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.

Keywords

Canada; kidney scarcity; renal care; rural health; health equity

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, bioethicists, 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.

Background

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 year 2040 there will be a 221% increase in the need for organs (from 7,247 in 2000 to 23,280 in 2040), leading to a 291% increase in the transplant gap between supply and demand (5,441 people whose transplant needs are unmet in 2000 to 21,265 people by 2040) (Baxter & 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 & 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, 2002a; 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 & Nguyen, 2010). However, this surge can also be understood to reflect the social determinants of health (Lock & Nguyen, 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 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.

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” (ibid, 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 (ibid). 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 (ibid). A number of studies have found transplants to be more cost effective than dialysis (Wong et al., 2012; Howard et al., 2009). 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).

The critical literature about organ transfer postulates that the perceived and actual shortage of valuable resources is fundamentally a matter of health equity. That is, the allocation and distribution of scarce resources are issues of social justice because they require determining who will live or thrive when not everyone can do so. These deliberations do not take place outside of the social systems that we experience every day. It is for these reasons that we designed the study described below.

Methods

We conducted an explanatory case study of dialysis and organ transplant policy and practice with a purposively selected rural dialysis clinic in the province of British Columbia, Canada (Yin, 2009). The data were gathered using qualitative critical ethnography methods (Thomas, 2003) and document analysis (Atkinson & Coffey, 1997). Ethics approval was granted by our university’s Ethics Review Committee.

Methodology

Feminist political economy (FPE) serves as the methodological perspective used in our research. Feminist political economists situate individuals in particular social and physical locations, relations, discourses, and understandings of the world (Armstrong, 2001). This framework informed the area selected for inquiry, the types of questions asked of participants, and our analysis/interpretation of the findings. FPE typically involves a project of contextualization and exploring the tension between structure and agency (Mutari, 2000). 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). By examining our findings through this lens, we were able to identify related matters of power and politics at multiple scales of insight (Vosko, 2002).

In this paper, we use the theoretical and analytical techniques of FPE to show how the scarcity discourse operates amongst and between macro, meso, and micro levels. This is not a project of extending FPE theory, but rather of applying it to an area of study that has received minimal attention from feminist political economists. Our reading of scarcity contributes an FPE analysis to the rich discussion and debates held largely between bioethicists, sociologists, anthropologists, economists, and health professionals.

Site selection

A satellite community dialysis unit was purposively selected because of its rural location and proximity to particular industries and services. The specific site will remain unidentified to protect the confidentiality of informants. We purposively selected participants who worked in renal care and had experience with the renal health care system, as well as those receiving dialysis or caring for someone on dialysis for in-person and telephone key informant interviews.

Research process and analysis

During the spring of 2013, the first author conducted 30 semi-structured, in-depth key informant interviews with individuals who have had direct experience as: hemodialysis patients at the community clinic, home-hemo and peritoneal dialysis patients, kidney transplant recipients, family care providers, and health care professionals. This included nurse(s), nephrologist(s), transplant coordinator(s), social worker(s), and administrative professionals located in a provincial organization. Participants were given a brief lay summary of the research and each signed an informed consent form prior to participation. The interviews lasted between 30 and 90 minutes each. They were digitally recorded and later transcribed verbatim. The transcripts were coded and critically analyzed using the constant comparison method (Glaser, 1965; Creswell, 2009), and a feminist political economy theoretical framework (Doyal, 1979; Mutari, 2000; Vosko, 2002) that highlights who benefits from policy changes and under what conditions. We used pens and highlighters to code repeated themes in the interview transcripts. NVivo data analysis software was then used for second-round coding and for producing thematic reports.

We also performed a thematic analysis of ~30 policy, practice and media documents. All of the documents are publicly available and were retrieved from related websites. The

documents covered dialysis and transplant policies, donor awareness initiatives, local news associated with this topic, and related practice guidelines. These documents were selected because they outline the structure of the system(s), the central values and priorities of related organizations, and the ways in which kidney health, treatment, and replacement are presented to the public in this context. The documents were read, highlighted, and thematically coded by hand. The findings from the document analysis were triangulated with the interview data.

We performed member checking with our key contact in order to, “seek corroboration or criticisms of the researcher’s account” (Bryman & Teevan, 2005) and to ensure that she felt that the observations were accurate and did not identify any of the participants. This conversation centred on the themes identified and the main arguments of the analysis. Our contact supported our analysis and her account confirmed a number of the findings. She did not have any concerns regarding confidentiality.

Findings

In this section, we document the scarcity discourses and treatment foci at the macro (policy/provincial), meso (health system/regional) and micro (satellite clinic/patient) levels.

Scarcity discourses at the macro level

Within policies and public health education, the dominant discourse surrounding renal failure involved the scarcity of transplantable kidneys. This message was consistent across documents from non-profit and charitable organizations such as the Kidney Foundation of Canada and the BCTS, from leading health professionals in this field, and from news and media sources. This discourse was also apparent in the interviews with upper level renal care professionals. The central message of many organizations’ public education initiatives is that Canadians are dying and it is up to each of us to “be a hero,” (Kidney Foundation of Canada, 2009) “give the gift of life,” (Trillium Gift of Life Network, 2013) and “live life and pass it on” (BCTS, 2015) by registering to be a kidney donor. The focus is fairly consistently on the extensive waiting lists, on the recipients whose lives have been saved by transplantation, and the number of Canadians who die before receiving a transplant. A CTV News piece discussing a report from the Canadian Institute for Health Information states that:

“229 people died [in 2010] awaiting a transplant. And there is concern that the number of deaths could rise if donations don’t increase... Last year, patient advocacy groups submitted recommendations to provincial health ministers aimed at boosting donation rates. The recommendations were taken from similar successful programs in other countries. But now these groups are going straight to the public. ‘You can’t use your organs when you are dead, you might as well give them up and save multiple lives,’ said Dr. Jeff Zaltzman from St. Michael’s Hospital in Toronto”

(Favaro, 2012, para 4, 21–23).

This piece, communicating this matter to the public, frames these deaths as the result of low donation rates, rather than increases in diabetes and vascular disease. When we asked about

patients traveling abroad to procure a paid kidney transplant, one health professional invoked the language of desperation discussed earlier:

“We do what we can, right? We counsel people, we tell them about all the bad stuff... You need to remember these are desperate people and we don’t know what that feels like. When you have an opportunity or some sum of money to get you out of your misery or avoid dialysis, I mean, many of us, I don’t know that we wouldn’t do the same thing if we had the means and the opportunity”

(Interview 28, 2013).

Both quotations suggest desperation for kidneys and an expectation for others to donate or sell. The rationale for demanding someone else’s kidney is expressed in these instances as a matter of life and death. This version of the scarcity discourse is consistent with the one identified in the critical organ transfer literature. This discourse is embodied in the mandates of these organizations, in the types of initiatives that they prepare, 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. The discourse employed by these national and provincial organizations is significant because it provides the broader context for the regional renal program’s activities. It also informs the public’s perception of kidney failure and inspired the changes in policy and practice discussed below.

Treatment focus at the macro level

When the problem of increasing kidney failure is framed in terms of a shortage of transplantable kidneys, the solution proposed is often to procure more donations and increase the number of transplants. The discourse of kidney scarcity has had a tangible impact leading to several changes in the province’s policies and practices. In addition to having the first provincial renal agency and first renal program guidelines in the country, British Columbia is a leader within Canada in terms of organ transfer innovation. For instance, in 2006 the BCTS undertook a research project to study the practical and ethical implications of Living Anonymous Donation. This project was motivated by the shortage of kidneys available for transplantation (BCTS, 2006). In 2006, the BCTS 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 allows for an incompatible couple to trade donors with another couple in the same situation (BCTS, 2006). In 2006, the BC Branch of the Kidney Foundation and the BCTS 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). Since LODER’s inception, all Canadian provinces have adopted programs to reimburse living organ donors for expenses related to their donation.

A nephrologist in our study discussed new ways that regional health authorities can increase their number of transplants. A notable example included procuring organs from patients who are not brain dead, but in a permanent vegetative state. The nephrologist said:

“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, 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... There have only been a handful of those kinds of organ donations in the province, but they are happening. And it is something that will happen more in the future... To help address the scarce organ resource [sic]"

(Interview 11, 2013).

Procuring organs from patients who have experienced cardiac death has become an increasingly common and accepted method of organ procurement. When discussing the province's growing number of transplants, the same nephrologist credited the BCTS director for recent improvements in kidney 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. 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).

These efforts described above are directed toward identifying potential donors wherever possible and expanding the profession of organ transplantation.

In a relatively recent article, several experts in this field discuss financial incentives for organ donation in Canada (Gill et al., 2014). 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 and its potential for commodifying bodies, some experts are quite seriously contemplating the benefits of financial compensation for organ donation. While covering the costs associated with donating or procuring donations may be categorically distinct from directly paying for a kidney, potential donors and their organs are still framed as health care resources. This implies some form of an external systemic claim to the parts of these individuals – and a sense that their parts are tradable items distinct from themselves.

In addition, the promulgation of the kidney scarcity discourse has accompanied an increased number of transplants performed. In 2013, the BCTS had a record breaking number (127) of living donor kidney transplants (BCTS, 2014), having already set a new record high each of

the previous two years. In 2012, “BC’s donors-per-million rate exceeded the national average, for both living donors... and deceased” (BCTS 2014). After the first BC Transplant Consensus Summit hosted by the Kidney Foundation in 2015, “the jury has recommended that British Columbia adopt presumed consent legislation, with appropriate safeguards in place, to increase the number of kidney transplants in this province” (Kidney Foundation of Canada, 2015). Canada currently has required consent legislation for organ donation. Unless an individual has registered as a donor or explicitly consented to donation, his or her organs will not be donated. Presumed consent is the opposite; consent is assumed unless an individual has actively opted out of organ donation (Healy, 2005). This recommendation has been released to the media and is a priority in their five-year Kidney Transplantation and Organ Donor Registration Campaign (Kidney Foundation of Canada, 2015). In sum, our 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 and transplants.

At this macro level, there was little distinction between the transplant needs and options of rural and urban Canadians, ones living in poverty or wealth, men or women, or people from particular ethno-racial backgrounds. Most policy recommendations were urban-centric in that they assumed reasonable access to transplantation, recovery, and other health care services. As the next sections show, our meso and micro level data reveal the challenges posed by geographic isolation, low socioeconomic status, and other intersections of marginalization.

Scarcity discourses at the meso level

At the regional health care system level, there was less emphasis on transplant even though health professionals do suggest it for all eligible candidates. Participants expressed more concern with an effective and efficient health care system than with transplant and scarcity of organs. For instance, discussions focused on providing adequate renal care and dialysis treatments and the main discourse that emerged in these narratives was one of a *scarcity of human and health care resources* – including, but not limited to, shortages of health care professionals and funding for rural health services.

The regional renal care staff noted that they were constantly reminded of the limited system resources that were available and made 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 appears to be common in rural health care provision in Canada (Kulig & Williams, 2011).

Since the full renal care team (composed of nephrologists, social workers, and others) was located in a town ~450km from the satellite clinic and patients saw them so infrequently, the satellite community nurses took on additional roles. For instance, they did patient education as well as advocacy, counseling and administrative duties. One nurse identified how satellite unit staff and patients were affected by not having nephrologists present:

“Years ago there was only one nephrologist [at the regional unit]. And then he stopped and then we had Dr. [nephrologist] come onboard. He’s the only one that’s ever, ever come out here... We now have three nephrologists who rotate call. ...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”

(Interview 1, 2013).

Because of their large catchment area and limited/transient staff, members of the regional renal care team also took on heavier workloads. As is common in other areas of rural health (Hanvey, 2005), dialysis nurses adopted multiple care roles in order to compensate for the limited staff:

“[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... I’d far rather be a nurse than an administrator”

(Interview 1, 2013).

The medical staff also experienced heavy workloads. For instance, one nephrologist told us that even when he visited the satellite clinic, he was unable to see all of the patients that were referred to him. This includes patients who have kidney disease, but are not yet on dialysis and are trying to prevent further deterioration:

“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”

(Interview 11, 2013).

Similarly, a social worker at the regional unit said that her caseload consisted of over 700 patients (Interview 15, 2013). She noted that a social worker from Vancouver told her that 700 patients is sufficient for about four social workers there. All of the rural health professionals interviewed identified the challenges associated with the scarcity of funding, the shortage of staff, the resultant workload, and the impacts on patients. In response to these challenges, and because administration and specialists were regionally centralized in larger cities, there was a discursive focus on patient-led care at home.

Treatment focus at the meso level

At the meso level, we noted a growing emphasis on home hemodialysis and peritoneal dialysis. Home dialysis and/or PD are encouraged by several provincial organizations and

are popular in documents regarding renal care in BC. For instance, the British Columbia Provincial Renal Agency (2013) put out a brochure titled *Dialysis Options in BC: A guide to making the treatment choice that is right for you* 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 own dialysis care (ibid).

Opening additional satellite clinics in rural and remote areas is challenging because, as one health professional said, “you are too beholden to nurses coming and going.” She went on to say:

“That has partly, although not completely, fueled our focus on home therapies... I think that’s sort of reflective of the larger health care sector or larger perception of how care can be provided and where it can be provided – and who should be taking responsibility. So a lot of it goes back to early, early on around patient responsibility and are they good care partners?”

(Interview 27, 2013).

Bringing dialysis to patients’ homes is touted as an effective way to reduce high system costs, reduce travel time, and provide flexible, high quality care to rural living patients (BCPRA, 2013). However, this overlooks the political and economic incentives for encouraging home-based care, as well as its implications for those providing unpaid care at home (Brassolotto & Daly, 2015). For instance, dialysis patients and satellite clinic nurses noted a number of socioeconomic factors that limited one’s ability to be a “good care partner.” We present these findings in the next section.

Scarcity discourses at the micro level

At the satellite clinic level, the discourse had more to do with the *scarcity of health and life sustaining resources* and spoke to the socioeconomic status of patients. Not only were nurses aware of the limited funds and health care resources that they were working with, they were also acutely aware of the limited socioeconomic resources available to their patients. The nurses recognized the high costs of travel and transportation to dialysis, the expensive nature of the kidney-friendly diet for those on low incomes in isolated areas, the lower levels of formal education and health literacy, the limited access to supports and services, and the social and/or financial hardships that many of their patients experience. For example, this meant not recommending home dialysis for a patient because he lived on a First Nations’ reserve without consistent access to the running water required to operate a dialysis machine.

Health care professionals spoke about the challenges associated with caring for patients who experienced social, economic, and spatial marginalization:

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).

Affording care in rural places was also related to the high costs of transportation. It was common for both health care professionals and patients to identify financial strain as a barrier to attending dialysis. One health care provider noted the following:

R: We had one fellow where he just said, "I can't come more than twice a week" and he really needed the [dialysis] three or four 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... when money got tighter, then he would just say, "I just can't come"

(Interview 2, 2013).

One of the patients from the satellite clinic reinforced this when she told us:

"I think [dialysis] should be available all over the place. People can't afford this running around. It's hard on their life [sic]. There was one couple from here, they ended up moving down south. They lost everything they had here. They lost everything. And we're headed that way"

(Interview 4, 2013).

Another patient told us that he had lost his first transplant because he could not afford to take time off from work to have the necessary follow up testing done:

"I was working in the oil patch and 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. And you go to camp for months on end... 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).

When we asked about some of the biggest issues faced by patients, finances related to accessing care were the most frequently mentioned challenge. Another health care provider said:

R: 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).

When we asked another participant if anyone had refused a transplant because of the requirement to live in Vancouver for a period of time, we heard the following:

"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"

(Interview 15, 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 their patients' kidney transplants would be a valuable solution to the challenges identified. Their concerns reflected a deep understanding of the complexity of the everyday challenges that their patients face and their recommendations had to do with improving the effectiveness of the renal care system in serving the needs of their patients.

Treatment focus at the micro level

Given the challenges that satellite clinic dialysis patients face, the staff's emphasis was on simply getting patients to attend dialysis and maintain their renal care plans. In some situations, dialysis nurses felt that they had to advocate for their patients in a variety of inventive ways. For instance, the satellite clinic's nursing team sometimes went to great lengths to try and mitigate the effect of social issues on patients' care and treatment options. A nurse told us:

R: I got one of our patients into palliative care and got into so much trouble from [other health professional]. 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. 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).

This same nurse spoke about providing counseling for a 26-year-old patient who had “blown his kidneys out from drug overuse,” about coordinating transportation to dialysis, and scheduling the clinic's hours in order to accommodate patients who were still in the workforce. Thus, care at the clinic level involved treating the effects of chronic kidney disease as well as the effects of poverty, geographic isolation, and other determinants of health.

Discussion

Feminist political economists typically approach policy discussions by asking, “who benefits?” and exploring power relations (Armstrong, 2001). Our findings suggest that the kidney scarcity discourse benefits the health care system through cost savings; benefits transplant surgeons and related organizations by expanding their visibility, funding, and practice; and benefits transplant recipients by restoring renal function and improving quality of life. However, transplants are not universally accessible. Rural residents, people with multiple health conditions, people with low incomes, and people who experience various forms of social and geographic marginalization are less likely to be able to access transplantation services. Efforts to reduce dialysis expenses can offload costs and care from the system onto patients and their families. In terms of power relations, our findings reveal that some of the most influential parties in renal care (government, policy makers, members of policy sub-systems) are at a distance from the micro level struggles associated with renal health and everyday care.

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 how we do 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 our 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 prescriptive concept that drives and informs policy and practice in order to procure more donations. These findings may also reveal the expansion and professionalization of transplant programs. After mastering their surgical practices, these programs enter growth development phases with a primary focus on transplanting more patients and, in turn, procuring more organs.

Though several scarcity discourses surfaced, it is predominantly the scarcity of kidneys that has received widespread public attention and generated changes to policy and practice. These changes can have concerning implications with respect to donors and their parts being treated as potential medical resources and with continuing systemic neglect for the broader determinants of health. In this way, our findings confirm some of the conclusions of the critical literature regarding kidney scarcity.

We argue that the variation in emphasis and discourse across the macro, meso, and micro levels reflects different needs and goals at each level of care, as well as their varying proximity to renal care patients and their daily lives. This is not to suggest that those at the macro level are unconcerned with kidney disease prevention or that those at the micro level are disinterested when it comes to transplantation. Rather, we highlight the *primary* focus witnessed at each of these levels and the language that our participants used to frame their experiences.

Implications of the scarcity discourses

With less than 10% of Canadians able to identify diabetes as a risk factor for kidney disease (Kidney Foundation of Canada, 2010), there is certainly a disparity between the widespread awareness of the need for kidney donors and the knowledge required to help prevent kidney disease. A feminist political economy understanding of health recognizes that even though there are a number of lifestyle and therapeutic benefits to kidney transplant, replacing a single organ of someone who is living in poverty with several comorbidities can only do so much. It does not cure their diabetes or vascular disease, nor does it prevent more people from experiencing kidney failure. While BC's kidney donor registration and transplant rates have increased over the past 10 years, the number of British Columbians affected by kidney disease has increased by 60 percent (BCTS, 2013c). This reveals that while the kidney scarcity discourse has been effective in producing more transplantable kidneys, it has been less successful in terms of reducing and preventing renal failure for British Columbians.

To a lesser extent, the discourse regarding the scarcity of health care resources and rural health professionals has also translated into some action. Research on rural health has taken up some of these issues (Sutherns & Haworth-Brockman, 2012; Rourke, 1993, 2005; Kulig & Williams, 2011). Academics have also taken up the issue of increasing reliance upon charitable organizations, rather than the state, to provide support for rural residents at times of heightened vulnerability and dependency (Skinner & Joseph, 2007). However, these issues receive substantially less public and policy 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 can be read as 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 basic income or more comprehensive social services.

Kidney transplantation exists within a larger health system concerned with allocating dollars towards areas of need. Our analysis highlights the impact that fiscal pressures resulting from limited resources have on renal care policies and practices. Because of its increased prevalence and costs, renal disease has become a cause for policy concern. As noted earlier,

many macro and meso level approaches to renal treatment ignore the social determinants of health and the conditions in which people's kidneys fail. This can have negative implications for individuals experiencing renal failure as their basic needs may continue to go unmet and they increasingly bear the costs associated with their care. As noted by the Kidney Foundation of Canada (n.d.), rural Canadians receiving both home and hospital-based dialysis can experience annual out-of-pocket costs associated with their dialysis as high as \$20,000. One man in Ontario ended up having to spend upwards of \$60,000 in the installation and maintenance of the well water system to support his home dialysis (ibid). This state of affairs suits the system's needs to contain budgets, but individualizes costs and places the burden on sick and vulnerable individuals and populations. This shift is political in nature, but the politics are lost when we focus solely on economic implications. The increase in renal failure is not solely an economic issue for Canada, but also a matter of health equity.

A FPE analysis was central in bringing these conclusions to light. When considering the health system context, this framework assists in revealing that the 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 that offloads the costs and responsibility for care onto individuals. Transplant centres are predominantly located in tertiary care hospitals and serve affluent populations. Low income and/or remotely located individuals do not have the same opportunities for kidney transplantation as their more affluent urban counterparts. Using FPE, we connect the macro level policies with activities and everyday experiences at the regional and community levels. What our analysis reveals are the potential risks associated with the kidney scarcity discourse, its manifestations in this case study, and its limitations in terms of improving the lives of Canadian renal patients and their care providers.

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