(Dis)integrated Care: Barriers to Health Care Utilization for Trans Women Living With HIV

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*Transgender (trans) women have been particularly impacted by HIV. To seek insights into the dynamics of health service utilization, interviews were conducted with trans women living with HIV (*n = *14) as part of the Trans PULSE community-based research project in Ontario, Canada. Service providers (*n = *10) were also interviewed to provide additional details about communication between trans women, social service providers, and clinicians. Results highlight how both problematic interactions with individuals and health systems navigation challenges affect access to services and impede the development of trans-specific HIV supports. Participants described discrimination, identified strategies for navigating a dysfunctional system, and outlined specific ways in which health and social services may be failing trans women living with HIV. Findings support the importance of coordinating HIV services and transition-related care, and providing training for service providers.*

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Trans women have been particularly affected by HIV, but the impacts have not always been visible. Estimates are that 19% of trans women are living with HIV globally, and the possibility of contracting HIV is 49 times higher for trans women than all other adults of reproductive age (Baral et al., 2013). Actual population estimates, however, may be somewhat lower due to the over-representation of higher-risk urban populations within existing research (Bauer & Scheim, 2013). With growing awareness of the burden of HIV on trans women's communities (Baral et al., 2013) and the identification of trans women as a priority population, increased research

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attention has turned to the ways trans people interact with health care systems.

The term “trans” is used throughout this paper to refer to a variety of people who do not identify with the gender they were assigned at birth. This definition of trans is inclusive of people who express as gender ambiguous, genderqueer, or Two-Spirit, and does not imply that individuals need to be involved in surgical or hormonal transition. Here, the term trans woman is used, albeit imperfectly, to be inclusive of not only those trans people who identify as women, but also those assigned male at birth who do not identify as men.

Health services utilization is defined as the outcome of the interactions between patients and health professionals (Donabedian, 1973) and is reflected in the ways people use the health care services available to them (Aday & Andersen, 1974). Utilization is determined by multiple factors including characteristics of the health service system, individual determinants, and social determinants of health (Andersen & Newman, 2005). In this paper, we pay particular attention to the interactions between individual patients, service providers, and the health service system. Trans women’s experiences of accessing health care and social services are complicated by numerous barriers, including negative interactions with health care providers, deficits in provider knowledge, gender-segregated programs, and frequent pathologizing of trans identities (Bauer et al., 2009; Lombardi, 2001; Sevelius, Carrico, & Johnson, 2010; Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012; Stotzer, Silverschanz, & Wilson, 2013). These barriers have contributed to hostile service environments, which often deter trans people from attempting to access much-needed programs and services (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sevelius, Patouhas, Keatley, & Johnson, 2014; Stotzer et al., 2013).

Lerner and Robles (2017) recently conducted a review of 21 studies to better understand the perceived facilitators and barriers to health care utilization for trans people in the United States. Their findings highlighted four key barriers to health care: (a) provider lack of knowledge concerning trans identity issues and trans health issues, (b) trans patients’ previous negative experiences with health care or anticipation of these experiences, (c) the inability to pay for health care services, and (d) provider refusal to provide health care services to trans people. In Canada’s universal health care system, ability to pay would be expected to be a lesser barrier, given that basic medical services (but often not drugs) are covered 100% through public insurance.

Research focused on trans women living with HIV has provided insights into the barriers and facilitators for health service utilization across the HIV continuum of care. As part of a large-scale study of people living with HIV (PLWH) in four cities, San Francisco, Los Angeles, New York City, and Milwaukee, Sevelius and colleagues (2010) found that, regardless of whether they were currently prescribed antiretroviral therapy (ART), trans women reported significantly fewer positive interactions with service providers than other respondents living with HIV. Using data from the Medical Monitoring Project, Mizuno, Frazier, Huang, and Skarbinski (2015) reported that significantly higher proportions of transgender women, compared to cisgender men, needed services, including HIV case management, ART adherence support, HIV prevention counseling, mental health services, meal services, domestic violence services, transportation services, and housing services. In particular, “transgender women had higher unmet needs than non-transgender men for basic services such as food and housing” (Mizuno et al., 2015, p. 228). These findings underline the importance of addressing broader structural conditions in addition to health care service factors affecting trans women living with HIV.

In the Canadian context, Schilder and colleagues (2001) discovered that unprofessional behavior, mis-gendering, misuse of pronouns, and a lack of transgender competence in encounters with service providers resulted in inadequate care for trans women living with HIV. Gender affirmation refers to “the process by which individuals are affirmed in their gender identity through social interactions” (Sevelius, 2013, p. 675). In health care contexts, this multidimensional concept draws attention to social, psychological, medical, and legal factors, including preferred names and pronouns, respect for felt gender identity, access to medical transition and gender-confirming procedures as requested, as well as access to legal name change and gender markers (Reisner, Radix, & Deutsch, 2016). Gender affirmation in HIV testing and care settings has been identified as a crucial component for trans women accessing care, with implications for adherence to ART (Sevelius et al., 2014). In addition to dealing with frustrations related to possible contraindications for hormone therapy and HIV care, it has been noted that some trans women may prioritize trans-related care, to the detriment of adherence to ART (Sevelius et al., 2014).

Mizuno and colleagues (2015) identified significantly lower dose adherence and durable viral suppression for trans women when compared to cisgender men. On the point of adherence to ART, Williamson (2010) and Namaste (2000) insisted that medical treatment for trans women living with HIV must consider the complex reality of hormone care and the physical impacts of ART, yet hormone care can be difficult to access even for those who are not living with HIV. While the World Professional Association for Transgender Health has articulated standards of care for transition support (Coleman et al., 2012), many physicians reported feeling uncomfortable monitoring hormone therapy. In a study of physicians in Ontario, participants cited lack of trans-specific resources, education and medical knowledge deficits, limited referral networks, and sex-specific eligibility criteria as significant barriers to provision of adequate care (Snelgrove et al., 2012).

While we are beginning to understand the barriers and facilitators to health care access experienced by trans women living with HIV, research to date has not included the perspectives of service providers. In this study, we combine data from trans women living with HIV and service providers to explore health service navigation. Our overall project objective was to contribute to the development of a theoretical understanding of the ways in which social exclusion, transphobia, and erasure work in combination to produce unique health-related needs for trans people living with HIV. We specifically aimed to contribute information about barriers to effective HIV-related care for trans women living with HIV in Ontario, Canada.

The TransPULSE Project

The TransPULSE project aims to contribute to the growing body of literature on the health and well-being of trans communities through a multiphase, mixed-methods program of community-based participatory research. Since the inception of the TransPULSE project, trans community members from across Ontario have worked in close partnership with academic researchers to ensure that all major aspects of the project–from identifying research questions to determining relevant strategies for capacity-building and knowledge transfer–are in the control of trans community members (see Travers et al., 2013 for more details on the collaborative nature of the project). The most recent qualitative phase of the project focused specifically on the experiences of trans people living with HIV and the service providers who work with them. The phase of the project reported here received research ethics board approval through the Office of Research Services at Wilfrid Laurier University.

Methods

Participants

Participants were asked to self-identify their ethno-racial identity and were given the choice of selecting all relevant responses; as a result, some participants chose more than one response category. Of the 14 trans participants living with HIV, five self-identified as Aboriginal, First Nations, Native, or Metis; four as European; three as Caucasian; two as French Canadian; two as Latina; one as Hispanic; and one as Jewish. They ranged between 30 and 58 years of age, with an average age of 40, and were asked to self-identify their gender identities. Trans woman and transgender were the most commonly used self-descriptors. It is important to note that while sampling was not limited by gender, all of the PLWH who were interviewed identified on the transfeminine spectrum at some point in their lives. This included one person who used to identify on the transfeminine spectrum but no longer did.

The service providers we interviewed worked in the following types of organizations: organizations providing trans- and Two-Spirit-focused services, HIV community-based organizations (CBOs), and health services. Seven of the service provider informants identified as members of lesbian, gay, or bisexual (LGB) communities, with two of those seven also identifying as trans. Demographics of trans community and service provider interview participants are included in Table 1.

Data Collection

Participants were recruited through advertisements posted and circulated at health and social services for PLWH, as well as those with programming for lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) individuals in Ontario. Identifying as a transgender PLWH and older than 16 years of age were inclusion criteria for the study. Semi-structured, in-depth interviews with 15 trans women living with HIV were conducted by a peer (also trans) researcher. One of the interviews was not included in this analysis due to poor audio quality, which made transcription impossible. Interviews focused on gender identity, transition, perceptions of health and mental health, health care and social service utilization, and support from family, friends, and community. Participants also completed a brief demographic questionnaire that asked for details on racial identity, age, geographic location, gender identity, and sexual orientation. Trans women living with HIV who participated in the study received $30 as compensation.

Table 1. Participant Characteristics

Characteristics	*n*	%
Trans persons living with HIV		
Age (years)	(*n* = 14)	
30-39	6	43
40-49	7	50
50-59	1	7
Gender identity[a]	(*n* = 16)	
Trans woman	4	25
Transgender	3	19
Two-spirit	2	13
Gender Queer	1	6
T-Girl	1	6
Trans	1	6
Transsexual woman	1	6
Transvestite	1	6
Woman	1	6
Male	1	6
Ethno-racial identity[a]	(*n* = 17)	
Aboriginal, First Nations, Native, or Métis	5	29
European	3	18
Hispanic or Latina/Latino	3	18
Caucasian	3	18
French Canadian	2	12
Jewish	1	6
Region of province	(*n* = 14)	
Toronto	12	86
Southwestern Ontario	2	14
Service providers		
Type of work	(*n* = 10)	
HIV community-based organization	4	40
Health services	3	30
Trans and two-spirit services	3	30
Length of time at organization	(*n* = 10)	
1-4 years	2	20
5-9 years	4	40
10 + years	4	40

a. Participants provided qualitative information for demographic fields and, in some cases, identified in multiple ways.

Interviews were also conducted with 10 service providers who worked with trans PLWH. Service providers were recruited through advertisements sent to community-based HIV organizations in Ontario, community health centers, health services, and LGBTQ-oriented CBOs. Service providers did not receive compensation for their participation. For both PLWH and service providers, recruitment was stopped once saturation was reached and no novel themes emerged.

Data Analysis

We used a modified version of grounded theory in conjunction with collaborative coding methods to guide our analysis. Rather than starting from hypotheses or deductively established findings, a grounded theory perspective was used to ensure that theory emerged inductively from the data (Miles & Huberman, 1994). We modified this approach by creating a categorical coding framework prior to inductive coding, based on our knowledge of the literature and the importance of the broader social determinants of health in shaping health experiences and outcomes. The collaborative coding process involved members of our research team individually reviewing several transcripts while attending to descriptive, in vivo codes, as well as broader, structural codes. The group engaged in a process of sharing, refining, and organizing initial codes to develop the aforementioned coding framework.

The coding framework served as an organizing structure for open and in vivo codes and was used to analyze a selection of four transcripts (from interviews with two women living with HIV and two service providers) using a consensus coding approach. The consensus coding of these first four transcripts allowed for further refinement of the coding framework to ensure its relevance. This iteration of the framework was then used to analyze the remaining interviews, with additional modifications made as necessary.

A summary of the finalized analysis was brought to the research team along with information regarding most-used codes and potential themes. Team discussion allowed for deeper immersion in the themes, allowing us to further fine-tune and crystallize their relevance.

Quality and Rigor

Our research design and method contributed to the quality of our analysis. A grounded theory approach acknowledges that researchers are social beings who may have prior experiences that are relevant to the understanding of research data (Baker, Wuest, & Stern, 1992). As such, researchers are encouraged to make note of their assumptions at all stages of the research process and to use their knowledge to inform study design and analysis. While we ideally would have liked to undertake member checks (Lincoln & Guba, 1985) to enhance the credibility of our data, the daily lived experiences of more marginalized groups can make it difficult to expect such follow-through. Our research team determined that it would not be feasible to expect participants to be available and/or accessible for follow-up. Moreover, singular and objective truths that were verifiable only by a participant ignore a more commonly held belief in qualitative research that knowledge is co-constructed (Morse, 1994). Given the inclusion of trans people and service providers on our team, in addition to the involvement of the peer researcher in the analysis phase, the credibility of the coding process was enhanced by shared lived experiences with the participants.

Results

Our results underline the challenges trans women experience in attempting to access HIV care in Ontario. The findings presented in our paper relate to both interactions with individual service providers or agency workers, as well as to issues with navigating health systems. In the sections below, nine key themes are illustrated with quotes from trans women living with HIV (PLWH) and service providers (SP).

Interactions With Health Care Providers or Staff

In our study, service providers and trans women living with HIV identified the following four themes related to challenges in interactions with health care providers and other workers in community health center or community agency settings: (a) discrimination in health care encounters, (b) denial of service, (c) lack of training impacts HIV clinicians and trans people, and (d) agencies not perceived as welcoming to trans women.

Discrimination in health care encounters. When trans women living with HIV accessed services, they experienced discrimination from service providers. Both service providers and trans women living with HIV recounted transphobic encounters that impacted service use. Some service providers noted discrepancies in how trans people were treated in their agencies, depending on with whom they were interacting. Front desk staff, who are often the first point of contact in an agency, were noted by some PLWH and service providers as sources of discrimination. One trans participant explained how she regularly witnessed the intersection of racism and transphobia in the discrimination that Black trans women experienced:

> If they [Black trans women] were there he'd [staff person] make it a point to single them out and if they were moving around and things he would watch them … I said, "Shouldn't you be sitting behind your desk or something? Is it in your job description?" He would say, "Oh, we just have to watch them, they like to come in here and steal." (PLWH)

Health care providers themselves were often perpetrators of transphobic discrimination. After connecting a trans patient with an endocrinologist, one service provider noted that the transphobia present in larger society also permeated such professional encounters:

> I tried to make a referral … and the consult came back so acrimonious and so it was such a bad experience that, to be honest with you, since those couple of experiences within the established medical community I haven't made any referrals to anybody. (SP)

Another service provider mentioned trans clients who were very clearly in abusive relationships with their service providers. She described situations where trans women defended their caseworkers even when they were transphobic because they needed the services to survive:

> I've totally seen trans people living with HIV who become very protective of certain workers, even though they come to me and tell me how badly they get treated. Um, and this is also true of trans people living with intellectual disabilities. And the trans people who are HIV positive and have intellectual disabilities, it's even more amplified that they will have one worker. Like I'm thinking of a couple people in specific who have one worker and they've had them for like 10 years and the person still refuses to use the right name and pronouns, and they come to me really upset about it and then I'm like, "Well I can call them – tell me who the worker is, and we can get training in there and we can do this in a really non-aggressive way," and that sort of thing, and they're like "Nonononononono because they're the one who's treating me. They're the one who's getting me things." Um, it's very much a culture of necessity … Because people are trying to survive. (SP)

Recounting her own negative experiences and the harassment that other trans service users had experienced, one trans participant reflected on why some trans service users might not complain when they receive poor treatment:

> These are the same trans clients that gave me horror stories, and then when you ask them to complain … or that you both go make a complaint, you know, they don't for several reasons … The staff here are transphobic … the supervisor or manager isn't going to be any more helpful. If you want to make a complaint about me and my team … [they're] just going to have you banned. (PLWH)

The cumulative impact of discrimination in services was described by one service provider who pointed out that many trans people were reluctant to access health services, which could jeopardize their health (or have negative health consequences):

> A lot of them put off going to the hospital when they probably should go and they wait until the situation becomes serious before they access any kind of health care because of their negative experience, or even just the fear of a negative experience. (SP)

Denial of services. Despite the existence of clinical guidelines for gender-affirming surgeries for patients living with HIV infection (World Professional Association for Transgender Health, 2011), one service provider reported knowing of people who had been turned down for surgery because of their HIV status: "I've heard of experiences of trans people who … were denied access to surgery because of their HIV positive status" (SP). Indeed, one trans woman described being denied breast implants because she was infected with HIV. Because the surgery was conceptualized as elective, she was told that her legal options were limited:

> I finally got a hold of her [the surgeon] and she said, "Oh, I'm not gonna do the surgery" and I said, "Why?" and she said, "Well, putting the implants on your body, with a virus, could kill you within a year – don't want to take that chance" … (PLWH)

Similarly, another woman reported difficulty accessing hair removal services after disclosing her HIV status:

> I went to try to get laser for my chin, and of course in the paper that they give you, they ask if you have anything, any health issues. And I said that I – I wrote that I was HIV, I shouldn't have done that. And the lady when she looked at the paper, she look [sic] at me and said, "You know maybe you should go to your doctor first because, um, you might get

> sick or something and we cannot help you here." (PLWH)

Even for participants who were not denied services directly, there was a fear that HIV could influence attempts to access health services. For example, while vaginoplasties are routinely performed on HIV-infected trans women in Canada, one of the trans women participants explained, "I don't know if they're willing to do the surgery knowing that I'm HIV positive."

Lack of training impacts HIV clinicians and trans people. A lack of training for clinicians, including HIV specialists, to provide health care to trans people was evident in our study. When asked what kind of changes she wanted to see in relation to HIV care for trans people, one PLWH said, "We're [not just] passing through, it needs to be more specific for people with HIV and transition." Many of the service providers that we interviewed described themselves as "self-taught." When asked if she had ever received trans-specific training, one clinician said, "No, nope, self-learned. Self-learned but no trans specific training" (SP).

Some of the challenges were related to the lack of information and misinformation about hormones and gender-affirming care. One clinician lamented the lack of resources, stating:

> I think it would be nice if there was somebody who was an expert in terms of how to help hormonal transformation. It's not my expertise so I'm here prescribing these medications, injectable and oral, and trying to do my best to follow hormone levels and responses but it's not my expertise. I was never trained in it. It was never something that was absolutely encouraged let alone talked about when I went to med school. So, I feel, um, a little bit out of the loop, um, and I have no resources. (SP)

Misinformation on the part of health providers also contributed to increased confusion in trans communities. For example, some trans women living with HIV were concerned after hearing rumors about negative interactions between hormones and ART: "I've heard that [taking hormones] might cause cancer, cause you're on antiretrovirals and you're kind of altering your endocrine system and mixing all those could develop into a cancer somewhere in your body." One service provider worried that myths about hormones and surgery could negatively impact HIV testing rates:

> There's a myth that exists, that trans people can't access hormones or surgery if they are HIV positive. And they are often told this by doctors, which is not true. Even if you are on HIV medication, there are still ways of being on estrogen or testosterone. Personally, I think this is part of what discourages a lot of trans people from getting tested. (SP)

Agencies not perceived as welcoming to trans people. The issue of inclusion in agency materials came up in interviews with both service providers and PLWH. It was noted that services were rarely explicit about the inclusion of trans people:

> One of the things about trans people accessing services, especially HIV services, I feel, is that not only do trans people often have bad experiences, services are almost never explicitly inclusive in their outreach materials and where they do outreach. (SP)

Another service provider went on to say, "You know a lot of ASOs [AIDS service organizations] are considered not really trans friendly" (SP). The lack of inclusion translated into real discrimination. One PLWH described a particular CBO as marketed for men, so when trans women tried to access services they were turned away or treated like men:

> Some of the girls were complaining if they go to the [CBO] they would be neglected and turned away … when they go there or they go to [another CBO] then they would be turned away because they were treated like *men* with HIV it's just they didn't feel welcomed … cause a lot of the [trans] girls that came to me said, "We're upset because it's not fair, when *we* go to [the CBO] and we ask them for this, this, this, and this, we're turned away!" Whereas if a guy goes there, they're accepted right away, so … it's just not fair. (PLWH)

Referring to a different service organization, another participant expressed a similar view stating, "I think they're [CBO staff] very transphobic. I just find that they're cold when people go in there …" (PLWH). Talking about her time volunteering with a CBO, one trans woman said she never saw other trans people around: "No one is trans here, you know? … actually, I thought that I was the only one when I was doing volunteering here, because I never seen anyone who is trans that comes here." Another participant wondered if trans people were showing up at agencies, but not disclosing their gender identities: "I see only myself. I don't see too many visible [trans] clients, or they are all quiet, or they don't show up, or they show up more as gay people, regular person …" (PLWH).

One of the service providers emphasized that the issue of trans visibility had to do with efforts (or lack thereof) to make services more accessible to trans people: "Clearly we're not meeting a need there. If they're not identifying [as trans], or if they're not accessing the services, there's something that we're doing on our end, or not doing on our end to make it more accessible" (SP). Discussing the history of HIV work that has emphasized the involvement of people with lived experience, one service provider wondered if CBOs are truly connected to trans communities:

> One of the ways in HIV that we've always ensured that we're responsive is by ensuring that the people that are affected by the issue are at the forefront of leadership and thinking and the work. And I think we need trans people to be much more engaged in the sector … not just as a client, but actually in a position of, you know, volunteering, board work, providing service, sitting in staff meetings, talking about issues … In the same way that we want people with HIV to be engaged, or gay men to be engaged, you know you wouldn't want a bunch of straight people designing policies that are going to affect gay men. You wouldn't because they're not rooted in the community. So, I would wonder the extent to which ASOs are rooted in trans communities. Like, how deep are those roots really? (SP)

Health System Navigation Issues

Trans women living with HIV and service providers identified the following five themes related to systemic barriers in navigation of health systems: (a) lack of trans-specific services, (b) disjointed health care delivery models, (c) siloing reinforces limited service options, (d) system navigation complicated by discrimination, and (e) geographic barriers to HIV testing and care.

Lack of trans-specific services. Trans women living with HIV and service providers highlighted the lack of trans-specific services in Ontario. Participants noted that CBOs did not have programming for trans people and that even LGBTQ organizations often failed to address the concerns of the trans community. One participant indicated that she had no access to help as a trans person, "I haven't seen any help for trans people, it's mostly for gay and lesbian and all of that. Not for trans. No. I don't have any access to any real help." Another participant explained that trans people could go to CBOs for services, but that there were no trans-specific groups:

> We could still go there [to the CBO] and sort of access their services, but, you know, there was never nothing that was strictly identified as geared towards transgender people. It was just men's and women's groups that were support groups. (PLWH)

One service provider expressed frustration at the lack of inclusion of trans people in LGBTQ programs:

> It's also frustrating when [trans people] can't take part in other programs that tout themselves as being LGBT. It's always the little T that's not actually really there, which is true of most gay and lesbian organizations in North America and most of Europe. (SP)

Disjointed health care delivery models. In navigating complex referrals, providers expressed frustration at the compartmentalized nature of services. Specifically, HIV treatment and gender-affirming care were typically offered in separate locations by different providers. One service provider reflected on the difficulty of finding specialists in either area, let alone both:

> I think it's hard to find because those [hormone care and HIV care] are both two subspecialties. So, what are the chances of finding first someone who does HIV care and is accepting patients? Not great. What is the chance then separately just a separate issue of finding someone who does trans care, feels confident and competent? Not great. So, then those two not greats become more not great. Right? So, you go from a 10% chance to like a 2% chance. (SP)

Many PLWH talked about having to bounce between clinic locations to see multiple physicians. Some participants described relationships with general practitioners (GPs) who had to frequently refer them elsewhere because the GP did not have adequate knowledge of HIV care or hormone treatment. Talking about her GP, one participant remarked that getting connected to care was not always easy:

> She [the physician] says, "Well, you'll have to find a counselor" or, you know, she said, "There are places you can go to get that." Uh, she's not so great at referring me to like, counselors, and that kind. She's more okay with specialists. (PLWH)

One PLWH described being "let go" by her HIV specialist because he said he was unable to provide the mental health support she needed, which left her without a physician.

> I had a doctor here who was an HIV specialist, but he let me go because he didn't feel he could support me through my mental health issues, which is very unfortunate. Um, and so I currently don't have a doctor here. (PLWH)

Several service providers pointed out that HIV care was highly specialized. One clinician explained:

> All HIV care, pretty much doesn't happen at a primary care level. We do it, it happens at an … infectious disease level. So, it's done at a clinic, a hospital-based clinic. Those clinics do not do any of the primary care. I lie, they do a little bit. But they only do HIV. So, you become a box for just HIV. (SP)

Siloing reinforces limited service options. Trans women living with HIV who attempted to access services tended to be managed within pre-established pathways or trajectories. Service providers who were considered "trans experts" in their communities because they themselves were trans-identified or trans-knowledgeable, described how trans people seeking services were often funneled to them regardless of whether it was an appropriate service referral. One service provider pointed out that those who were not visibly trans or who did not disclose their trans identity would likely be referred to services more appropriate to their health needs:

> If they're coming for a specific thing, they usually get sent to me. Even if they would be better served by our newcomer program or by our older LGBT program or something like that they're almost always sent to me, which is an interesting dynamic because they could be coming in looking for a senior center, and get sent to me, because they're trans. Because they're visibly trans. If they're not visibly trans, or they don't say it, then they get sent elsewhere. (SP)

One service provider explained that having trans clients referred to him often meant that he could facilitate the appropriate connections for that person. However, he pointed out that the default with trans people is for providers to send them to an LGBTQ agency with no follow-up.

> They get sent here, just because they're looking for something and they happen to be trans. And it is often a good referral, because I can help those people gain other access to things, but it's kind of people's one response to trans people is that they refer them to [an LGBTQ agency] and then have nothing to do with them afterwards. (SP)

While having "trans experts" at agencies may facilitate effective referrals in the longer-term, one service provider raised the issue of sustainability in terms of organizations having one "trans expert." She expressed concerns about being the only trans-knowledgeable person, when the entire agency should be competent in this regard:

> When there's information needed, or there's questions, oftentimes those questions end up coming to me … they know to come to me if

> they need services here. So, I'm okay for the time being to be that person, but I can't always be here and I want them to understand that they can access all these services… it's an entire agency and it shouldn't hinge on one person. (SP)

System navigation is complicated by discrimination. Service providers spoke at length about the ways in which they navigated the social service system to ensure that trans women living with HIV received the care they needed. For some, this meant warning trans clients that they might experience discrimination through a referral; for others, it meant doing away with referrals altogether.

In discussing how he facilitated referrals for trans clients, one service provider explained that he was transparent with clients that they might experience discrimination, he would call ahead to the referring agency and check in after, with the hope that surveillance would elicit a better response. He said that, often, trans clients have had to endure discrimination in order to get the services they needed:

> When it comes to referrals, there haven't been historically that many choices and so what I've often done is sort of taking a two-pronged approach. Um, the first part of it is being really transparent with the trans person about what kinds of services exist and what doesn't exist. And making sure that I don't set them up for a bad experience. So, I let them know the kinds of things they might have to deal with … And then I also will phone an agency and say I'm sending over so and so and one of the reasons why I do that is because, in my experience, agencies respond so much better when they know they're being watched. And then of course you also have to follow up. So, I guess that's maybe a three-pronged approach. (SP)

Dealing with discrimination in the referral process was not uncommon. Another service provider shared similar stories of trans women living with HIV having to put up with discrimination in order to access essential services.

> Unfortunately, they [housing workers] were aggressively misgendering people and, well like all kinds of transphobic stuff. They were actually getting people housing so people were like, "Don't make them leave even though they're jerks!" 'cause they were really good at getting people housing. But they were so disrespectful, um, so when I have to refer people [to them] for housing, and to other actual organizations, I often give them a disclaimer like, "I can't guarantee that you're going to have a good, um, experience there but my advice is jump through the hoops to get what you need, 'cause you need to survive. Um, like someone might treat you like a total jerk, but if that person treats you like a total jerk and can get you housing, then deal with it and yell at them later. Or come to me and I will help you file a complaint later. Um, but the important thing is that you get the housing. Or you get, you know the shelter bed, or your HIV test, or whatever it is that you're coming for." (SP)

Geographic barriers to HIV testing and care. Women living with HIV and service providers often identified Montreal and Toronto as the only options for care for trans Ontarians. A service provider highlighted this. "People who live in Toronto are probably the best well off in terms of access to service. The further we go away from Toronto, the harder it gets." Finding appropriate HIV specialists provided an additional challenge. Trans women in rural areas discussed difficulties accessing services and mentioned long commutes to major city centers. One Indigenous PLWH noted the additional difficulties accessing services in her community:

> There isn't a lot of support [on reserve] and there continues to be not a lot of support or whatever. They have like an HIV educator that will come once a year or whatever, just to, you know, educate people on STDs (sexually transmitted diseases) but that's the only thing they have. Other than that, there is none. Nothing really, there is no support, no network or whatever for us people that are HIV positive. (PLWH)

Another trans participant, who lived in rural Ontario, described having more HIV-related knowledge than her physician and how she had to choose between HIV specialists in either London or Toronto:

> He wasn't really that educated about it [HIV] or whatever … I knew more about all the drugs, all the symptoms, what kind of things to watch for, or whatever. He said, "Well I don't think I'm, you know, I'm probably not the right doctor for you, you know, I think we need to find you like a specialist that deals with this," or whatever … and you know there was a choice between Toronto and London … (PLWH)

Reflecting on the difficulties of finding providers who can offer both HIV and gender-affirming health care, even in major cities, one service provider speculated that people living outside of the largest urban centers faced additional challenges in terms of access:

> If you were to take what's happening in the city of Toronto and magnify it outward, it probably gets even more complicated when you think about, you know, it's hard enough in some of the rural communities for anyone to find HIV primary care. And so, finding someone who could do good HIV primary care and understand the issues, the health issues of a trans individual and support their processes around medications they take and how they interact with their HIV meds, just it's a big enough challenge for some of the health care providers to live and do their practice in Toronto who are really good at what they do and have served trans individuals. So, I think if you took that outward into Ontario I can't imagine what it's like. It's probably mayhem. (SP)

Discussion

The stories shared by service providers and trans women living with HIV in our study demonstrated a host of challenges and vulnerabilities facing trans women living with HIV at interpersonal and organizational levels. In their interactions with health care providers, trans participants highlighted discrimination, denial of service, lack of training, and unwelcoming service environments. In navigating the health care system, disjointed health care delivery models, geographic barriers, lack of trans-specific services, siloing of trans people, and further complications related to discrimination were described.

The call to improve HIV prevention and treatment services for trans people is not new (Bauer et al., 2009; Lombardi, 2001; Namaste, 2000; Operario & Nemoto, 2010). Nor is the criticism of CBOs that fail to develop welcoming and accessible HIV services for trans communities. Sandra Laframboise highlighted the irony in the lack of HIV materials addressed to trans communities, saying:

> [HIV] is a condition of living, and a teacher. And people have not learned yet. Because if I look around, there's nothing for transgendered people. All over again! Then I'm going, "Geesh! Guys, this is chicken shit! You know?" Like, fuck. We were in the forefront for gay community activists. We raised thousands of dollars for your projects, transvestites on the stages. And now we're here, and you're putting us aside again … And that's the bottom line. What I've found [from predominantly gay-defined AIDS service organizations] is a lot of patronizing (Namaste, 2000, p. 12).

HIV prevention and treatment services in Ontario that are sensitive to the experiences of trans women are underdeveloped and often, nonexistent. While trans communities have emphasized the desire for culturally competent care and trans-specific services, change has happened slowly (Schilder et al., 2001; Sevelius et al., 2014). In order to enhance care for trans women living with HIV, it is essential that health care and social service workers receive training and resources to make their services more accessible. Research by Poteat, German, and Kerrigan (2013) described the impacts of lack of education, which has been reflected in negative interactions with health care providers who manage uncertainty by reinforcing stigma with trans patients.

Regarding medical care, service providers underlined the difficulty of finding separate providers for HIV treatment and gender transition-related care, including specific challenges identifying clinicians who do both. Furthermore, discrimination on the part of service providers represented a significant barrier to trans women accessing care (Lombardi, 2001). Acknowledging that HIV care was often housed within infectious disease clinics, and the reality that many nurses and health care staff had limited understanding of trans communities, Keiswetter and Brotemarkle (2010) suggested that Clinical Nurse Leaders (Advanced Practice Nurses in Canada) were ideally situated to advocate for culturally competent care for trans PLWH. While they acknowledged that all health care staff, regardless of specialty, needed to be trained in trans issues, Keiswetter and Brotemarkle (2010) highlighted the potential for Clinical Nurse Leaders to influence organizations and assist with the implementation of hospital and system-wide gender-affirming policies. In their article outlining best practices in LGBTQ primary care, McNamara and Ng (2016) highlighted the importance of creating a welcoming environment for LGBTQ patients by making organizational changes that included (a) avoiding the use of program names that appear welcoming to only one gender, (b) establishing gender-neutral washrooms, and (c) amending intake forms and electronic records to collect information about pronouns and gender identity.

Combatting hostility, insensitivity, and discrimination in health care and social service settings is crucial to the well-being of trans women living with HIV, although the importance of care coordination cannot be ignored (Ferron, Young, Boulanger, Rodriguez, & Moreno, 2010; Sevelius et al., 2010). However, current approaches to HIV care focus solely on the infectious disease component and rarely integrate primary care, let alone gender-affirming care. Service providers with clinical experience highlighted their own gaps in knowledge of hormone therapy and called for integrated care and more appropriate referral options. While difficulties finding trans-competent referrals appear common across different areas of care (Bauer et al, 2009; Snelgrove et al., 2012), the heightened need for multiprofessional care for trans PLWH will magnify the adverse impact of referral difficulties.

At the very least, service providers need to take advantage of available resources on hormone therapy (Center of Excellence for Transgender Health, 2016; LGBT Health Program, 2015) and work to challenge misinformation about hormone therapy and HIV treatment (McNamara & Ng, 2016). If trans women are concerned that ART might interfere with their hormone treatment, it is possible that adherence may be impacted (Mizuno et al., 2015; Sevelius et al., 2014). Beyond HIV treatment and transition care, Ferron and colleagues (2010) suggested that care coordination for trans women living with HIV should also include access to social support resources, mental health support, and timely referrals for comorbidities. It was clear from the perspective of our service providers that care coordination needs to extend beyond the medical sector.

According to the service providers we spoke with, trans women living with HIV were being steered toward trans experts regardless of the services they needed, which led to a fragmented care experience. Although the funneling of clients to trans-knowledgeable providers may mean that trans women living with HIV were treated with more compassion and were ultimately able to make additional connections to health and social services, the path was disjointed and unfairly burdened for both trans women and service providers who had made a point of expanding their knowledge of trans issues. The informal referral network for trans women living with HIV may mitigate some barriers but, as service providers pointed out, there were still scenarios where trans women and their advocates had to tolerate discrimination in order to access services. Furthermore, exposure to discrimination in health and social service settings led to mistrust of providers and, often, avoidance of health care for trans women living with HIV (Schilder et al., 2001; Sevelius et al., 2014).

Considering our results within the HIV care continuum (Mugavero, Amico, Horn, & Thompson, 2013) may provide additional insight into where change is most needed. For example, when thinking about HIV testing and diagnosis and a lack of trans-specific HIV services, agencies perceived as unwelcoming to trans people, misinformation about HIV treatment, and gender-affirming care are factors that could contribute to lower HIV testing and diagnosis rates. In the context of engagement and retention in health care, challenges with system navigation, geographic barriers to accessing services, and discrimination in health encounters may all impact the ways trans women living with HIV access care. In addition, accessing ART is likely impacted by disjointed health care delivery models, lack of clinician training in gender-affirming health care, and gaps in appropriate information about how to best provide HIV care for trans women.

Reflecting on women's access to the health care system in Ontario, Canada, Lombardo and colleagues (2014) cited many examples where women had been "resourceful and resilient in overcoming access disparities" (p. 575). However, individual efforts to overcome such challenges did not represent a long-term solution, as the systemic barriers themselves must be addressed. While Lombardo and colleagues (2014) did not specifically discuss the experiences of trans women, our findings revealed the strategic ways in which this group and their providers have had to navigate a flawed system. In their recommendations for increased community engagement, the authors stated, "Women, especially those who encounter the greatest disparities, should be partners in policy and health system redesign" (Lombardo et al., 2014, p. 575). We contend that trans women living with HIV have a major stake in this endeavor and must be prioritized in efforts to identify and address the root causes of inequity in women's health and social services.

These data contribute new information highlighting potential intervention opportunities to improve the experiences of health service utilization for trans women living with HIV. It is important to note that while recruitment efforts were made, no trans women from African, Caribbean, and Black (ACB) communities participated in our study. Although we do not have Canadian data about ACB trans women specifically, ACB communities have been disproportionately affected by HIV (Public Health Agency of Canada, 2015). It is imperative that future research with trans women living with HIV include these groups. In addition, while recruitment was not specific to trans women, no trans masculine persons living with HIV participated in our study. Most research looking at HIV in trans communities has focused on trans women or broader transfeminine spectrum persons; however, trans men should not be excluded from HIV prevention and care considerations.

Conclusions

A key strength of our research lies in the integration of service provider perspectives with those of trans women living with HIV. Most often, qualitative accounts have been limited to one group or the other, and it is less common to see an integrated account, where providers and navigators of systems are given an opportunity to comment on the complex factors that make access challenging at diverse levels. As Snelgrove and colleagues (2012) highlighted, it is important and necessary to include service provider perspectives on this topic, so that access barriers can be addressed from the vantage point of both providers and service users. It is clear that trans individuals have unique concerns that need to be considered in the development and delivery of HIV prevention and care. Attending to the layered interactions between trans women and service providers, and across the health care system, provides opportunities to improve health care utilization.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

Key Considerations

- Combatting hostility, insensitivity, and discrimination in health care and social service settings is crucial to the well-being of trans women living with HIV. Clinical nurse leaders can be advocates in this regard.
- Transition-related care, including hormone therapy, requires better integration with HIV care.
- Care coordination for trans women living with HIV should include access to social support resources, mental health services, and timely referrals for comorbidities.
- It is essential that social and health care workers receive training and resources to increase service access for trans women living with HIV. More well-informed service providers could take better advantage of resources related to hormone therapy and can work to challenge dangerous misinformation about gender-affirming health care and HIV care.

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