



# Scarcity discourses and their impacts on renal care policy, practices, and everyday experiences in rural British Columbia



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## ABSTRACT

Drawing from a qualitative case study in rural British Columbia, Canada, this paper examines the discourse of kidney scarcity and its impact on renal care policies and practices. Our findings suggest that at different levels of care, there are different discourses and treatment foci. We have identified three distinct scarcity discourses at work. At the macro policy level, the *scarcity of transplantable kidneys* is the dominant discourse. At the meso health care institution level, we witnessed a discourse regarding the *scarcity of health care and human resources*. At the micro community level, there was a discourse of the *scarcity of health and life-sustaining resources*. For each form of scarcity, particular responses are encouraged. At the macro level, renal care and transplant organizations emphasize the benefits of kidney transplantation and procuring more donors. At the meso level, participants from the regional health care system increasingly encourage home hemodialysis and patient-led care. At the micro level, community health care professionals push for rural renal patients to attend dialysis and maintain their care plans. This work contributes to critical, interdisciplinary organ transfer discourse by contextualizing kidney scarcity. It reveals the tension between these discourses and the implications of pursuing kidney donations without addressing the conditions in which individuals experience kidney failure.

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## 1. Introduction

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, kidney 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. Though health care professionals, bio-ethicists, and popular media use scarcity in these ways, the concept itself is seldom queried or empirically investigated. In this context, the term refers to the shortage of transplantable kidneys in relation to the increasing demand for them.

Through the use of a feminist political economy framework, we unpack the ways in which kidney scarcity is experienced in participants' lives and explore how the discourse is defined, utilized, and represented in popular media, policy, and the related literature.

Using the example of British Columbia and a rural town in the province, we show how the concept of scarcity operates in kidney transfer policies, practices, and the everyday experiences of individuals. "Organ transfer" is a term coined by Sharp (2007) in reference to the practices of organ donation and transplantation. The term is intended to link the often-compartmentalized roles of the kidney donor, transplant surgeon, and kidney recipient. The concept of scarcity serves as a point of entry into broader political and economic issues surrounding kidney transfer. Our findings show how health care professionals at macro, meso, and micro levels invoke these discourses. Our analysis reveals that, at each of these levels, there are resource scarcity and health inequities.

### 1.1. Background

#### 1.1.1. Organ scarcity as a fraught discourse

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, a report written for the British Columbia Transplant Society (BCTS) claims that by the

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year 2040 there will be a 221% increase in the need for organs (from 7247 in 2000 to 23,280 in 2040), leading to a 291% increase in the transplant gap between supply and demand (5441 people whose transplant needs are unmet in 2000 to 21,265 people by 2040) (Baxter and Smerdon, 2000). These predictions were developed through an examination of trends in organ transplant waiting lists, age-specific recipient and donation rates, and projected characteristics of Canada's population (Baxter and Smerdon, 2000).

Organ exchange is frequently framed in these market terms, as a matter of scarce resources. However, several scholars (Scheper-Hughes, 2006, 2010; Lock, 2002; Koch, 2002) claim that organ scarcity is simply a matter of perspective. They 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. 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” (2006, p. 49). The focus on the need to increase organ donation limits discussion of why transplants are becoming increasingly routine and required in the first place. For instance, the expansion of transplant recipient eligibility criteria over the last 20 years means that the donor pool can never meet the increasing demand within our current means of procurement. Infants, patients over 70 years old, patients with comorbidities, and patients whose transplants have been rejected are now eligible for the kidney transplant wait list.

One in 10 Canadians now lives with some level of kidney disease, which is one of British Columbia's fastest growing illnesses (BCTS, 2013) and the tenth leading cause of death in Canada (Statistics Canada, 2011). The surge in kidney failure in Canada is largely credited to growing rates of diabetes and high blood pressure (Canadian Institute for Health Information, 2015) associated with the population aging and rising rates of obesity (Lock and Nguyen, 2010). However, this surge can also be understood to reflect the social determinants of health (Lock and Nguyen, 2010; Dinca-Panaiteanu 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 kidney failure in isolation from the social, political, economic, environmental, and cultural contexts in which people become ill is to ignore the origins of kidney scarcity.

### 1.1.2. *Why should we be concerned about the organ scarcity discourse?*

We should be concerned about the organ scarcity discourse because it informs our policies and practices, because of its narrow clinical biomedical focus, and because treating human parts as scarce medical resources can have troublesome implications for the commodification of human bodies – particularly when the risks and benefits of these practices are inequitably distributed. Koch (2002) discusses the concept of lifeboat ethics and how this approach is 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 describes 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” (Koch, 2002, p.5). 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).

The repeated emphasis on the scarcity of donor organs and the number of people dying on the transplant wait list paints a picture of a desperate organ crisis in Canada and abroad. With a crisis in mind, many 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 example, procurement from death row prisoners and encouraging suicidal people to kill themselves in ways that leave their organs viable for transplant (Cohen, 1991). Such proposals used to be quickly dismissed, but they are increasingly entertained in academic journals and popular media (Joralemon, 1995). 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. Koch (2002) claims that organ scarcity is exacerbated and even created by racial and regional inequalities in the American health care and transplant systems. Similarly in Canada, Special Olympic gold medalist Terry Urquart was denied access to the heart transplant eligibility list on the grounds of his having Down Syndrome (ibid). Such decisions are made on the utilitarian grounds that the organs may ‘better serve’ individuals without such limitations. People with disabilities and other intersections of marginality have been discriminated against when ‘scarce organs’ require allocation (Ne’eman et al., 2013) and utilitarian criteria for waitlist inclusion are applied to individuals.

Scheper-Hughes (2010) has identified concerns about the dominance of a transplant discourse focused on saving lives that has created a “moral imperative” (p. 8) – a duty to donate – and the resulting perils for both living and deceased donors. Situating organ transfer within the context of an increasingly neo-liberal global economy, she provides evidence of the shift toward a notion of the self as a source of medical materials and a sense of entitlement to the parts of others (Scheper-Hughes 2010). It is interesting that lifeboat ethics have been evoked in this context, given that renal transplants are not life-saving procedures in the way that heart transplants are. No other therapy can replace the function of the heart. A kidney transplant may improve and/or extend a life, but a patient can still live for years on dialysis. This underscores the fact that kidney transfer is not strictly a matter of life and death, but rather, a practice that occurs within particular social, political, and economic systems and reflects the different relationships that have been institutionalized between the individual, the market, and the state (Healy, 2005).

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). Health care discussions are framed in market terms of supply and demand. This is increasingly the case in a context of globalization and trades in services with the United States, who have a privately funded and more marketized health care system. Provincial governments struggle with long wait times for health care services, as well as increasingly limited funds, staff, and resources. These shortages are particularly pronounced in rural parts of Canada. In-clinic dialysis treatments cost the health system about \$83,000 per patient annually, whereas home dialysis costs about \$48,000 – \$53,000 annually, and the one year cost of a kidney transplant is about \$120,000 and then \$22,500 annually for subsequent years (Kidney Foundation of Canada (2013)). Over a five-year period, a kidney transplant saves the health care system over \$100,000 compared with in-clinic dialysis (Kidney Foundation

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