Domesticating dialysis: A feminist political economy analysis of informal renal care in rural British Columbia

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Abstract

Drawing from a case study in rural British Columbia, this article examines the experiences of individuals providing unpaid care for family members on hemodialysis and how these experiences fit within larger political and socio-economic policy contexts. We suggest that the current shift towards home-based renal care, the “domestication of dialysis,” reflects a broader trend toward a reduction of public health services, assumptions about the feasibility of unpaid care work in rural settings, and an increasing reliance on individuals—rather than the state—to support dependency and produce healthy citizens. This article confirms the challenges that come with providing daily care to a family member with a chronic disease and the gendered nature of unpaid care work. It also extends discussions of unpaid care to include how these challenges can be applied to renal care and complicated by rural residence.

Keywords

Care work; rural health; feminist political economy; health geography; British Columbia

Introduction

This paper presents findings from a qualitative case study of dialysis care in rural British Columbia with a focus on the shift towards home hemodialysis and peritoneal dialysis led by patients and family members. We have identified scarcity discourses observed in this study at macro (policy), meso (health services), and micro (individual health) levels of analysis (Brassolotto and Daly 2016). Drawing from the narratives of family members, the present paper focuses less on broader scarcity discourses and particular renal replacement therapies. Instead, it addresses the informal care work performed by family members and its relationship to the rural setting in which care takes place. As Milligan illustrates, experiences of informal caring “can be seen as a function of a carer’s social and spatial location” (2000, 51). In what follows, we use a feminist political economy lens to examine the nature of informal renal care work, the various forms that it takes in this rural context, and the broader implications of shifting responsibility for care. We argue that when dialysis

treatments are domesticated, informal care providers are required to perform medical tasks and intensive care work that overestimates their capacity and willingness to do so. This work often requires them to reconfigure major elements of their lives, sacrifice their own pursuits, and puts them at heightened vulnerability for their own negative health and economic outcomes.

This work contributes to feminist political economy scholarship that addresses the shifting of care from health care institutions to individuals and their families (Armstrong and Armstrong 2001). This work confirms the negative effects that broad, neo-liberal policy trends have on unpaid care workers and extends feminist political economy to address renal care and rural Canada. It also contributes to health geography scholarship that critically examines trends toward home spaces as the preferred location of health and social services (Milligan 2000), and understands health and social care as embedded in place (Hanlon et al. 2007). Much like these scholars, we consider the ways in which place encompasses broader political, economic, and social conditions, while also being enabled and constrained by the particulars of the geographic and cultural locale (Andrews and Evans 2008).

Childerhose and 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 (Childerhose and MacDonald 2013). 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 and MacDonald 2013, 1). In other words, this is not only a matter of shifting *work* from health care institutions to the home; it is also about locating responsibility for good health and care at the individual level.

We conducted this study in order to explore how kidney scarcity manifests in policies, practices, and everyday experiences in this rural context. Our findings revealed that multiple forms of scarcity were present at the site. This included the scarcity of kidneys, of health care funding and staffing resources, as well as of health and life sustaining resources for participants (Brassolotto and Daly 2016). In this paper, we focus specifically on findings related to the scarcity of health services and supports to enable families to provide care work. Our findings reveal the ways in which the ideology behind shifts in policy and practice are in conflict with the realities of these rural families.

Context for caring

Rural Canada and health care restructuring

Neo-liberal restructuring of health care that started in the mid-1990s, aided by advances in medical technologies, has resulted in health care provision moving from institutions into rural homes, and a resultant downloading of care work to individuals and families (Cloutier-Fisher and Joseph 2000; Keating et al. 2001). Rural communities have experienced closures of both federal and provincial services, largely as a result of “government withdrawal from social programs and the deliberate reduction in support payments under national debt and efficiency ideologies” (Thein and Dolan 2011, 26–27). Provincial health care reforms have

also led to a regionalization of services and as a result, many people living in rural British Columbia have experienced a downsizing of health care services and witnessed a centralization of these services in urban cities (Hanlon and Halseth 2005; Hanlon et al. 2007). Following this, there has been an increased reliance upon communities' informal and unpaid workers to provide health and social care (Hanlon et al. 2007; Skinner and Hanlon 2015).

Restructuring has had distinct implications for rural populations due to factors such as: limited or distant job opportunities, minimal access to child or elder care, low levels of formal education, and fewer opportunities to earn a good income (Hanlon and Halseth 2005). This is particularly true when the local economy is dominated by a single industry or natural resource—as is the case for the site of this study, which is identified as having one of the least diversified regional economies in the province (Horne 2009). During times of economic decline, rural resource-based communities are most affected by a loss of services (Fiske et al. 2012). Skinner et al. confirm that after “decades of government service devolution, divestment, and downloading” (2014, 4) rural resource frontier communities in British Columbia increasingly rely on voluntary organizations and unpaid volunteers to provide support. Rural carers face particular challenges in terms of: access to adequate and culturally appropriate health services; lengthy travel to regionalized centres, sometimes in perilous weather conditions; reliance upon informal and costly transportation; and social and geographic isolation (Crosato and Leipert 2006). Changing demographics have also led to a “greying” of rural Canada, with many young people moving to larger cities and larger populations of seniors “ageing in place” (Hanlon and Halseth 2005). In addition to the considerable implications this has for service demands, it also means an increase in the number of older adults performing informal care work for spouses and relatives.

Health equity implications for care workers

Rural Canada is diverse and experiences of restructuring vary. Rural health care and support service withdrawal can have distinct implications for vulnerable and/or marginalized populations. Broadly speaking, in rural Canada there are lower levels of literacy and formal education than urban centres, fewer immigrants and visible minority populations, higher proportions of First Nations, Métis, and Inuit (FNMI) peoples, and a larger presence of religious groups such as Mennonites and Hutterites (Kulig and Williams 2011). In addition, rural areas have higher mortality rates and lower life expectancies when compared with urban areas (Halseth and Ryser 2010). There is a well-established rural-urban health gradient (Thein and Dolan 2011), with distance from an urban centre positively correlating with health decline.

The movement of health care to the home also has particular relevance for women because, like paid care work, unpaid care work is highly gendered. A coupling of geographic place with socio-economic and gender relations is especially revealing since rural women, who provide the bulk of unpaid care, are more likely than urban women to experience higher numbers of deaths from accidents, chronic diseases, poverty, and single-parenthood; and women who identify as FNMI, are older, or have disabilities are especially vulnerable (Thein and Dolan 2011).

A significant feminist literature addresses the complex nature of unpaid care, including its gendered nature and its status as work (Graham 1983; Ungerson 1983; Dyck et al. 2005; Benoit and Hallgrimsdottir 2011; Armstrong and Braedley 2013). Early literature focused particular attention on women's unpaid care role outside of institutions (Finch and Groves 1983; Twigg 1989). More recently, England (2010) addresses how the gendered dynamics of neo-liberal social policy affect informal care work in the home, what she refers to as "changing spatialities of care work." Literature on the geography of care has also highlighted changing locations of care (Dyck et al. 2005), welfare offloading and the restructuring of care responsibilities (Chouinard and Crooks 2005), and gendered caring (Thein and Hanlon 2009). While this paper speaks to health care challenges experienced by residents in this region, we recognize that many rural residents and care providers are incredibly resourceful, resilient, and provide high quality care. This paper is not meant to ignore their successes, but to address the implications of health care restructuring and policy changes.

Renal care in rural British Columbia

Kidney disease is one of British Columbia's fastest growing illnesses and over the past decade, the number of British Columbians affected by the disease has increased by 60% (British Columbia Transplant Society 2013). Recently, diabetes was identified as the main cause of kidney failure in 36% of new renal patients and more than half of newly diagnosed patients are 65 years or older (Canadian Organ Replacement Register 2015). With the aging of rural communities and rural residence being associated with diabetes, its complications, and its risk factors (PHAC 2011), it is of pressing importance to understand how unpaid renal care work is experienced in rural Canada. In recent years, there has been a move towards containing dialysis costs by shifting away from care in dialysis centres towards care and dialysis performed by family members at home. In the following section, we outline the methods used to explore this form of care provision.

Methods

We present data derived from a single case study (Yin 2009) conducted in a rural town in British Columbia, Canada. The data were gathered using qualitative methods of critical ethnography (Thomas 1993) and document analysis (Atkinson and Coffey 1997). We received ethics approval from our university's Ethics Review Board. With the assistance of a key contact at a satellite community dialysis unit, we used purposive sampling to recruit participants who had firsthand experience with the scarcity of kidneys and the scarcity of other resources associated with renal health and care. For reasons of confidentiality, the specific site will remain unidentified. All of the participant names used throughout are pseudonyms. In order to provide some general context, the satellite clinic town's population is approximately 19,000 – 20,000 people and it has a primarily resource extraction-based economy, which makes it vulnerable to cycles of boom and bust. The town is over 400 km from the nearest full dialysis clinic (which has nephrologists, dieticians, social workers, FNMI support workers, and other services not provided in the satellite clinic) and over 1,000 km from a transplant centre. Much of the surrounding region is farmland. This town offers a satellite community dialysis clinic for residents and neighbouring communities in a very

wide and diverse catchment area. Patients who attend this clinic come from across and outside of the region and have one-way commutes ranging from ten minutes to over four and a half hours. None of the family care workers discussed in this article lived in the town itself. All of them drove for at least one hour to get to the clinic—and some no longer attend the clinic regularly as their family members receive home dialysis.

In the spring of 2013, we conducted 30 semi-structured, in-depth interviews with individuals who have had direct experience as: hemodialysis patients at the community clinic (n=7), home-hemodialysis and peritoneal dialysis patients (n=6), kidney transplant recipients (n=4), family care workers (n=5), and related health care professionals. These 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). Two of the transplant recipients are now on home dialysis, so they represent both categories.

We relied on thematic repetition and saturation to guide our sample size. The low numbers of particular participant groups in this relatively isolated area also limited our sample. In this paper, we draw on a sub-sample of our data: our interviews with the five unpaid family care workers. We have done this because the participants' narratives stand out as exemplary cases of the major care work themes that surfaced across all of our data sources. We have chosen to focus primarily on these narratives in order to allow unpaid care workers to speak for themselves and to reveal the depth of the related challenges and the extent to which unpaid care work has reconfigured these families. Two of the family care workers were male and three were female. They ranged in age from 50 to 80 years old. All of them were relying on government benefits or a single income in the household.

The interviews each lasted between 30 and 90 minutes. They were digitally recorded and later transcribed verbatim. The transcripts and field notes were coded and critically analyzed using the constant comparison method (Glaser 1965; Creswell 2009). After reading over the interviews and field notes, we used highlighters to identify and connect repeated themes. We used QSR NVivo 10 data management software for producing thematic reports of interview quotations. In addition, we performed a thematic analysis of roughly 30 publicly accessible policy, practice, and media documents. The documents covered dialysis and transplant policies, donor awareness initiatives, local news associated with kidney scarcity, and related practice guidelines. We selected these documents in order to better understand the structure of the British Columbia renal care system, the values and priorities of related organizations, and the ways in which kidney dialysis and transplantation are discussed. The documents were read, highlighted, and thematically coded by hand. We triangulated the findings with the interview data.

Our study is grounded in feminist political economy (FPE), an analytic framework that addresses the highly gendered nature of care and acknowledges the expertise held by the people who perform the work on a daily basis (Armstrong 2001). FPE involves consideration of the contexts and constraints within which people perform work and the tension between structure and agency (Mutari 2000). This tension highlights the social, economic, or political structures that frame the choices that individuals make about their lives and their health (Vosko 2002). This lens led us to examine who performs what work,

and who benefits and does not benefit from particular policy decisions. Given the focus on situating knowledge in context, many feminist political economists also concern themselves with place, geography, and geopolitical/historical factors that influence health (Moss 2002; Fiske et al. 2012). Much like feminist geographers, they have come to understand “gender” as a “relational, contested, differentiated, place-based, and performative category” (Johnson 2008, 570) and “place” as being constituted by a variety of social and spatial relations (Johnson 2008). FPE was used in determining our area of research focus and case study methods, as well as in the theoretical analysis of the findings. In the following section, we outline these findings.

Findings

Earlier findings from this study revealed an increased popularity in the use of home dialysis and a discourse of rural independence and autonomy that supported this shifting of the site of care (Brassolotto and Daly 2016). In fact, the British Columbia Provincial Renal Agency has the largest home renal therapies program in Canada (British Columbia Provincial Renal Agency 2016). In this section, we present our findings related to the following themes: conscripted care; gender, place, and the role of the state; the economic and social costs of rural renal care; and the challenges associated with having lay experts provide dialysis care at home. We draw primarily from the narratives of informal care providers. These specific narratives capture the trends identified across the interview data. These stories provide a detailed experiential foundation for our discussion of domesticating dialysis.

Conscripted care: Whose time and what place?

In this section, we discuss how care provision was not always a choice made freely. Factors such as finances, a sense of duty, and a lack of other options influenced these decisions. Three female participants in the study performed full-time care work because there were no other supports available for their partners. For instance, one participant, Margaret, provided care for her husband John. Margaret and John were separated and living in different provinces for several years before this arrangement took place. She noted that John had not always treated her well. 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 since he was no longer able to live on his own. She told us, “he asked me if I would come and look after him. And he said, ‘Because if you don’t, I’m going to die.’” Margaret has since relocated provinces, left her social network, given up paid employment, and the two of them now live off of his long-term disability benefits.

Margaret and John’s home did not have running water, which made him ineligible for home dialysis. This is an important determinant of access to rural home-based renal care that is rarely discussed. Though John received dialysis at the satellite clinic, Margaret spoke about the strain of everyday care tasks such as administering medications, driving to dialysis, and “the hard work of caring for a home”—particularly when that home is a farm. Margaret and John live over 300 kilometres from the satellite dialysis clinic and so the travel to appointments twice each week 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 inconvenient. 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 perilous driving conditions during long winters in the region, it is easy to understand how any outing can become burdensome, expensive, and possibly dangerous for them.

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 ailments:

I said [to John], '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.

This highlights both the impact of geographic isolation on Margaret's care work and the impact of her caring duties on her ability to practice self-care. Another care worker, Sue, also provided care for a spouse while navigating her own health issues: "what we were dealing with was me first because I've had kidney problems. I've had strokes and heart trouble and all that. And I've got arthritis... So I get all his medication and stuff, and then I've got to remember: did I take my own?" This reveals the extent to which those providing care also require health services and supports.

Similar to Margaret, Lois, quit her job in order to provide full-time care for her husband. She did this because their ranching business, run by him and in his family for several generations, was their primary financial support. She told us that they had struggled with making the trips to the dialysis clinic, 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]." For Lois and her husband, economics very much shaped their treatment decisions and care arrangements. Her experience offers another example of what can be considered conscripted care—of women in the region having to sacrifice their livelihoods to provide care because, despite assumptions about rural independence, there are limited supports available for their partners during times of dependency.

Margaret's, Sue's, and Lois's experiences confirm some of the challenges associated with providing renal care in rural homes. Not having running water, having to perform added domestic labour associated with rural and remote living (for instance, maintaining a farm or ranch), and commuting lengthy distances in perilous driving conditions are elements of care that are often overlooked in dominant renal care discourse and service delivery. These challenges are then compounded by low incomes that limit the choices available to participants. Their stories, and those that follow, illuminate several issues regarding care work: its financial impact on families; the work's complete and unrelenting nature; the challenges and demands that this work poses in terms of everyday tasks; and the financial, emotional, and health-related vulnerability that care workers experience.

“It does take your life”: The economic and social costs of rural home dialysis

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, and redistributing kidneys between family members. For example, six of the dialysis patients and one transplant recipient 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. Those with little to no family to care for them are especially vulnerable in this context.

Frank is the primary care provider for his adult daughter Alice. Alice has an intellectual disability and lives with Frank several days of the week. Several years ago, Frank’s wife left them and moved out of the country. Because he disliked the commute and long waits during treatments at the clinic, he opted to perform Alice’s dialysis at home. Home dialysis was more convenient for Frank and Alice, but that does not mean that it was easy. Frank was candid about the sacrifices involved with this work—particularly since he was 80 years old at the time:

I’m in an apartment. So give us a two-bedroom apartment [sic] and convert one bedroom into a medical room. 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.

He emphasized that he would do anything for Alice, but was also honest about the personal and financial tolls that this work involved:

When [Alice’s] kidney was failing [and we had to travel for care] we had no health benefits because Alice is on welfare. All they would pay for was one trip to Vancouver and that was it ... 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.

Despite having universal health insurance, Alice’s care put her father into debt. Similarly, Lloyd told us that caring for his wife was costly. He said they often borrowed money from their children at the end of the month when funds ran out, skipped appointments if they did not have the money for gas and/or overnight accommodations, and would soon be moving in with their daughter because they could no longer keep up with the work and expenses associated with maintaining their home. When asked about the cost of the kidney-friendly diet, Sue said, “It’s expensive, of course. One of the reasons you eat poorly in the first place is because it’s the cheapest way to eat.” The costs associated with rural renal care can be enormous and our findings confirm that those with low or limited incomes feel them most deeply.

Inability to travel was another notable theme in the interviews, which can leave care providers feeling socially isolated and/or trapped in their care work. Frank said:

[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.

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, Lois said:

[i]t does take your life. You don't go anywhere because every second day, you have to dialyze him ... 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 a day or two 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.

Dialysis patients looking to travel can book sessions in advance at other clinics. However, these clinics are not always close to the travel destinations and some patients expressed hesitation about being dialyzed by unfamiliar nurses. With the travel already required for renal and other health care appointments, many families do not have the time or resources to travel for pleasure. These narratives reveal that providing dialysis at home can be extremely cost intensive, time consuming, and socially isolating.

Lay expertise: Dialysis at home, but far from help

Performing informal medical care work was sometimes stressful for participants not only because of the amount of work, but also because of their lay training and the limited assistance available to them. Laundry, cooking, and other housework tasks were tedious and tiresome for Frank, but did not seem to induce anxiety or concern. It was the need to perform the dialysis-related interventions that he seemed to feel somewhat uneasy about. For instance, when speaking about the challenges that come with being 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 ... So you're on kind of, you're walking a tightrope, if you like. That's the best I can explain it. Hoping you're not going to fall on either side, to keep things in a steady balance.

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 peritoneal dialysis, Layla, told us about the difference it made to have trained nurses administer her care when she dialyzed at the clinic:

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

I: How did they do that?

L: Well, my fistula opened and [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.

L: Yeah. So at that time, I was very, very happy that I was doing it in a unit and not at home.

Family members cannot always provide the same care at home that patients would receive in clinic. Though they have been trained to administer home dialysis, this does not mean that they are always confident about doing so. Sue identified the increasing extent to which home-based care providers are required to perform medical interventions. She spoke about administering insulin, taking blood sugar three times daily, giving eye drops, performing dialysis, monitoring oxygen, preparing kidney diet-specific meals, and more. Even with dutiful note taking and a meticulous care schedule, Sue expressed concern about whether she was doing everything correctly, saying it would be nice to have someone come by and check in on them. Her story captured 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 family member. Performing medical interventions and diagnoses can be stressful, particularly if the care workers have few service providers available to assist them, limited service hours, or long distances to travel in order to access help.

Gender, place, and the role of the state

Interestingly, Frank never explicitly attributed his challenges to being a single parent. Instead, he discussed his frustration with a social system that does not provide adequate support during times of vulnerability. He acknowledged the politics of performing dialysis at home. This is not something that was mentioned by female care workers in our study—perhaps because unpaid care work has historically been expected of women, particularly rural women. Frank discussed his experiences with references to broader 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 [satellite 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.

Frank rejected the 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 possible that gendered expectations about what constitute work are relevant here. Lloyd said his wife still did the majority of the domestic work around their home. The care that he provided for her was more administrative, such as driving her to appointments and keeping track of receipts for tax rebates or Kidney Foundation funding where possible. However, he noted that this work was complex as well:

R: Because we have nobody. It's sort of like we're out on a limb, and what's going to happen next?

I: Do you ever get to speak with a social worker here?

R: Oh, they say there's not much they can do. That's the answer ... you can go through the government and get the gas tax and that back. But I had to do some hunting to find that out. No, they don't tell you ... And I also went to the government, and the paperwork, oh my god! But you've got to dig. Nobody tells you about these things!

In sum, with cuts to health and social services in the region, a number of participants were left feeling that they bore the burden of care on their own—as though they were “out on a limb” or “walking a tightrope.” The nature of the care work and the language used to describe it varied somewhat by gender, but both women and men revealed the extent to which care work consumed their lives.

Discussion

The findings from this study both confirmed and extended our thinking about rural renal care. They confirmed the challenges associated with having lay experts perform care in the home and the invisibility of this work to policy makers. Our findings also extend current discussions of unpaid care to address how these challenges manifest in renal care specifically and are complicated by rural residence.

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, but increasingly men too) are best suited to perform care work, that they will willingly do so without personal expense, and that these services will be sustainable and of adequate quality. This highlights a tension between conceptions of care work as unskilled labour that can be performed by anyone, and the training and technical skills required to perform dialysis. It also highlights a need for gender-sensitive caregiver supports that reflect the realities of these rural women and men. Skinner and 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, socio-economic limitations, and their actual capacity and ability to provide such care. They claim that this is particularly the case in rural Canadian communities where self-reliance 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 and Joseph 2007, 123). Our research confirms that there was indeed an expectation that rural families would be willing

and able to provide renal care and dialysis treatments for their family members, and highlights the difficulties that arise as a result of this expectation.

Feminist political economists generally turn to the state to explain the current context of health care (Fiske et al. 2012). In their work in rural British Columbia, Fiske et al. (2012) found that by framing social policy in neo-liberal discourses of individual responsibility, “care giving is depoliticized and citizens’ right to health care is marginalized” (Fiske et al. 2012, 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. Though framed as a matter of efficiency and geographical convenience, the reduction of care services in rural areas is very much related to state deficit and debt fighting strategies. Harrington-Meyer et al. (2000) argue that, “locating dependency within individual families serves as yet another method that sustains, and even magnifies, socioeconomic inequalities” (2000, 3). Rural families of lower socio-economic status generally lack the resources necessary for accessing supports such as respite care, paid companions, or privatized care services. All of the family care workers we interviewed discussed the limited options available to them, often resulting from or made worse by their limited finances. Our findings reveal the ways in which family members exercised agency and provided care in spite of the restrictive systemic barriers that they encountered and their own health issues.

Through a feminist political economy lens, the shift towards home-based renal care reflects the domestication of health care 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 rural residents from lengthy commutes and permits them the flexibility to dialyze at times and for durations that are best suited to their needs. It can also 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, a consequence of shifting treatment from the clinic to the home is the substantial amount of invisible work, costs, and responsibility transferred from institutions to patients and their families. Informal care and self-regulation also have implications for how we understand risk, responsibility, liability, and blame (Hogle 2002).

In summary, there has been very little research on renal care in rural Canada and this case study offers insight into related issues and experiences. This research contributes to Canadian health geography literature that identifies rural residence as an important determinant of health and situates renal care work within this social and spatial context. It demonstrates the negative effects that restructuring and the concentration of renal care services in urban centres has had on unpaid care providers and their care recipients. It also reveals the ways in which the ideologies behind these policy shifts are at odds with the realities of these rural families. The domestication of dialysis has distinct implications within these conditions of care.

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Key messages

- The movement of dialysis care to homes has distinct and under-explored implications in a rural Canadian context.
- The negative effects of this policy shift are felt most deeply by socially and economically vulnerable care providers.
- The domestication of dialysis reflects a broader trend toward a reduction of public health services and reliance upon individuals, rather than the state, to provide the conditions for good health.