reveal the ways in which the ideologies behind these policy shifts are at odds with the realities of these rural families.

Because of the complexity of caring for a renal patient, most of the families of dialysis patients had to be re-structured in order to provide the necessary care. This includes spatial, financial, organizational, and anatomical re-structuring. For those providing home hemodialysis, this also included re-structuring and medicalization of the home. Based on my findings, I identify home dialysis as unpaid care work provided by lay experts and as a part of the broader domestication of health. I suggest that the current shift towards home-based renal care reflects a broader trend toward a reduction of public health services, gendered assumptions about the feasibility of unpaid care work, and an increasing reliance on individuals – rather than the state – to support dependency and produce healthy citizens. Similarly, kidney donation has previously been spoken about as an extension of one's familial obligation (Simmons & Klein, 1977), but my work contributes to our understanding of it as a form of care work. By recognizing these forms

of care provision as *work*, particularly work that is gendered, this labour can be made more visible and its challenges can be better identified by health care professionals and policymakers.

### *Masculinities*

This dissertation extends feminist political economy literature on the social construction of masculinity and its impact on health equity. It also provides some insight into the unpaid care work that is provided by men. Traditional constructs of masculinity suggest that a man's primary means of caring for his family is through financial provision. All of the male dialysis patients and one male transplant recipient had worked in the resource industry to support their families. Unfortunately, this work often kept them away from home for long stretches of time and had negative effects on the health of their kidneys. My findings demonstrate the ways in which the needs of the broader economy can be at odds with the needs of a man's familial economy of care – an example of the tension between structure and agency. This construction of rural masculinity (that encourages toughness and self-reliance) can make it challenging for local men to acknowledge that they need help and/or reluctant to ask for it. This can also make it challenging for men to adopt a caring role that has traditionally been deemed feminine. These men may be less familiar with doing various types of emotional or domestic work because it has never been expected of them. Frank's narrative highlighted gendered performances of care work; gendered conceptions of what is considered "work," and potentially gendered expectations regarding support from the state. As a single father caring for his daughter after his wife left, Frank's case also provides an example of how lived realities can diverge from gendered norms and traditions. Given that there are a number of men who provide care for relatives on dialysis, their needs and experiences ought to be considered in the development of gender and sex-specific policies and services to support unpaid care providers. This is an important step in ensuring a more equitable distribution of care work between the sexes.

### *Thesis summary*

In sum, my thesis is that the scarcity of transplantable kidneys is the dominant public discourse about renal failure, but it is limited because it neglects the contexts in which people become sick and subsequently receive their care. My main argument is that greater attention needs to be paid to the social determinants of health. When people experience various forms of marginalization or vulnerability, they are more likely to become sick and are less equipped to manage their care and treatment plans – particularly when these involve substantial travel, expenses, or time off from work. I also argue that attention needs to be paid to the various types of care provision that patients receive. This includes the exhaustive work that the dialysis nurses perform as well as multiple forms of care work provided by family members.

### **Recommendations**

#### *Recommendations for changes in regional practice*

The following recommendations are directed towards health care professionals and the regional renal care/transplant organizations discussed in this dissertation. These individuals are responsible for the prevention, detection, and treatment of chronic kidney disease. The following recommendations are aimed at improving service for rural and remote residents.

First, a mobile screening unit is a worthwhile option to consider. The “Screen for Life” coach buses in Ontario (Cancer Care Ontario, 2013) provide an excellent model for this. A mobile coach could be set up outside of the town’s health care centre, local grocery stores, recreation centres, or shopping mall. This could create visibility for chronic kidney disease, generate conversation, and motivate people to become informed about their status. A mobile screening coach could also visit sites where there is a high risk for CKD, such as industrial work camps or Aboriginal reserves. For those who have already been diagnosed with kidney failure, a mobile dialysis unit may be of help. This model has been tested in Quebec, Canada and won an award from the Quebec College of Nurses (Lehoux et al., 2007). Mobile units are more flexible than fixed dialysis clinics

and can divide their time between patients at several different sites. Given the great distances that many of my participants have to travel in order to attend dialysis, a mobile unit could be beneficial for those in more remote regions.

Another recommendation would be for the region to consider establishing a Community Health Centre (CHC). These centres are staffed with multidisciplinary health care teams that include nurse practitioners, social workers, dietitians, and other health care professionals. CHCs are typically designed to serve at-risk and vulnerable populations and take local needs into consideration during the planning and development of their services. They also “advocate for increased focus, healthier public policy and a more effective, equitable and comprehensive primary health care system that addresses the determinants of health” (Association of Ontario Health Centres, 2014). Residents from the region of study could visit multiple health care professionals and specialists all at the same site at a CHC. This could reduce the amount of travel for patients and could help improve coordination and communication amongst health care professionals in the region. Being a member of a multidisciplinary team may also help staff to feel less isolated when working in a rural and remote area. This could help with recruiting and retaining health care professionals.

Home care services for home dialysis patients could also benefit both patients and family care providers. These services could include nursing services related to chronic disease management, transportation to various appointments or errands, and caregiver relief. Additionally, the establishment of a BC Renal CKD clinic in the community dialysis unit’s town would be valuable in terms of preventing or slowing the progression of the disease. Patients with CKD and those identified as being at high risk could have their conditions monitored more closely and more frequently than they can with existing arrangements. As one of my participants noted, there is speculation that the opening of a local CKD clinic could be one of the major changes to the regional renal program over the next few years.

As suggested in Chapter 3, there is a need for greater public education regarding the risk factors, prevention, early detection, and management of chronic kidney disease and

kidney failure. One way of addressing this is by shifting the public discourse. Rather than (or as well as) posting advertisements about organ donor registration, kidney care organizations could create public awareness campaigns about kidney disease prevention and generate broader media interest in the Kidney Foundation's online risk assessment tool and similar resources. At the site of study, radio advertisements might be an effective tool, given that residents spend so much time in their cars, often listening to the radio. Any of these initiatives should include collaboration with the province's diabetes, cardiac, and chronic disease prevention groups. These organizations may have different mandates, but their areas of concern certainly overlap.

Lastly, to assist with improving equity in the region, health care professionals need to be reflexive about their prejudices. This is important given that social and demographic characteristics can influence treatment recommendations or contribute to someone not being considered for transplant candidacy. Efforts to address this could involve staff training/re-training about the social determinants of health, professional development workshops, or online resources circulated through their professional associations. Health professionals should always be mindful of negative biases based on gender, ethnicity, class, religion, age, and disability, but also of other forms of prejudice that may be somewhat more insidious in a rural and remote context. For instance, there may be prejudice against those who have low levels of formal education, or are viewed as "white trash," "red necks," or "rig pigs." These monikers – and the perceptions or assumptions that may accompany them – have the potential to negatively influence the care that is provided, or denied.

Many of the challenges and inequities identified in this dissertation extend beyond the reach of the health care system. Improving the health and well being of the residents of this region will require change and collaboration at multiple levels and across multiple sectors. In the following section, I discuss several recommendations for addressing health equity at a broader social level.

### *Recommendations for broader social change*

In order to improve health equity, there is a need for broad, system level change. One step towards achieving this is through increasing engagement in intersectoral collaboration and civic engagement. This collaboration can include those who are responsible for providing and/or subsidizing housing, transit authorities, social services, health care professionals, the Kidney Foundation, the BCPRA, grassroots community organizations, labour and trades unions, First Nations bands, and municipal governments. If these groups work together towards reducing health inequities (via education, service delivery, advocacy, and activism), they can reduce the number of silo-ed or duplicated services and create complimentary supports and initiatives. This collaboration should also include partnerships with politicians who are committed to social justice.

There is also a need for activism in the resource industry to encourage better working conditions and supports for employees. Data regarding the health impacts of this work should be collected and disseminated to industry employers, trade associations, unions, and policymakers in order to develop more appropriate regulations. Special attention should be paid to work schedules; living and working conditions in industrial camps; and workplace accommodations for dialysis patients, transplant recipients, kidney donors, and family care providers. A great deal of feminist political economy research focuses on the macro level of policy and government service provision, but meso level workplaces must also recognize their role and responsibility in creating the conditions for good health.

Members of these organizations, agencies, and local communities should engage in advocacy for all of their vulnerable rural and remote residents. The growing literature on rural health in Canada provides excellent data that can be used in support of these advocacy initiatives. Special attention should be paid to the health risks and negative health outcomes for rural and remote seniors and those living in poverty, as well to the development of policies that are sensitive to sex and gender. These policies need to protect wages, unpaid care providers, and access to services and high quality care. Public services need to be protected from leaning, privatization, and tax cuts and resources should be allocated towards building and strengthening grassroots community organizations and their capacity to provide care for their residents. Of course, these types

of policy changes are not limited to the rural and remote context. In order to address the social determinants of health more broadly, there needs to be political change at the provincial and federal levels as well.

### *Recommendations for future research*

Given the limitations of small-scale research, the breadth of a dissertation project is somewhat restricted. There are a number of issues that have been touched upon that merit further research. These issues are discussed below.

The first area worthy of further exploration is organ transfer research in rural and remote areas. Most research on kidney dialysis and transplant is urban-centric in that it makes assumptions about demographics and about the accessibility and availability of services. It is also worth further exploring the ways in which rural-living is a determinant of kidney health in Canada. Some potential research questions include: do the findings of my study resonate in other rural and remote towns in Canada? How do they compare to the challenges experienced in urban centres? How do my participants' challenges and experiences compare with those who live in rural and remote locations in Sweden or in other countries with more substantial social welfare policies?

My second recommendation is for further research into the relationship(s) between gender, work, and health outcomes in resource frontier communities. For instance, this could involve conducting health impact assessments of the labour performed in various positions in the resource industry. When people spend over 40 hours per week at work, it is important for them, their employers, and their health care providers to know how this can affect their health and what they can do to mitigate the negative health effects. As noted earlier, my study did not capture the experiences of women working in this industry. Further inquiries could consider: how do gender, work, and health intersect in resource industry labour for both men and women? How does the masculine nature of the industry (Miller, 2004) affect the women who work in it? How are the workplace hazards and culture, the organization of this work, and the related

health outcomes gendered? What type of policies and practices might be useful in addressing these challenges?

It would also be fruitful to investigate the gender-specific work roles and health outcomes for health care professionals in rural and remote areas. Nine of the 10 health care professionals that I spoke with were women. My participants' narratives revealed that these women, particularly the dialysis nurses and social workers, perform extensive care work with limited resources and a varying scope of practice. It is worth exploring the impacts that working in a traditionally gendered profession, under "moral distress" (Interview 1, 2013), can have on the mental, physical, and emotional health of these women.

I also recommend further inquiry into the experiences of CKD and renal health care for Aboriginal populations. Though Aboriginal health came up as theme in my transcripts and analysis, more data came from documents than from participants. When these issues were discussed in the interviews, it was by health professionals and not by Aboriginal persons themselves. Research on dialysis and transplant in/for Canadian Aboriginal communities is very important, particularly for those concerned with health equity, but I did not see it appropriate to pursue the theme further without contributions from this population. Moving forward, related research questions could include: why are Aboriginal Canadians so disproportionately represented in the renal patient population? What are the experiences of First Nations, Metis, and Inuit people who are on dialysis, who receive kidney transplants, who donate kidneys, and who provide care for someone with kidney failure? How can renal care and renal replacement therapies be made more accessible for Aboriginal populations in rural and remote British Columbia? What are the views and beliefs held by Aboriginal communities in the area about dialysis and transplant? How effective and/or beneficial have efforts to provide culturally appropriate services been?

Further research is also needed regarding the ongoing shift towards home dialysis and its implications for families. Future research projects could focus exclusively on this shift and speak with more family care workers, more decision-makers, and more

representatives from provincial organizations in order to gather a larger data set and gain deeper insights. It would also be worthwhile to take a historical perspective and examine these changes in practice over time, alongside other social and political shifts that have taken place in the province. In my analysis, I was critical of this institutional shift, but it may also be interesting to inquire more deeply about its social, economic, and systemic benefits. What have been some of the benefits of providing care at home – for the care workers, patients, their communities? Are there ways in which caring at home has allowed families and communities greater capacity to meet their care needs? Following my earlier recommendation that more supports be provided for unpaid care workers, it is important to research how best to do this. Conducting a needs assessment for unpaid care workers could help to identify the areas of most pressing concern and the most appropriate, feasible, gender-sensitive, and desirable local solutions. Several of the female care workers I spoke with had withdrawn from the workforce in order to provide unpaid care. Remaining in the workforce and continuing to receive a salary could help prevent families with a member on dialysis from falling into [further] poverty. Researchers could inquire about how governments and workplaces can accommodate those providing unpaid care work at home. Are there any care provider-friendly workplace policies that could be explored and introduced by employers in the region? Are there any related benefits or resources that the government can offer? Lastly, a number of the patients and care providers I spoke with were seniors. This finding opens up possibilities for future research on rural aging and rural “caregiving.” For instance, how is care work for renal patients complicated by aging –both the aging of patients and of those providing care?

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## **Appendix I: Informed Consent Form**

### **Informed Consent**

**Date:** December 2012- June 2013

**Study Name:** *Querying Organ Scarcity: Experiences, Representations, and Policy Implications in a Rural Canadian Context*

**Researcher:** Julia Brassolotto, PhD candidate

**Sponsor:** York University

### **Purpose of the Research**

The purpose of this study is to learn more about the experiences, representations, and policy implications of the scarcity of transplantable organs in Canada. Specifically, I am interested in how the shortage of organs and other resources is experienced in [town], British Columbia.

### **Criteria for Inclusion as a Key Informant in this Study:**

I am looking to speak with individuals who have first hand experiences with scarcity. This includes dialysis patients potentially awaiting kidney transplants, dialysis clinic nursing staff, and patients' relatives or caregivers. Advocates and community organizers may also be included.

### **What you will be asked to do in this study:**

After signing the consent form, you will be asked a series of open-ended questions, and then given a brief questionnaire to complete. This process should take about one hour to complete. Interviews will be audio-recorded and transcribed verbatim to allow the researcher to review your information.

### **Risks and Benefits:**

I do not foresee any risks or discomfort from your participation in this research. Potential benefits from participation may include: having an outlet to express concerns about the issue, developing a connection with a researcher interested in addressing these concerns, and contributing to scholarship in the field.

### **Privacy and Confidentiality:**

Your participation in the study is completely voluntary and you may choose to stop participating at any time, for any reason, if you so decide. Your decision to withdraw will not be met with any penalty. If you decide to withdraw from this study, all associated information collected will be immediately destroyed.

All information you supply during research will be held in confidence and your name will not appear in any report or publication of the research. Your data will be safely stored on a password-protected computer in a locked facility and only the researcher and her academic advisors will have access to this information. Confidentiality will be provided to the fullest extent possible by law.

If you have any questions about the research in general or about your role in the study, please feel free to contact Julia Brassolotto (PhD student, Principal Investigator) by email at [jbrass@yorku.ca](mailto:jbrass@yorku.ca) or her supervisor Dr. Tamara Daly at [dalyt@yorku.ca](mailto:dalyt@yorku.ca). This research has been reviewed by the Human Participants Review Subcommittee, York University's Office of Research Ethics and conforms to the standards of the Canadian Tri-council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact Ms. Allison Collins-Mrakas, manager, Research Ethics, 309 York Lanes, York University (telephone 416-736-5914 or email [acollins@yorku.ca](mailto:acollins@yorku.ca)).

I \_\_\_\_\_, consent to participate in *Querying Scarcity* conducted by Julia Brassolotto. I understand the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

**Signature** \_\_\_\_\_  
Participant

**Date**

**Signature** \_\_\_\_\_  
Principal Investigator

**Date**

## Appendix II: Demographics Survey

Please be assured that all your responses will be kept strictly confidential and are used only for my research purposes.

1. Are you: Male \_\_\_ Female \_\_\_ Other/no gender identification \_\_\_
2. In what year were you born? \_\_\_\_\_
3. What is the highest level of formal education that you have *completed* to date?  
(Please place a checkmark beside only one answer)
  - \_\_\_ Some elementary school completed
  - \_\_\_ Elementary School Diploma
  - \_\_\_ Some high school completed
  - \_\_\_ High School Diploma
  - \_\_\_ Some post-secondary completed
  - \_\_\_ College, vocational, or trade school Diploma
  - \_\_\_ Undergraduate University Degree
  - \_\_\_ Graduate or Professional University Degree

4. With which ethnic group or groups do you most identify yourself?

- Canadian
- French
- Aboriginal
- Latin American
- Central American
- South American
- Caribbean
- Pacific Islands
- European
- British Isles
- Arabic
- West Asian
- East Indian
- South Asian
- East and Southeast Asian
- Asian
- African
- South African
- Australasia or Oceania
- Other (Please specify: \_\_\_\_\_)

5. What is your religious affiliation, if any?

- Catholic
- Protestant
- Christian Orthodox
- Christian
- Mennonite
- Mormon
- Muslim
- Jewish
- Buddhist
- Hindu
- Sikh
- Other. Please specify: \_\_\_\_\_
- No religious affiliation
- Prefer not to disclose

6. When it comes to organ donation and transplantation, is your religion:

- Supportive
- Opposed
- Silent

Not sure

7. What is your political affiliation, if any?

New Democrat

Green Party

Liberal

Conservative

Left-leaning

Right-leaning

Moderate

Other. Please specify: \_\_\_\_\_

Prefer not to disclose.

8. Which of the following income ranges best describes your annual household income, before taxes? [Please place a checkmark beside only one answer]

Under \$20,000

\$20,000 to just under \$40,000

\$40,000 to just under \$60,000

\$60,000 to just under \$80,000

\$80,000 to just under \$100,000

\$100,000 or more

9. How long have you lived in [town]? \_\_\_\_\_

10. Are you insured under British Columbia's medical services plan (MSP)?

Yes  No

a. If not, why? \_\_\_\_\_  
\_\_\_\_\_

11. Are you a registered organ donor?  Yes  No  Not sure

12. Do you want to have the opportunity to review the transcript of your interview after it has been transcribed?  Yes  No

If yes, please provide contact details where we can get a hold of you:

Name \_\_\_\_\_

Telephone No. \_\_\_\_\_

E-mail address (if applicable) \_\_\_\_\_

## **Appendix IIIa: Interview Protocol (semi-structured) for dialysis patients**

### **Introduction:**

Hi there. It's nice to meet you. I'm Julia. I'm a researcher from York University. My research deals with organ transplants and who is able to get a transplant. This includes a shortage of organs, but also other resources as well. I'm doing this study to get a better idea of what the experience of kidney dialysis is like for people in a rural community like [town]. I'd like to begin with having you read over this informed consent form. Please let me know if you have any questions before you sign it.

The interview should take roughly one hour and at the end you will be asked to fill out a brief, confidential questionnaire just to let me know a little bit more about you. Do you have anything that you want to ask me about before we begin?

### **Questions about experiences of scarcity:**

- Why don't we start with you telling me a bit about yourself? What do you do? Where do you live? How long have you lived here?
- Why are you receiving dialysis treatments?
- For how long have you been receiving dialysis treatments?
- Can you tell me about what your dialysis experience has been like?

**Prompts:** How has being on dialysis affected your day-to-day life? How has it impacted your

family? Your work life? Your finances? Your relationships? Your mental health? Your emotions?

- Are you on a transplant waiting list?

**If yes:** How long have you been waiting? What has this experience been like? What would receiving a transplant mean for you, your family, your work? If your beeper went off tomorrow, take me through what would have to happen – this could include moving, taking time off from work, etc.

- What types of comments have you heard from health care professionals in reference to the availability of transplantable kidneys?
- Do you know anyone who has received an organ transplant?
- Do you know anyone who has donated a kidney or other organ?
- How has your experience been with the [regional] B.C. health care system?
- Has anyone recommend you travel to another city or province within Canada for treatments or medications?
- Has anyone, professional or personal, ever suggested that you travel to another country to get a transplant?

**If so:** do you mind telling me what they said?

- Have you heard about other people doing or considering this?
- What do you think keeps people from going abroad to get a kidney?
- Why do you think some people do go?
- How do you think that your experience in [town] might be different than that of someone on dialysis living in Vancouver or Edmonton?

**Prompt:** What kinds of challenges or benefits does living in the North create for you? Do you feel as though you have access to all of the resources that you need? This could include doctors, support groups, care centres, medications, etc.

**Questions about perceptions of scarcity:**

- Before this experience, were you familiar with the organ shortage in Canada?
- What had you seen or heard about organ transplantation?
- What are your own feelings about organ transplantation?
- Did you hear about the [town] Kidney Walk that was hosted this September? What do you think about that initiative?

**Photo elicitation:** This collection of images inspired by Eva Markvoort have become the face of organ donation in B.C. What do you think or feel when you look at the images from this campaign? What do you think about these people? What kinds of stories do you think these photographs tell? Do you think that these photographs might make someone want to become an organ donor? What do you like about the images? What do you dislike about them? Do they remind you of anything? Do you identify with these people?

- Some people claim that we don't actually have a shortage of organs, but that we are relying too much on transplantation and putting too many people on waiting lists instead of, say, better preventing kidney disease in the first place. How do you think you might respond to these people?
- If a kidney became available to you, would you have any hesitations or concerns about receiving a transplant? Why or why not?
- Would the fact that the closest pharmacy to get the transplant follow up drugs from is in Prince George affect your decision at all?
- How would you feel about receiving a kidney from someone that you know (living or deceased)?
- Do you think that you would feel differently if the donation came from a stranger? Why or why not?

**Questions about remedying scarcity:**

- How do you feel about what's being done right now in Canada to encourage more organ donors?
- What do you think about the suggestion that organ donors be paid to donate?

**Examples:** Picture someone with a healthy kidney who has lost his job and is tight for cash. He

has tried to find work, but there is nothing available in the area. He puts an ad in the paper or on E-Bay saying that he is willing to sell his left kidney for \$10,000 to someone who needs one. Someone waiting on the transplant list, who has \$10,000 that they are willing and able to spend, calls him up and arranges to purchase the kidney from him. What do you think about that? What do you think are the pros and cons of allowing this? What if he isn't paid directly? What if after a person donates an organ, the province covers his or her funeral costs when he/she eventually dies?

- How do you think that residents of [town] would respond to this idea?

- What do you think about presumed consent policies, that is, assuming that everyone would be willing to donate their organs in the event of their death unless they have signed something saying otherwise?
- How do you think that we could best get more people to donate organs? Do you think we should be trying to increase donation in the first place?
- Do you think there is anything else that we could be doing better to improve the lives of people on dialysis?

**Conclusion:**

- Is there anything else that you would like to add about this topic that we haven't covered?
- Do you have any questions for me?
- Thank you very much for your time. Here is my e-mail address and telephone number. Feel free if to contact me if you have any questions or concerns that come to you later.

## **Appendix IIIb: Interview Protocol (semi-structured) for dialysis centre staff**

### **Introduction:**

Hi there. It's nice to meet you. I'm Julia. I'm a researcher from York University. My research deals with organ transplants and who gets a transplant. This includes a shortage of organs, but also other resources as well. I'm doing this study to get a better idea of what the experience of dialysis is like for people who live and work in a rural community like [town]. I'd like to begin with having you read over this informed consent form. Please let me know if you have any questions before you sign it.

The interview should take roughly one hour and, at the end, you will be asked to fill out a brief, confidential survey just to let me know a little bit more about you. Do you have anything that you want to ask me about before we begin?

### **Questions about experiences of scarcity:**

- Why don't we start with you telling me a bit about yourself? How long have you worked here? Do you live in the area?
- What drew you to work in this field?
- What does your role at this clinic involve?
- Do many of your patients end up on transplant waiting lists? Why or why not?
- Have you witnessed anyone from [town] relocate to receive a transplant?
- Do you know of anyone in the community (living or deceased) who has donated a kidney or other organ?

**Scenario:** If I were to come in as a dialysis patient in need and want of a transplant, take me through what the protocol would be. Where would I go and what would you and I each have to do?

- What is the transplant situation like in [town]?

**Prompts:** In other words, are many people registered organ donors? Is it something that is often discussed with or amongst the dialysis patients? Are there any medical staff in town who can legally pronounce brain death? Do patients often move to Edmonton or Vancouver if they need a transplant? Do people seem supportive of the practice? Is organ donation generally seen as a gift exchange within the community? As more of a formal transaction? Differently?

- Have you seen friends or relatives come forward to donate kidneys to any of your dialysis patients? Is this encouraged? Why or why not?
- Have you ever heard patients talk about going to China, India, or elsewhere abroad to get a transplant that they couldn't get in Canada? What did they have to say about this?
- Have you heard medical professionals discuss this practice? What was their reaction to it?
- What are your feelings about this practice (transplant tourism)?

### **Questions about perceptions of scarcity:**

- Before your experience working here, were you familiar with the organ shortage in Canada?

- What are your thoughts on it now?
- Some people claim that we don't actually have a shortage of organs, but that we are relying too much on transplantation and putting too many people on waiting lists instead of, say, better preventing kidney disease in the first place. How do you think you might respond to these people?
- What do you think are the biggest challenges that your patients in [town] struggle with?

**Probes:** Are there support groups available? What do you make of the fact that patients would have to travel 8 hours to Prince George to obtain the necessary follow-up drugs after a transplant? Why is it that so few pharmacies carry these drugs?

- What do you think could be done at the health care system level to better the situations of your patients?
- What are the biggest challenges for you as a health care worker treating people with kidney failure?
- What could be done at a systems level to make your job easier?

**Questions about remedying scarcity:**

- How do you feel about what's being done right now in Canada to encourage more organ donors?

**Photo elicitation:** This collection of images inspired by Eva Markvoort has become the face of organ donation in B.C. What do you think or feel when you look at the images from this campaign? What do you think about these people? What kinds of stories do you think these photographs tell? Do you think that these photographs might make someone want to become an organ donor? What do you like about the images? What do you dislike about them? Do they remind you of anything? Do you identify with these people?

- Did you hear about or participate in the [town] Kidney Walk in September? What did you think about this event?
- What do you think about presumed consent policies, that is, assuming that everyone would be willing to donate their organs in the event of their death unless they have signed something saying otherwise?
- How do you think that residents of [town] would feel about such a policy?
- What do you think about the idea of people being paid to donate organs?

**Examples:** Picture someone with a healthy kidney who has lost his job and is tight for cash. He has tried to find work, but there is nothing available in the area. He puts an ad in the paper or on E-Bay saying that he is willing to sell his left kidney for \$10,000 to someone who needs one. Someone waiting on the transplant list, who has \$10,000 that they are willing and able to spend, calls him up and arranges to purchase the kidney from him. What do you think about that? What would be the pros and cons to allowing this? What if he isn't paid directly? What if after the person donates an organ, the province covers his or her funeral costs when he/she eventually dies?

- How do you think that residents of [town] would respond to this idea?
- How do you think that we could best get more people to donate organs? Do you think we should be trying to increase donation in the first place?

- Do you think there is anything else that we could be doing better to improve the lives of people on dialysis?

**Conclusion:**

- Is there anything else that you would like to add about this topic that we haven't covered?

- Do you have any questions for me?

- Thank you very much for your time. Here is my e-mail address and telephone number. Feel free if to contact me if you have any questions or concerns that come to you later.

## **Appendix IIIc: Interview Protocol (semi-structured) for patients' relatives or caregivers**

### **Introduction:**

Hi there. It's nice to meet you. I'm Julia. I'm a researcher from York University. My research deals with organ transplants and who gets a transplant. This includes a shortage of organs, but also other resources as well. I'm doing this study to get a better idea of what the experience of kidney dialysis is like for people in a rural community like [town]. I'd like to begin with having you read over this informed consent form. Please let me know if you have any questions before you sign it.

The interview should take roughly one hour and, at the end, you will be asked to fill out a brief, confidential survey just to let me know a little bit more about you. Do you have anything that you want to ask me about before we begin?

### **Questions about experiences of scarcity:**

- Why don't we start with you telling me a bit about yourself? What do you do? Do you live in the area? How long have you lived here for?
- How long has your loved one been receiving dialysis treatments?
- Can you tell me about what his or her dialysis experience has been like?
- How has his/her being on dialysis affected *your* day-to-day life? What is your role in his/her caregiving? How did you come to take on this role?
- How has it impacted your family? Your work life? Your finances?
- Do you know anyone who has received an organ transplant?
- Do you know anyone who has donated a kidney or other organ?
- If a kidney became available for your loved one, how would you feel about the idea of him/her receiving a transplant?
- How has your experience been with the [regional] B.C. health care system? With the dialysis clinic? What have the costs been like?
- Are there any support groups for dialysis caregivers in the area? Have you had any experience with them? Where do you turn for support?

### **Questions about perceptions of scarcity:**

- Before your experience with your loved one's dialysis, were you familiar with the organ shortage in Canada?
- What had you seen or heard about organ transplantation?
- What are your own feelings about organ transplantation?

**Photo elicitation:** This collection of images inspired by Eva Markvoort has become the face of organ donation in B.C. What do you think or feel when you look at the images from this campaign? What do you think about these people? What kinds of stories do you think these photographs tell? Do you think that these photographs might make someone want to become an organ donor? What do you like about the images? What do you dislike about them? Do they remind you of anything? Do you identify with these people?

- What do you see as the biggest challenges in caring for someone on dialysis while living in [town]?
- What are your best supports here? This could include people, places, organizations, etc.
- How do you think your experience might be different than that of someone who is living in Vancouver or Edmonton?

**Questions about remedying scarcity:**

- How do you feel about what's being done right now in Canada to encourage more organ donors?
- Did you hear about the [town] Kidney Walk that was hosted this September? What do you think about that initiative?
- What do you think about presumed consent policies, that is, assuming that everyone would be willing to donate their organs in the event of their death unless they have signed something saying otherwise?
- How do you think that residents of [town] would feel about such a policy?
- What do you think about the idea of people being paid to donate organs?

**Examples:** Picture someone with a healthy kidney who has lost his job and is tight for cash. He has tried to find work, but there is nothing available in the area. He puts an ad in the paper or on E-Bay saying that he is willing to sell his left kidney for \$10,000 to someone who needs one. Someone waiting on the transplant list, who has \$10,000 that they are willing and able to spend, calls him up and arranges to purchase the kidney from him. What do you think about that? What are the pros and cons to allowing this? What if he isn't paid directly? What if after the person donates an organ, the province covers his/her funeral costs when he/she eventually dies?

How do you think that residents of [town] would respond to this idea?

- Have you ever heard people talk about going to China, India, or elsewhere abroad to get a transplant that they couldn't get in Canada? What did they have to say about this?
- What do you think about this practice?
- How do you think that we could best get more people to donate organs? Do you think we should be trying to increase donation in the first place?
- Do you think there is anything else that we could be doing better to improve the lives of people on dialysis and their families?

**Conclusion**

- Is there anything else that you would like to add about this topic that we haven't covered?
- Do you have any questions for me?
- Thank you very much for your time. Here is my e-mail address and telephone number. Feel free if to contact me if you have any questions or concerns that come to you later.

#### Appendix IV: List of people interviewed

	<b>Role</b>	<b>Sex</b>	<b>Date</b>
Interview 1	Dialysis nurse	Female	March 15, 2013
Interview 2	Dialysis nurse	Female	March 15, 2013
Interview 3	Dialysis nurse	Female	March 19, 2013
Interview 4	Dialysis patient	Female	March 19, 2013
Interview 5	Caregiver	Male	March 19, 2013
Interview 6	Transplant coordinator	Female	March 22, 2013
Interview 7	Dialysis nurse	Female	March 25, 2013
Interview 8	Dialysis patient	Male	March 25, 2013
Interview 9	Transplant recipient, PD patient	Female	April 11, 2013
Interview 10	Caregiver	Female	April 11, 2013
Interview 11	Nephrologist	Male	April 15, 2013
Interview 12	Social worker	Female	April 17, 2013
Interview 13	Dialysis patient	Male	April 19, 2013
Interview 14	Dialysis patient	Female	April 13, 2013
Interview 15	Social worker	Female	May 1, 2013
Interview 16	Caregiver	Male	May 6, 2013
Interview 17	Home dialysis patient	Male	May 10, 2013
Interview 18	Caregiver	Female	May 10, 2013
Interview 19	PD patient	Female	May 10, 2013
Interview 20	Dialysis patient	Male	May 13, 2013
Interview 21	Transplant recipient	Female	May 13, 2013
Interview 22	Transplant recipient	Male	May 14, 2013
Interview 23	Dialysis patient, PD patient	Female	June 6, 2013
Interview 24	Dialysis patient	Male	June 6, 2013
Interview 25	Caregiver	Female	June 6, 2013

Interview 26	Transplant recipient	Male	June 11, 2013
Interview 27	Transplant recipient, home dialysis patient	Male	June 25, 2013
Interview 28	Representative from related provincial organization	Female	June 25, 2013
Interview 29	Dialysis patient	Male	June 26, 2013
Interview 30	PD patient	Female	June 26, 2013