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'It's a very isolating world': the journey to HIV care for women living with HIV in British Columbia, Canada

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ABSTRACT

HIV health services research conventionally defines place in terms of proximity to care. However, understandings of place must also include the social spaces that women living with HIV (WLWH) occupy which shape their experience of health and access to care. Drawing on focus group data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study, we explored how 28 WLWH navigate geographic place and social space in attempting to access HIV-related healthcare within and across a range of urban to rural localities in British Columbia (BC), Canada. We describe how existing services, even if physically close, can be socially marginalizing as women confront HIV stigma, racism, and classism, which operate to exclude women from the places and spaces they must access for care. We also emphasize how women enact 'geographies of resistance' and succeed in carving out their own safe options for care and support. Finally, we share recommendations identified by women themselves towards developing local and community-driven 'geographies of change' that support the health and healing of diverse communities of WLWH. Our findings stress the urgent need to acknowledge and redress socio-spatial barriers to care and to work with WLWH to co-create a therapeutic landscape that reflects women's diverse identities, localities, emotions, and experiences.

'Es un mundo muy aislante': el viaje hacia el cuidado del VIH para las mujeres con VIH en Colombia Británica, Canadá

RESUMEN

La investigación de los servicios de salud de VIH convencionalmente define el lugar en términos de la proximidad del cuidado. Sin embargo, las formas de comprender el lugar deben también incluir los espacios sociales que ocupan las mujeres que viven con VIH, los cuales dan forma a sus experiencias de salud y al acceso al sistema de salud. Basándose en datos provenientes de grupos focales del Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), exploramos cómo 28 mujeres que viven con VIH navegan el lugar geográfico y el espacio social al intentar acceder el sistema

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关键词

HIV; 女性; 地方; 空间; 社会—空间; 疗愈地景; 加拿大; CHIWOS (加拿大爱滋病毒妇女的性与生殖健康群组研究)

de salud, en relación con el VIH, a lo largo de un rango de localidades que van de urbanas a rurales, en Colombia Británica, Canadá. Describimos cómo los servicios existentes, incluso si se encuentran físicamente cerca, pueden crear marginalización social cuando las mujeres enfrentan el estigma del VIH, el racismo y el clasismo, lo que opera para excluir a las mujeres de los lugares y espacios que ellas deben acceder para su cuidado. También enfatizamos cómo las mujeres adoptan las 'geografías de resistencia' y tienen éxito en forjar sus propias opciones seguras para el cuidado y el apoyo. Finalmente, compartimos recomendaciones identificadas por las mujeres mismas para el desarrollo de 'geografías del cambio' locales impulsadas por la comunidad, que apoyen la salud y la curación de las diversas comunidades de mujeres viviendo con VIH. Nuestros resultados subrayan la urgente necesidad por reconocer y reparar las barreras socioespaciales al acceso a la salud y por trabajar con las mujeres viviendo con VIH para co-crear un paisaje terapéutico que refleje las diversas identidades, localidades, emociones y experiencias.

‘这是个非常孤立的世界’：加拿大英属哥伦比亚省中·与爱滋病共存的女性之HIV照护旅程

摘要

HIV的健康服务研究，传统上以获得照护的邻近性来定义地方。但对地方的理解，必须同时包含与HIV共存的女性所占据的社会空间，该空间形塑了她们的健康经验，以及获得照护的管道。我们运用取自加拿大爱滋病毒妇女的性与生殖健康群组研究(CHIWOS)的焦点团体数据，探讨二十八位与HIV共存的女性，如何在地理地方与社会空间中航行，以试图在加拿大英属哥伦比亚省(BC)城市至乡村的一系列地点之中及之间，取得HIV相关的健康照护。我们描绘既有的服务——即便在物理上是邻近的——仍然有可能在社会上具排除性，因为女性面临了HIV的污名化、种族主义以及阶级歧视，将之排除于她们必须取得照护的地方及空间之外。我们亦强调女性如何采取“反抗地理”，并成功地刻划出自身获得照护与支持的安全选项。最后，我们分享由女性自身所确认的建议，该建议迈向建立由地方与社群所驱动的“改变地理”，支持与HIV共存的女性的多元社群的健康及疗癒。我们的研究发现，强调认清并矫正健康照护的社会—空间藩篱、以及与HIV共存的女性共同致力于创造反映女性多样的身份认同、地点、情绪与经验的疗癒地景之急迫需求。

Introduction

HIV health services research conventionally defines place in terms of proximity to care. While studies have shown that HIV outcome disparities exist by *geographic place* (a term used in this paper to refer to the spatial location of HIV services vis-à-vis where women living with HIV (WLWH) live) (Reif, Golin, and Smith 2005; Pellowski 2013), such estimates insufficiently consider the more complex features (political, economic, institutional, physical, and sociocultural) of place which shape women's experience of health and access to care (Kearns and Joseph 1993; Cummins et al. 2007). Thus, understandings of place must also include the *social spaces* that women occupy (a term used in this paper to refer to the social and structural context of sites where HIV care is delivered vis-à-vis women's identities) which intersect with geographic factors to create a *socio-spatial context* in which access to healthcare is structured (Kearns and Joseph 1993; Rhodes et al. 2005; Veenstra 2005; Tempalski and McQuie 2009; Fast et al. 2010).

Previous studies have examined how socio-spatial dynamics contribute to health and care disparities among people living with or at increased risk of HIV in Canada (Robertson 2007; Fast et al. 2010) and elsewhere (Beazley 2002; Malins, Fitzgerald, and Threadgold 2006; Rhodes et al. 2007). However, this research has primarily focused on specific populations (e.g. street-entrenched sex workers, people who use drugs) in inner-city areas. We undertook the present study to explore socio-spatial barriers to care among diverse communities of WLWH in British Columbia (BC), Canada, who navigate a range of

HIV-related health care services within and across various geographic locales, towards understanding the relative and intersecting effects of marginalization by *geographic place and social space* on women's access to care.

Diverse communities: epidemiology of HIV among women

Women comprise nearly one-quarter of the estimated 9300–13,500 individuals living with HIV in BC (BC CDC 2012). Of all WLWH, 49% live in the Vancouver health care region, the most densely populated area with several distinct service neighborhoods; 25% in the Fraser region, east of Vancouver that serves a large population of refugees and newcomers to Canada; 10% on the islands to the west of Vancouver; 6% in BC's large southern interior region, which includes a mix of small urban, rural, and geographically dispersed communities; and 7% in northern BC, consisting of a multitude of rural, remote, and First Nations communities where women account for almost 40% of HIV cases (BC CDC 2011).

Beyond geographic locale, HIV among women is inequitably distributed along several intersecting social axes. Aboriginal and other racialized women, trans women, and women with injection drug use and sex work histories are disproportionately affected, stemming from an HIV risk environment shaped by poverty, violence, discrimination, unequal gender and power relations, and the legacy of residential schools (Shannon et al. 2007; Shannon, Kerr, et al. 2008; McCall, Browne, and Reimer-Kirkham 2009; Marshall et al. 2011; BC CDC 2012).

This geographic and social diversity underscores the need to move beyond basic understandings of access defined as physical distance to care towards framing access as intrinsically tied to *both* geographic place and social space (henceforth, referred to as place and space).

Places and spaces of care for WLWH

In BC, HIV care programming is rooted in the gendered discourse of the early years of the epidemic with HIV described as a 'male virus,' a disease targeting 'immoral behaviour,' and the subsequent mobilization of gay and lesbian communities in the HIV response (Cain 2002; Cooper and Keating 2004). Accordingly, the vast majority of HIV-related services are centralized in large urban communities such as Vancouver and targeted towards gay men, people who inject drugs, or sex workers.

One notable exception is the Oak Tree Clinic, BC's only HIV speciality clinic for WLWH. While located in Vancouver, Oak Tree Clinic cares for WLWH across BC, and like all clinics in the province, HIV care and medications are provided free of charge, along with government assistance for transportation to HIV-related medical appointments. Nonetheless, many women, especially those living outside Vancouver and who have identities that extend beyond the dominant, stigmatized narrative of 'risk groups,' remain excluded from much of the HIV service landscape (Cooper and Keating 2004). Embedded within this built environment are gendered, medicalized, and stigmatized health care spaces that, as Robertson (2007) describes, are 'coded with a social taxonomy that defines access and exclusion' (528). This socio-spatial context has important implications for where, whether, and how women utilize health care services.

What follows is an analysis of how WLWH navigate place and space as they attempt to access HIV-related health care services in BC. The discussion draws from an analysis of qualitative data from focus groups with WLWH who participated in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS; www.chiwos.ca). We chronicle women's journeys as they move through place and space, highlighting the kinds of services women can or cannot access and the negotiations evoked for women in the process. We also describe strategies women employ to actively resist their socio-spatial marginalization to receive appropriate care and support according to their own needs. Finally, we share recommendations identified by women themselves towards developing local and community-driven 'geographies of change' that support care access among diverse communities of WLWH. Critically, we have looked toward feminist perspectives in health geography as a route to deepening our analysis and developing a response to health care places and spaces that exclude WLWH.

Feminist perspectives in health geography

Feminist perspectives in health geography centre on the meanings of gender, place, and space and their relationship to women's health. As Dyck (2003) asserts, 'feminist geographers have long looked to women's voices and the "local" in investigating how gendered power relations carve out the conditions and opportunities in women's lives' (362). While critical health geographers employ a number of theoretical feminist perspectives (Dyck 2003; Dolan and Thien 2008), the common thread amongst these scholars is 'a desire to unravel the complex links between global power relations, local experiences of place, and women's subjective experiences of health, illness and disability' (Dyck 2003, 364). A key objective then is to ensure that a geographical analysis of women's health is seen as part of the larger social, economic, cultural, and political context of women's lives.

Leipert and Reutter's (2005) research provides a strong example of how a feminist geographical analysis of women's health is enacted. Through interviews with women living in northern BC, Leipert and Reutter found that the north's historical location (characterized by colonization, impoverishment, and resource exploitation of Indigenous people) contributed to women's ongoing marginalization and poor health compared with men and non-northern women. Research by Wilson (2003) reveals more about the intersection of health and place by incorporating an explicit cultural approach into her analysis. Drawing on interviews with First Nations people in northern Ontario, Wilson highlights how place not only represents a physical location, but also a complex social, cultural, spiritual, and emotional site that shapes health and healing.

Of particular significance is the therapeutic landscape literature within feminist health geography, which is concerned with emotions, and its contribution to enhancing understandings of women's relationship to place (see Davidson and Milligan 2004; Smyth 2005). Work by English, Wilson, and Keller-Olaman (2008), for example, has drawn attention to the strong interplay between emotions and place for breast cancer survivors, for whom therapeutic landscapes contribute to healing and recovery from cancer. More recent geographic work (Love, Wilton, and DeVerteuil 2012) has shown that sites of formal health care delivery also represent landscapes of healing. Examining women's experiences of drug treatment programs, Love, Wilton, and DeVerteuil (2012) describe the impact of therapeutic spaces (e.g. programmatic rules, neighborhood settings, organizational structures, and actions of staff) on women's health and well-being.

Our analysis of the socio-spatial accessibility of health care services for WLWH in BC parallels other health research informed by a feminist and emotional geography lens. Drawing on these critical health geography approaches has offered insights into the emotional experience of place and the impact of built and social environments on women's journeys to access care (Davidson and Milligan 2004). These perspectives have also drawn our attention to how the emotional impacts of inclusion or exclusion within BC's health care service landscape may motivate WLWH towards creating their own safe places and spaces for care and support (Davidson and Milligan 2004).

CHIWOS: a research project by, with, and for WLWH

CHIWOS is a multi-site, longitudinal, community-based research (CBR) study conducted *by, with, and for* WLWH. CHIWOS is enrolling 1400 WLWH from three Canadian provinces, (BC, Ontario, and Quebec) to assess barriers and facilitators to use of women-centered HIV services, and the impact of such patterns of use on reproductive, sexual, mental, and women's health outcomes. CHIWOS is grounded in Critical Feminist theory and guided by a Social Determinants of Health framework, which enable consideration of intersectionality and the influence of multiple systems of exclusion (geographic, social, and otherwise) on health care access, whilst engaging in community-driven research and action to support social change (see Carter et al. 2014).

As part of CHIWOS' formative research phase in BC between August and October 2011, 4 focus groups (in Vancouver ($n = 2$), Victoria ($n = 1$), and Prince George ($n = 1$)) were conducted with 28 WLWH, and this paper presents an analysis of participants' health care experiences. Consistent with our CBR methodology, WLWH and allied clinicians, researchers, and community partners were involved in all

stages of the research process, from defining the research question, through data collection, to analysis, interpretation, and dissemination of findings.

Focus groups were facilitated by three Peer Research Associates (PRAs) – WLWH, who lived in the communities being researched and had familiarity with the local health care context. Research capacity of PRAs was supported through training in CBR and focus group facilitation (AK and SG). All focus groups were co-facilitated by a PRA and the Research Coordinator (AC).

WLWH were recruited through advertising at local HIV clinics, AIDS Service Organizations (ASOs), peer networks, and other informal channels. Eligibility criteria included self-identifying as a woman, living with HIV, aged 16 years or older, and residing in BC.

Participants completed a brief demographic questionnaire and participated in a semi-structured focus group, which centered on their experiences accessing local health and social care services. The focus groups formed part of a larger study focused on understanding the meaning of women-centered HIV care. Within these discussions, the dynamics of place and space emerged as a priority issue around access to care. Each focus group took place in a local community-based agency, lasted 2–3 h, and was audio-recorded and transcribed verbatim.

Transcripts were analyzed using thematic analysis, where key emerging themes were identified, compared, and discussed across transcripts. Three investigators (AC, SG, and AK) engaged in multiple readings and reflexive discussions of the transcripts to conceptualize the data, paying particular attention to conversations that touched upon socio-spatial accessibility of health care services as outlined above. Following from Malin's approach (2006), the data analysis was dynamic, iterative, and evolved as the study progressed. Throughout, we used the concept of social positioning to understand how women negotiate socio-spatial contexts in a variety of ways depending on their position within society (Fast et al. 2010). Similarly coded narratives were extracted and restructured into major data clusters to draw out the major dimensions in which socio-spatial marginalities were discussed. To ensure rigor and validity, peer debriefing occurred after each focus group, and investigator triangulation (between AC, SG, and AK) and interviewer corroboration (with VN) was conducted at multiple points in the analysis process.

Ethical approval was provided by the Research Ethics Boards of Simon Fraser University and the University of British Columbia. All participants provided informed consent, and pseudonyms were used to protect participant confidentiality.

Participant demographics

Of the 28 WLWH whose stories are presented here, 14 were from Vancouver and the surrounding suburban areas, 7 lived in communities in and around Victoria, the capital city of BC on Vancouver Island, and 7 were from Prince George, a northern city surrounded by First Nations communities. Participants represented diverse communities: 50% identified as Caucasian and 39% reported being of Aboriginal ancestry; 25% identified as lesbian, gay, bisexual, transgendered, or queer; 14% were 18–30 years of age, 65% were 31–50 years, and 21% were older than 50 years; 43 and 32% had drug use and sex work histories, respectively; and over half reported an annual household income below \$20,000. Most participants were linked to HIV services: 85% received care from an HIV specialist in the last year and many accessed a range of support services, including ASOs (54%), income support (39%), counseling (32%), and food bank (21%) services.

Navigating Vancouver's Downtown Eastside

At the geographic core of the HIV service landscape in BC is Vancouver's Downtown Eastside – home to a plethora of clinics, drop-in centers, addiction services, and outreach support dedicated to caring for populations pushed to the margins of Canadian society. Nancy shares:

Originally, I came from Downtown Eastside. I was a drug user and I worked on the street. I still go into the X-Clinic I used to go ten years ago, which has my HIV specialist ... They're just there for people who couldn't afford it ... They do everything for you there ... Paps ... full blood work ... They have a TB office ... social worker ... counsellor ... They have everything in there ...

As Nancy's narrative demonstrates, the Downtown Eastside offers a spatial convenience of services integral to the health of women who live in this community. However, the particular socio-spatial dynamics of the area present challenges for other communities of women who have either made their way out of the Downtown Eastside or who have never lived there. Nancy continues:

I just wish there were more ... clinics like that because not everyone can travel that long to go to [X clinic] or come downtown ... It's really hard ... I wish there was more places that have HIV specialists ... not only Downtown Eastside ...

For Nancy, moving away from the Downtown Eastside resulted in challenges that made it 'really hard' for her to continue accessing HIV care in that area. Lisa, who lives in Surrey, BC's second largest city, echoed these challenges:

The services are sorely lacking in the more rural areas like Surrey, Langley, Abbotsford ... I know for myself, I don't access the services that I could be accessing because it's just too difficult ... to get into town.

Beyond the geographic clustering of services in downtown Vancouver, women also often navigate a terrain shaped by popular media as a 'skid row' place beset with poverty, criminality, addiction, and disease (Robertson 2007). In their narrated journeys to an HIV clinic in a similarly situated inner-city area in the Fraser Valley, Lisa, a former substance user, and Mae, an African immigrant, highlight the tension between the need for services located in these particular places and the reality that accessing these services can feel unsafe for some women:

Mae: There is one clinic that is available for the HIV people ... But ... If you have no experience with drug addiction. It is like you're in a strange place ...

Lisa: Yeah ... the area that it's in ... everybody is in active addiction and people asking you if you want to score right out front. If you're in recovery, or if you're not a person that's been using, it can be a really intimidating area.

Mae: Yeah, I don't really want to go there.

Lisa: And there's a lot of violence there. There's cops and sirens. It can be an intimidating ... That's a barrier to seeking treatment.

This challenge was echoed by Barb, an Aboriginal woman living in Prince George:

I used to go to this street clinic a lot more ... But now I don't go there anymore because it's too big of a trigger.

Thus, urban clinics were 'in proximity' to some women and therefore met their criteria for accessible care. However, this was defined primarily by distance to care, which results in making assumptions about the needs of people living with HIV in urban areas. Echoing findings by Chouinard (1999), Dyck (1999) and Moss (1999), these assumptions resulted in experiences of physical and emotional vulnerability and barriers to care.

Journeys for women outside the 'big city'

Outside of Vancouver, women describe a disconnect between the places where women live and where HIV clinical services are accessed. This is reflected in a conversation between women living in Victoria, who travel to Vancouver – about a 4-h one-way journey by road and ferry – for care:

Shelia: It's worse here ...

Mary: Yes, it is.

Shelia: Just the distance, taking the boats. Having to take a day off work is really hard to do.

Mary: Not to mention how damn tired you are when you get home, and you have to go back to work the next day.

Shelia: Yeah, and paying for gas to drive there is a lot ... You have to eat.

Mary: Parking ...

Rebecca: There are so many trade-offs too, because you go and you separate that time from your life to do your X visit. And that means that you don't do A, B, and C. Maybe because you then don't have any money to do it, you don't have any time, and you don't have any energy.

Clearly, women face numerous place-based barriers to care, which are amplified by the effects of intersecting social and economic factors (financial resources, work demands). These multiple, competing demands were especially significant for HIV-positive mothers:

Michelle: I live in Victoria, and people always assume that we're just over there and it's easy. We don't have a centralized HIV clinic ... For me to get to X-Clinic [in Vancouver] it's a 12-h day for a 2-h appointment, and depending on whether I can afford it ... And I've had to bring my children with me to my appointments many, many times, which interferes with their education ... It's obviously a barrier.

Hence, emerging from these narratives is not only a story about the geographical journey facing women, particularly mothers, who live outside the 'big city'; but also about the underlying emotional journeys they negotiate as they attempt to arrive at their physical destination for care.

Traveling long distances to access care in Vancouver was a considered response to the lack of accessible HIV clinical care for women elsewhere. Women living in Prince George and Victoria voiced concern around the 'very, very limited services' in their home communities, with some highlighting how even if HIV clinics do exist, they have limited expertise in women's health or they don't have female health care providers:

Sarah (from Prince George): Unfortunately some of our members had to go through a traumatic experience to get what they have [HIV infection] and they don't want to see a male gynaecologist or a male HIV specialist ...

Indeed, a key factor influencing women to endure the trip to Vancouver was to access BC's only HIV specialty clinic for WLWH, where women can receive integrated, comprehensive, women-centered HIV care from a multidisciplinary team of health care professionals. Clare and Ann explain further:

Clare: I access X-Clinic. That's it ... Everything that I need regularly is there ... like the gynecologist, the pharmacist, the nutritionist. I don't have to go running from place to place ...

Ann: I'm currently also at X-Clinic ... it's kind of ... like a one-stop shop ... You've got your addiction counsellors. You have your nurses and your doctors. So in that respect, I think it's really awesome because you can take care of everything.

Of course, not all women could or wanted to travel to Vancouver for care and instead chose to access care in their home communities. Unfortunately, any benefits that came with resisting a long journey to care were offset by the emotional costs of having to navigate multiple, unintegrated, and suboptimal health care services at home. This was voiced by Kim:

... I don't go to X-Clinic [in Vancouver], but listening to you guys, one of the differences is that you are actually accessing services that probably every woman should go to. But because [I'm] doing it on [my] own ... [I] have to find a counsellor, [I] have to find a nutritionist and all that, on [my] own. And ... every time [I] go in [I'm] going, okay, yes, and I am HIV-positive. So you're constantly doing that. Whereas if you've got a place that – yeah, you're not doing that over and over and over, every time you see a doctor, or see a pharmacist, or see somebody, you're not having to repeat your life story ... When you don't have a place that's a centre like X-Clinic ... it's exhausting and very difficult to try and find help ...

And yet, women like Kim who were able to articulate their own challenges of navigating place and space in their journeys to care were acutely aware that they were better off than women who were living in remote regions of BC. This was highlighted by Sarah who said:

The thing I feel really bad about is those poor women that are up in those communities and they're all alone ... they're totally frickin' isolated. They're in tiny villages, and sometimes they get discriminated and hated on just because of their HIV status ... Up there they have nothing.

Hence, whether or not this is truly the case, some of the women believed that if they lived in a 'smaller community, it would be even worse,' supporting earlier arguments that place not only represents a physical location ('up there they have nothing'), but also a complex social, cultural, spiritual, and emotional site ('they get ... hated on') with the potential to stigmatize WLWH (Wilson 2003; Leipert and Reutter 2005). As Jenna reveals, this impacts not only on where women choose to access care, but also on where women choose to live:

Why aren't the doctors and nurses trained in empathy or whatever training they need to deal with us, in every hospital in the province ... I would love to move to [X, a small rural community on Vancouver Island], but I'm afraid to go anywhere. If what you say is true about the care over there, I'll be frightened to leave ...

Hence, as women move away from urban areas and the concentration of services that are available within those places, they experience a range of challenging geographical and emotional journeys to

care. Their narratives highlight the 'everyday experience of emotional highs and lows that accompany [women's] struggle to [negotiate] a changing embodied relationship with a restrictive social and built environment' (Davidson and Milligan 2004, 524).

Women need a space to just be ...

Regardless of where women live, perhaps the most striking finding was that women need a space to just be – where they can exist without judgment or exclusion. Sarah, whose lived experiences (poverty, drug use, homelessness) are often viewed by society as liabilities, was able to access one local ASO that has succeeded in creating a safe space for young WLWH:

... they have a lot of workers there that are young and they are positive, and they're on the Board, so they run the place ... it's just a really warm, comforting environment ... when I did go there I was able to open up a little bit because, for me, I felt like my word was valued ... that it was actually cared about ... I felt like I was being heard there.

This longing for a space where you feel 'cared about,' 'valued,' and 'heard' was also reflected in a conversation by women accessing the province's women-centered HIV clinic:

Jessica: ... He doesn't just check with your health. He wanted to know if your kids were okay, and how your relationship was going.

Mary: And everything, sexual health, emotional health, all of it. He was interested in all those aspects that make you a whole person.

Jessica: And are you doing good things for yourself?

Mary: He'd always ask me if I'm working in my garden.

Jessica: Yeah, exactly. When I started gardening again, oh, I'm so glad you're gardening.

Mary: Yeah, because he knew it made me happy ... You felt cared about. You felt like he cared enough about you to know a little bit about you. You weren't just a chart with a bunch of numbers ... I felt like he cared about me as a whole person, and not just a disease.

In this way, health care environments can provide an important emotional landscape for health and healing among WLWH (English, Wilson, and Keller-Olaman 2008). Nevertheless, as our conversations continued, women reported feeling pushed to the margins of care, where spaces are ordered by rules and regulations, bodies are governed by medical interventions, and women are dependent on medical authority figures for access to essential services (Malins, Fitzgerald, and Threadgold 2006; Robertson 2007). Becky, from a community in northern BC, articulated:

... the clinic doesn't have enough time for everybody. They have way too many patients and, as far as I'm concerned, they don't give the proper care that needs to be given to a lot of us women. We're shuffled in and shuffled out ... like a cow. You go down this thing and you go down that and wait there. It seems like the personal interaction is pretty well gone ... and it's really hard.

This was also the case for Ann who shared:

I also see Dr. X. The first time I met him I just knew that he rushed me through. He wasn't answering my questions ... or addressing my concerns. It made me feel like I was just another number, like he didn't even care.

These narratives of feeling 'like a cow' and 'just another number' draw our attention to care environments that can reduce women to nothing more than a body, a vessel void of context. Becky and Ann experienced what Greene (2008) has called 'embodied exclusion' – although the women viewed themselves as embodying meaningful intersecting identities and experiences, the providers they came into contact with did not. Rather, their needs and complexities as women, mothers, living in poverty, and so forth are ignored. Only the HIV in their body gets recognized, often in stigmatizing ways. So, although a place may be physically close, it is not always accessible.

Stigmatizing spaces

For many women, their experiences of embodied exclusion from health care spaces are exacerbated by racism, classism, and HIV-related stigma:

Nancy (Vancouver): A lot of women, they're trying to struggle and they have HIV. And they walk into the hospital and they don't treat them like everybody else ...

Kay (Prince George): I hate going to our hospital ER ... If you're Aboriginal and you're complaining. Say if you had been drinking that night or whatever, it does not matter. They are ... all White, all the staff, and they're very racist ... They will help you eventually. But you are so tired at one point that you're either trying to curl up on a chair or you've got to leave. And then you haven't been helped and they're saying well you know you were next in line. Well that's bullshit. You know exactly where you stand in line and it's right at the very bottom of the list ...

Echoing findings by Robertson (2007), these stories highlight how 'multiple stigmata accumulate in the lives of Aboriginal women who use drugs, who have worked in the sex trade, and who live with HIV' (534), which exclude them from accessing essential care. A key factor impacting women's embodied relationship with place is their experience of cultural safety. This finding is particularly important as we consider the relationship between place and health for Indigenous women, for whom the multiple meanings of place greatly shape their physical, emotional, mental, and spiritual health (and vice versa) (McCall and Pauly 2012; McAlister 2013; Wilson 2003).

Importantly, constrained space is not only an issue for those with traditionally marginalizing identities. Kim, a straight, white woman living in Victoria, highlights how her gender, sexual identity, and other social factors coalesce to shape her experiences of isolation from the spaces she attempts to access within her home community:

I can tell you from being a heterosexual woman, you end up with a huge stigma and there is a barrier to getting support as well ... because you don't fit into any cubby hole. And if you're my age and you're working, it's even actually worse ... I think for a couple reasons you isolate more, so you back yourself off even more, and you hide it even more.

This sense of isolation resonated with other women in the focus group:

Sheila: Yeah, just being a straight white woman.

Kim: It's a very isolating world.

Jules: The other part of it is ... just because someone has HIV does not mean that they're my peer.

Kim: Exactly.

Sheila: Totally. Yeah I never went to X-ASO because it seemed just like it was more focused towards drug users and gay men, and not ... straight white girls like me.

As the women illustrate, even if care sites are proximally close, not being able to see yourself reflected within the services provided or community served can be marginalizing, particularly for those not fitting within the typical 'risk groups,' which as one participant said can lead to 'huge barriers to getting resources.'

From 'geographies of resistance' to 'geographies of change'

Although much of what we learned tells us about the socio-spatial barriers that women face in accessing care, we were also privy to stories of strength and resilience. Frustrated with navigating marginalizing places and spaces, women in all four focus groups described employing strategies to resist their socio-spatial marginalization and appropriate care and support according to their own needs. We understand these tactics as 'geographies of resistance' (Beazley 2002).

Highlighted in many of the stories are examples of women rejecting available services. Acts of resistance were first articulated by Lisa from Surrey, who explained that she declines to 'access the services that [she] could be accessing' because of the placing of HIV services in downtown Vancouver. Kim and Becky also described resisting accessing stigmatizing spaces within their home communities of Victoria and Prince George, respectively:

Kim: After a while what happens, for me anyway, is I don't want to access anything, I don't want to, it's like, no, I'm done. It's too exhausting ... It is really emotionally difficult.

Becky: I get really frustrated and I give up, which leads to infections getting bigger and worse and everything, and I'm not getting the proper care that I need because they're not listening and they're just shuffling me aside.

These stories are a powerful demonstration of the negative impact that disparate places and exclusionary spaces have on the service utilization and emotional and physical health of WLWH.

Importantly, many women's narratives also revealed a great sense of survival, with women not only rejecting available services, but also taking care into their own hands. Michelle, the mother from Victoria who faced multiple, competing demands along her journey to Vancouver for care, recounted how she once went nine months self-managing her HIV, seeking out doctors only for a 'second opinion':

I've started doing my own HIV care ... What I mean by that is I just call them when I need a second opinion ... I get all my labs, I get all my copies of my blood work myself ... I've learned how to manoeuvre through the system, and if I'm not concerned about something, I don't ... go to the doctor.

For Michelle, this resistance strategy was aimed at reducing the emotional and physical harm associated with traveling long distances to care, even if it meant avoiding health care altogether. Notably, Michelle, like many others, also took direct action to carve out her own relatively safer spaces for care and support:

Facebook. I have a community of women ... that I support, I network, I share information, and that's my big thing is sharing information, helping people manoeuvre, because nobody's going to tell them ... Aside from a few close friends, I think I have one friend in Victoria that I actually laugh and I can cry with that's a peer. All my [positive] friends live everywhere else ... so that's what's been a big support for me is having that connection on Facebook with my positive friends, because even if we're not talking about something deep, I just know that today they're okay. Or if they're not okay, then I can send them a bit of encouragement without outing them ... So, that's kind of how I filled that gap ...

Echoing previous research on the benefits of integrating peer-driven services into the overall care system (Campbell, Phaneauf, and Deane 2004), Michelle argues that peers serve as important sources of informational, social, emotional, and practical support. This was reiterated by the women who participated in our focus groups in Vancouver and Prince George, and who stated that:

Peer support is huge ... What we're doing right here is peer support. You know, like we're talking, helping each other, getting information. That's what it's all about ... We're a wealth of resources.

... having a peer support group just to let out your stresses of the day ... I have my sister and stuff, but she doesn't totally get it, and it would be really nice to have a group of women who understand each other, who have similar life experiences and stuff like that.

Such narratives bring into sharp focus the extent to which healing among WLWH 'is not just physical but also psychological and emotional – it requires *feeling* better, *feeling* supported' (English, Wilson, and Keller-Olaman 2008, 76). Thus, peer communities (in-person or virtual) represent important therapeutic landscapes because of the emotional healing they impart on WLWH.

During the closing stages of each focus group, women were asked to reflect on the discussions and share their visions for change, or what we've termed 'geographies of change'. Women discussed technologies such as telemedicine and web conferencing as straightforward solutions to overcoming several socio-spatial barriers care, especially in rural and northern communities. Reflecting on the challenging geographic and emotional landscapes of her peers living in northern BC, Nicole shared:

I would like to see some ... infectious disease specialists available for web conferencing with the medical doctors in those communities, and the nurse practitioners in those communities. There's different ways to provide health-care today.

Also, re-emerging in our concluding discussions was the importance of peer support and peer networking. Barb, from Prince George, suggested that peers could not only deal with the shortage of HIV providers in smaller communities, but also, as the previous narratives suggested, assist with creating therapeutic landscapes and fostering emotional healing:

Something has got to be done as far as way more doctors and nurses. Maybe this is where peer support might come in ... you'd be surprised what you can alleviate or get rid of just by women talking to women ...

Clearly, peers were integral to women's vision for safe (physical, emotional, and cultural) care environments that respect, understand, and respond to women's unique health and social needs. Rhonda, from Vancouver's Downtown Eastside, added:

I would like to see a women's-only clinic where I can ... be comfortable seeing a woman doctor, woman social worker, someone that has gone through menopause even. Somewhere where I can sit around like here and talk to a group of women that have so many wonderful ideas ... Just a safe space where I can actually talk about my period's really heavy, my boobs have got, just something that some other people can relate to ...

And so, we continue to hear narratives of imagined therapeutic landscapes where WLWH can access care in ways that are relevant to women's diverse realities – places that are accessible not just physically, but also socially, emotionally, culturally, and spiritually. As Jenna clearly articulates:

The gay men that came before us, if it weren't for them we wouldn't have this. So it's not about lack of gratitude ... or prejudice. It's about reality ... when we were five percent ... then those five percent of women that had to go and access those services, kudos to them. But we are becoming higher in numbers. And when there's one in four, maybe that environment will change.

It is our hope that their imagined geographies of change will become a reality.

Discussion

Each woman whose story appears here experienced a journey to HIV care through contested places and spaces. Framing women's individual health cartographies was a restrictive social and built environment (Davidson and Milligan 2004; Robertson 2007), with HIV services largely concentrated in urban centers like Vancouver and targeted towards particular sub-populations such as gay men, people who inject drugs, or sex workers. While these are essential services, women in this study raised an important ethical question around how to ensure that HIV programming continues to be available in high-service areas for highly affected populations while not creating barriers (physical and social) to care for other women who feel they cannot access these places.

This socio-spatial order had a significant bearing on women's choice to access care in their home community or travel to Vancouver in search of women-centered HIV care. Both of these decisions carried their own set of emotional, financial, and physical costs and benefits. This reflects previous research on place-based barriers to care for WLWH (Seals et al. 1995; Schuster et al. 2000; Stein et al. 2000; Reif, Golin, and Smith 2005) and also highlights the ways that emotional and physical pains are dynamically related to place (Davidson and Milligan 2004). Interestingly, more often than not, women chose to travel to Vancouver in order to access what previous researchers (Whitzman 2006; Robertson 2007; Fast et al. 2010) call health care sites, where they feel *in place*.

What was particularly striking, however, was that, beyond geography, women's experiences of the spaces where they seek care and support emerged as the most defining barrier to health care, challenging the traditional notion of proximity and distance as defining the separation of people and places (Veenstra 2005; Cummins et al. 2007; Tempalski and McQuie 2009). In navigating personal identities (or how women see themselves) in relation to the socially and politically constructed spaces in which they receive care, women highlighted how existing services, even if proximally close, can be socially marginalizing as they are confronted with HIV stigma, racism, classism, and other forms of oppression. Similar to findings from earlier studies (Malins, Fitzgerald, and Threadgold 2006; Robertson 2007; Fast et al. 2010), women recounted how these 'geographies of power' (do Rio Caldeira 2000) operate to isolate and exclude women from the places and spaces they must access for care.

For the women in this study, experiences of exclusion from HIV services put them in challenging positions that were at times constraining and at other times liberating. Forced to weigh the risks and benefits of accessing care in places and spaces bound by multiple forms of marginalization, many women chose to enact 'geographies of resistance' (Beazley 2002). This was demonstrated through recounts of rejecting available services and relying on peer communities, and self-care to manage their health. These 'spatial tactics,' a term used by Fast et al. (2010) to emphasize how people act within society's larger power structures, helped to free women from their marginal position in place and space.

Of equal importance was the women's geographical turn from resistance to change. One of the most critical study findings was the shift from resisting unwelcoming therapeutic landscapes to offering insights for the development of places and spaces where emotional healing and support is more readily accessible. Technological solutions figured prominently in women's visions for change, which would enable women to receive the care and support they want and need within their home communities and alleviate several geographical barriers to care. Women's narratives also called for more women-centered HIV programming (Carter et al. 2013) towards creating safer and more inclusive care

environments for women. Lastly, of particular significance were the women's desires for more opportunities for peer-driven care and support (both in person and virtual). Similar to findings in emotional geography studies (English, Wilson, and Keller-Olaman 2008), peer support offers relief from the emotional impacts of marginalization and is key to the healing process for WLWH. More opportunities must be made for WLWH to contribute to the health care services that impact their own lives and their lives of their communities (Carter et al. 2014).

While geographic access to care is important, available care doesn't mean accessible care. The relative and intersecting effects of marginalization by geographic place *and* social space on the health care options for WLWH in BC underscore the importance of reconceptualizing understandings of access as related to both physical *and* social distance to care. Consistent with previous work (Rhodes et al. 2005; Robertson 2007; Shannon, Rusch, et al. 2008; Fast et al. 2010), the results of this study illustrate an urgent need for policy-makers and care providers to acknowledge and redress socio-spatial barriers to care and to work with WLWH to co-create a therapeutic landscape of HIV services and support that reflect women's diverse identities, localities, emotions, and experiences.

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