A qualitative exploration of barriers to HIV prevention, treatment and support: Perspectives of transgender women and service providers

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Abstract
Transgender (trans) women experience barriers to access to HIV care, which result in their lower engagement in HIV prevention, treatment and support relative to cisgender people living with HIV. Studies of trans women’s barriers to HIV care have predominantly focused on perspectives of trans women, while barriers are most often described at provider, organisation and/or systems levels. Comparing perspectives of trans women and service providers may promote a shared vision for achieving health equity. Thus, this qualitative study utilised focus groups and semi-structured interviews conducted 2018–2019 to understand barriers and facilitators to HIV care from the perspectives of trans women (n = 26) and service providers (n = 10). Barriers endorsed by both groups included: (a) anticipated and enacted stigma and discrimination in the provision of direct care, (b) lack of provider knowledge of HIV care needs for trans women, (c) absence of trans-specific services/organisations and (d) cisnormativity in sexual healthcare. Facilitators included: (a) provision of trans-positive trauma-informed care, (b) autonomy and choice for trans women in selecting sexual health services and (c) models for trans-affirming systems change. Each theme had significant overlap, yet nuanced perspective, between trans women and service providers. Specific recommendations to improve HIV care access for trans women...
1 | INTRODUCTION

Transgender (trans) women, a diverse group of people assigned male at-birth who typically identify as women, trans women and/or transfeminine, experience a high prevalence of HIV and inequitable access to HIV prevention, treatment and support due to social and structural drivers (Baral et al., 2013; Becasen et al., 2019; Lacombe-Duncan, 2016; Lacombe-Duncan et al., 2019; Logie et al., 2011). Specifically, trans women are less likely to be tested for HIV than cisgender (cis, meaning non-trans) men (Pitasi et al., 2017), and trans women living with HIV are less likely to be retained in care (Yehia et al., 2013), take antiretroviral therapy (ART; Kalichman et al., 2017), adhere to ART (Baguso et al., 2016) and be virally suppressed (Mizuno et al., 2015; Wiewel et al., 2016) compared to cis people living with HIV. Access to HIV prevention, treatment and support are necessary to promote individual health and well-being and to prevent community transmission (Cohen et al., 2016; Rodger et al., 2016). As such, understanding the barriers and facilitators to accessing HIV prevention, treatment and support among trans women is critical for both health equity and public health initiatives.

Studies conducted to date have shown that trans women experience multiple barriers and facilitators to accessing HIV prevention, treatment and support (collectively referred to as ‘HIV care’). A major barrier to access to all types of HIV care is anti-trans stigma and discrimination in healthcare settings (Dowshen et al., 2017). Many healthcare providers hold stigmatising views and lack the knowledge, skills and training necessary to support trans women (Dowshen et al., 2017).

Accessing HIV pre-exposure prophylaxis (PrEP) can also present unique barriers for trans women. PrEP is an HIV prevention technology that involves the use of combination ART in the form of a once-daily pill to substantially reduce HIV risk (Fonner et al., 2016). Despite its high efficacy, many barriers to PrEP implementation have been reported (Pinto et al., 2018). Many trans women report being concerned that PrEP may negatively interact with feminising hormone therapy (Perez-Brumer et al., 2018), or find taking both PrEP along with hormone medications burdensome (Deutsch, 2018; Rael et al., 2018). Moreover, one small study found that feminising hormone therapy may decrease the efficacy of PrEP, suggesting more trans women-specific safety and efficacy research is warranted (Hiransuthikul et al., 2019). Adherence to taking a daily medication may be especially challenging for trans women, who as a group experience higher than average rates of housing instability and frequent gaps or changes in insurance coverage (Deutsch, 2018). Shame related to being perceived as “high risk” for HIV infection, or as connected to HIV in some way due to being trans, can also present a barrier to accessing and using PrEP (Deutsch, 2018). Finally, PrEP information and research often primarily respond to the issues and needs of men who have sex with men (MSM) – and either overlooks trans women or treats them as similar to MSM – when in fact the concerns of trans women are distinct from those of sexual minority men (Sevelius, Deutsch, et al., 2016; Sevelius, Keatley, et al., 2016).

Barriers to HIV testing also exist for trans women. The fear of experiencing stigma in the case of a positive test result may encourage some individuals to avoid testing, as may laws that criminalise HIV non-disclosure (Harper et al., 2019). Alternately, a major facilitator to HIV care is access to gender-affirming healthcare (Reback et al., 2015; Sevelius, Keatley, et al., 2016), including non-judgmental and trans-positive clinic environments (Deutsch, 2018; Klein & Golub, 2019). This includes not conflating trans women with MSM in research or health promotion activities (Klein & Golub, 2019; Sevelius, Keatley, et al., 2016), and hiring trans women as part of medical teams and/or as peer educators and researchers (Dowshen et al., 2017; Reback et al., 2015).

What is known about this topic?
• Transgender (trans) women experience pervasive barriers to accessing HIV prevention, treatment and support.
• Most studies have explored perspectives of trans women; fewer have included both trans women and service providers’ perspectives, despite that barriers usually lie at provider, organisation or systems levels.

What this paper adds?
• Both service providers and trans women endorse systemic changes to increase access to HIV care for trans women.
• Systemic changes that may increase access to HIV care for trans women include the development of trans-specific services/organisations, led by trans women, delivered from a trans-positive and trauma-informed lens.
Many barriers to healthcare are experienced at the intersection of multiple systems of oppression (Lacombe-Duncan, 2016; Logie et al., 2011). Intersectionality is a critical social theory emerging from Black feminism that can be used to understand how systems of privilege and oppression such as cisnormativity, heternormativity, heterosexism, sexism, racism and classism that are operating at the macro level of society impart multi-level impacts on trans women's access to HIV prevention and testing (Bowleg, 2008, 2012; Crenshaw, 1989; Hill Collins, 2000; McCall, 2005). To date, scant studies have applied an intersectional approach to understand trans women's access to HIV prevention and testing. Additionally, literature about trans women's access to HIV prevention and testing is limited in that it predominantly focuses on perspectives of trans women themselves, while barriers and facilitators reported are often at the provider- (e.g. stigmatising patient–provider interactions) and systems-level (e.g. lack of access to integrated HIV and gender-affirming healthcare; Reback et al., 2015). As providers may work directly with trans women to reduce barriers to care, their perspectives on barriers and facilitators to HIV care for trans women are vitally important. Moreover, comparing the perspectives of trans women and providers through a qualitative study with both groups may enhance understanding of alignment between trans women and providers' perspectives. Thus, the study aim was to explore barriers and facilitators to accessing HIV prevention, treatment and support for trans women, from the perspective of both trans women and service providers.

2 | METHODS

2.1 | Study design

This study utilised a community-based research (CBR) design, involving a process of reciprocity, capacity building and knowledge development with, by and for trans women (Canadian Institutes of Health Research, 2016). This study was designed and delivered in collaboration with, by and for trans women (Canadian Institutes of Health Research, 2016). The study was designed and delivered by trans women and worked to build capacity for trans women researchers to directly impact social conditions affecting trans women communities (Lacombe-Duncan et al., 2020).

2.2 | Participant recruitment

The focus group participants included: (a) trans women, including women of transfeminine experience; (b) living in Toronto, Vancouver or Montreal and surrounding areas; (c) with verbal and written fluency in English or French and (d) over 18 years of age. Focus group participants were purposively recruited through the personal and professional networks of the study team with the use of a study flyer distributed via the study team's email listservs and social media accounts (e.g. Facebook). Service provider participants included those who: (a) provided medical (e.g. physicians) or social services (e.g. social workers) to at least one or more trans persons in the past 2 years; (b) lived in Toronto, Vancouver or Montreal and surrounding areas and (c) with verbal and written fluency in English. Potential service providers known to provide care to trans women were recommended by the study team to the first author, and then recruited by email by the first author until 10 interviews were completed.

2.3 | Data collection

Focus groups lasting 60–90 min were conducted at local transgender-friendly community-based organisations with trans women in Toronto, Montreal and Vancouver, by the fifth, sixth and seventh authors, respectively, September–December 2018, facilitated by use of a semi-structured focus group discussion guide, co-facilitated by a research assistant who also identified as a trans woman. Topic areas explored included trans women's experiences accessing HIV healthcare and desired healthcare provider and organisational/provider characteristics. Prior to completing the focus group, participants completed a sociodemographic questionnaire and were asked about their HIV status, and healthcare experiences, access and uptake.

The first author conducted semi-structured individual interviews with service providers lasting 30–70 min over the phone January–April 2019, facilitated by an interview guide. Topic areas explored included barriers to and facilitators of delivering HIV prevention and other services to trans women and gaps in programs/services to meet the needs of trans women. The alignment of focus group questions and interview questions was purposely designed to facilitate a comparative analysis between the results.

Trans women received a $50 honorarium for participation in the focus group. Service providers did not receive compensation as they voluntarily participated during their paid work hours. Written informed consent was obtained from all participants. All study procedures were reviewed and approved by the University of Toronto Research Ethics Board.

2.4 | Data analysis

All focus groups and interviews were digitally recorded and transcribed verbatim. The data were interpreted by the team of cis and trans authors, including transfeminine and transmasculine team members. We applied a thematic approach to data analysis (Attride-Stirling, 2001; Braun & Clark, 2006), using both inductive and deductive coding. Specifically, two team members (the first and fourth authors) independently open-coded two focus group and two interview transcripts and met together four times to generate a code list, a process of inductive coding. These open codes were used to create a coding framework, in which the open codes were sorted into 11 overarching categories (e.g. HIV testing). These categories were driven by the data and also informed by the focus group and interview guides. Then, the fourth author coded
the remaining two focus group and eight interview transcripts, a process of deductive coding, facilitated by the use of NVivo12 software, meeting with the first author every 2 weeks to discuss the coding process. The first author then reviewed the NVivo12 file, creating a draft of overarching categories and supporting quotes, which was passed onto the second author. The second author independently reviewed the overarching categories and quotes, abstracting the analysis into six higher-level themes and writing a first draft of the results. These results were then shared with the broader research team, including those who conducted the focus groups (fifth, sixth and seventh authors), to further corroborate interpretation of the findings. This systematic process and engagement of multiple members of the research team reviewing transcripts and analyses enhanced the reliability of the findings and was consistent with a CBR approach to qualitative research.

3 | FINDINGS

3.1 | Participant characteristics

Trans women participants (n = 26) represented a diverse range of sexual orientations and racial/ethnic backgrounds (Table 1). The mean age of participants was 40.7 years (SD: 12.5). Most participants (n = 23, 88.5%) reported having had an HIV test at some point in their lives, of which 4 (17.4%) reported living with HIV. One fifth (n = 5, 19.2%) of participants reported that they had avoided healthcare in the previous 12 months. Service provider participants (n = 10) were in a range of roles, including direct service (e.g. case managers) and leadership (e.g. executive directors). They had been at their current organisations for 2–15 years.

3.2 | Barriers and facilitators to HIV prevention, treatment and support for trans women

Themes highlighting barriers included: (a) anticipated and enacted stigma and discrimination in the provision of direct care, (b) lack of provider knowledge of HIV prevention and care needs for trans women, (c) absence of trans-specific services and organisations and (d) cisnormativity in sexual healthcare (Table 2). Themes highlighting facilitators comprised the following: (a) the provision of trans-positive trauma-informed care, (b) autonomy and choice for trans women in selecting sexual health services appropriate to their needs and (c) models for trans-affirming systems change.

3.2.1 | Anticipated and enacted stigma and discrimination in the provision of direct care

Several trans women indicated having developed expectations of encountering stigmatising sexual health service providers, specifically in the areas of HIV prevention and care, based on their past interactions with general healthcare providers.

...Accessing testing has been more or less positive, I think sometimes I avoid it because I expect to be mistreated because so much of health care has treated me like shit. (Trans woman, Vancouver)

And you know the whole life story thing. I often get asked like ‘what are you doing that like you need an HIV test?’ And I don’t necessarily want to go into that for a variety of reasons. (Trans woman, Vancouver)

This second quote highlights invasive questions that many of the trans women in our sample reported typically being asked in sexual health settings, and thus reflected intersecting forms of HIV stigma and transphobia in HIV prevention and care. Service providers also noted this occurrence, and offered better approaches:

If you just ask, ‘how many sexual partners have you had?’, then that’s not cool. But if you’re like I need to know that like have you had more than 5 or I need to know if you do this sexual practice because it will influence the testing we will do for you today. (Service Provider P5, Montreal)

Some participants who were marginalised on intersecting grounds felt a heightened susceptibility to negative encounters in sexual health settings. For example, one participant who also identified as being Two-Spirit (a term used by some Indigenous gender minorities in the North American context) and a sex worker reported this:

Back a long time ago, for most of us sex workers it was scary.... But now going to the doctors and stuff, it’s a little bit easier but being a Two-Spirit person, it’s never easy. There’s nothing about it that’s easy. (Trans woman, Vancouver)

Another trans woman described the unique expressions of stigma and discrimination that migrant trans sex workers often experience in the context of HIV prevention, highlighting distinctive intersections of racism, xenophobia, HIV stigma and transmisogyny:

One thing that I think is missing from that conversation is specifically for migrant sex workers because although they can’t be convicted of doing sex work in Canada it can be used as evidence for deportation.... So, for like migrant sex workers and migrant trans sex workers, carrying condoms can be used as evidence of sex work in deportation cases. (Trans woman, Vancouver)
A number of service providers in our sample corroborated the accounts of trans participants, additionally discussing the frequency with which these women actually encountered such hostility:

> We've had experiences of women who've had absolutely horrible experiences when just seeking to get basic care so we know that we have a lot of women in terms of just getting regular testing they don't really do that they'll do it if they have symptoms if they really feel like they have no choice but they won't otherwise go and seek care just even basic testing. (Service Provider P5, Toronto)

Moreover, service providers were acutely aware of intersectional considerations with respect to discrimination faced by trans women:

> So, when a trans woman is a sex worker accessing care there's often profiling that happens where people assume she's a sex worker and that will create problems for trans women to do sex work but also for trans women who don't. (Service Provider P5, Montreal)

### 3.2.2 | Lack of provider knowledge and experience

Numerous participants discussed encountering sexual healthcare providers who appeared to lack knowledge of trans women's issues, HIV or both. Many additionally attributed much to the stigmatising attitudes of these providers, described earlier, to their low level of

**TABLE 1** Focus group participant characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%) or M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) (n = 24)</td>
<td>40.7 (12.5)</td>
</tr>
<tr>
<td>City</td>
<td></td>
</tr>
<tr>
<td>Toronto</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>Vancouver</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>Montreal</td>
<td>4 (15.4)</td>
</tr>
<tr>
<td>Sexual orientation (n = 25)</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>6 (24.0)</td>
</tr>
<tr>
<td>Two-spirit</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>Gay</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Queer</td>
<td>3 (12.0)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>4 (16.0)</td>
</tr>
<tr>
<td>Pansexual</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>Other sexual orientation</td>
<td>3 (12.0)</td>
</tr>
<tr>
<td>Multiple sexual orientations</td>
<td>4 (16.0)</td>
</tr>
<tr>
<td>Racial or ethnic background</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>7 (26.9)</td>
</tr>
<tr>
<td>African, Caribbean, Black</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Latin</td>
<td>4 (15.4)</td>
</tr>
<tr>
<td>Asian</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Middle Eastern and Northern African</td>
<td>1 (3.8)</td>
</tr>
<tr>
<td>Indigenous</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Other racial or ethnic background</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Multiple racial or ethnic backgrounds</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>Attended some or completed college</td>
<td>7 (26.9)</td>
</tr>
<tr>
<td>Attended some or completed university</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>Completed graduate school</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Immigration status in Canada</td>
<td></td>
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<tr>
<td>Citizen or permanent resident</td>
<td>22 (84.6)</td>
</tr>
<tr>
<td>Refugee</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Employment status</td>
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</tr>
<tr>
<td>Employed full-time</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>9 (24.6)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (3.8)</td>
</tr>
<tr>
<td>On income assistance or disability benefits</td>
<td>9 (24.6)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3 (11.5)</td>
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<tr>
<td>Self-employed</td>
<td>1 (3.8)</td>
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<tr>
<td>Multiple sources of income</td>
<td>1 (3.8)</td>
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<tr>
<td>Have stable housing (n = 25)</td>
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<tr>
<td>Yes</td>
<td>17 (68.0)</td>
</tr>
<tr>
<td>No</td>
<td>8 (32.0)</td>
</tr>
<tr>
<td>Avoided healthcare in past 12 months</td>
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</table>

*5 = 26 unless otherwise specified.

*Percentages represented in the table are calculated based on reported values.
### TABLE 2  Themes and exemplary quotes, organised by sample

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Trans women (n = 26)</th>
<th>Service providers (n = 10)</th>
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<tbody>
<tr>
<td><strong>Anticipated and enacted stigma in the provision of direct care</strong></td>
<td><em>Still – when I’m going to the service provider and I’m like applying – when I’m testing my HIV status, I still feel a little bit nervous and you know I have a fear of being, you know, treated HIV phobic or something like, how can I say that? Like it’s like people will treat me different because I’m, if I’m affected by HIV.</em> (Trans woman, Toronto)</td>
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<td><em>And on the subject of sex work I learned very quickly that even with health care providers that I liked, you know, you do not tell them that you’re a sex worker. Which I think makes it quite complicated when it comes to sexual health.</em> (Trans woman, Toronto)</td>
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<td></td>
<td><em>I mean my experiences with health care have been kind of universally oppressive. So When I access testing services which are usually run by organizations that are a little bit more, you know, trans competent I still sort of have this experience of it’s health care it’s going to be awful and I’ll put it off.</em> (Trans woman, Vancouver)</td>
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<td></td>
<td><em>I have a horror movie experience going to an AIDS service organization.</em> (Trans woman, Toronto)</td>
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<tr>
<td><strong>Lack of provider knowledge and experience</strong></td>
<td><em>They should learn more about, you know, how to- if they have a trans client, they shouldn’t wait for the trans client to ask them for hormone, they shouldn’t wait for the trans client to ask them about PrEP, even though the trans client is not positive [and] are not taking a hormone right now.</em> (Trans woman, Toronto)</td>
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<td></td>
<td><em>Also healthcare providers also need to know about these people, trans women who are affected with HIV... sometimes they feel like they can’t access that kind of science it’s their lack of information.</em> (Trans woman, Toronto)</td>
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<td><em>...Even accessing like testing, I’ve always kind of felt like I needed to know what the, you know, what the ins and outs of my health care was going to be because I knew the chances are the person that the health care provider that I was dealing with wasn’t going to and have very rarely been proven wrong by that.</em> (Trans woman, Vancouver)</td>
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<td></td>
<td><em>The other thing is I’m just exhausted by having to educate my health care providers, like part of avoiding health care is really just – I’m exhausted by having to teach them how to treat me like a patient. So sometimes I avoid it because I just know that the questions might get asked nicely but I’m still like I’m going there because they’re the expert...Like put some of that book learning to use and take a fucking trans 101 course, you know?</em> (Trans woman, Vancouver)</td>
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<tr>
<td><strong>Absence of trans-specific services and organisations</strong></td>
<td><em>I want to go into an organization and see trans-specific programs because we are not at a point in time right now that, you know, having you know women brackets, trans women welcome, you know – if a fucking bracket is the only thing that’s protecting me from your other clients that I am not safe there... I want organizations to let me know that I’m a priority by seeing the fact that my needs are different, not because of my health care, but because of oppression.</em> (Trans woman, Vancouver)</td>
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<td></td>
<td><em>I have gone to a mixed HIV support group. There are no groups for trans women with HIV.</em> (Trans woman, Montreal)</td>
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<td></td>
<td>*“Definitely [stigma] can make folks feel less safe overall less likely to seek health care that they really do need. Yeah it can really worsen their physical and mental health outcomes.” (Service Provider P10, Toronto)</td>
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<td></td>
<td>*“As soon as a doctor finds out that you’re a sex worker they immediately want to run a full panel of blood testing. No actually, I was just tested last week....” (Service Provider P2, Vancouver)</td>
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<td></td>
<td>*“The same thing for HIV treatment and other services that there’s very few doctors that we can refer to that we feel are able to give adaptive services to trans women that obviously the entire field of reproduction in general is extremely problematic and not adapted to the needs of trans women.” (Service Provider P5, Montreal)</td>
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<td>*“But if someone would approach me as a new person [about hormone therapy] I think I would I would refer them. Like starting it [hormone therapy] that thing I would not have the whole perspective to discuss all the options and what to expect and everything. I never started it for someone.” (Service Provider P8, Montreal)</td>
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<td></td>
<td>*“Yeah I guess just in general I think it’s it’s is hard for patients to kind of find practitioners who are familiar with either hormone therapy in terms of HIV care I guess sort of specialized as well.” (Service Provider P6, Toronto)</td>
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<td><em>And they [my trans patient] were like Well your learning shouldn’t be at my expense. And that definitely really kind of shook my whole world because it made me realize that yeah you’re right.</em> (Service Provider P9, Toronto)</td>
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<td></td>
<td>*“I think that one area I would love to see a little more of is some of the specifics around STI screening and HIV screening like thinking about do we need trans only hours or not or how do we refer people.” (Service Provider P10, Toronto)</td>
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<td></td>
<td>*“...Whenever there’s anything new in HIV that it started with MSM, so men who have sex with men then a professional doctors or even some organization will try to sort of like include trans women in the MSM category. And that’s always super problematic and only once there’s enough trans women using a certain service that then it becomes trans-specific.” (Service Provider P5, Montreal)</td>
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### Table 2 (Continued)

<table>
<thead>
<tr>
<th>Cisnormativity in sexual health</th>
<th>Facilitators</th>
<th>Service providers</th>
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<tbody>
<tr>
<td>“The nurse that time was a woman and she said that the test is confidential, then she asked me for my medical card... Then she put my legal name. So when I went to pick up the results the week after, they asked me for my name. And they couldn't find it. So they were confused.” (Trans woman, Montreal)</td>
<td>“…How do we help providers to integrate this into their practice to not make it not a special snowflake. It’s not special like how do we just make it be like yep this is normal. This is what you do. This is part of the care you provide.” (Service Provider P10, Toronto)</td>
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<tr>
<td>“Cis supremacist HIV thorns are everywhere... Majority of the people who are employed are cis gay men.” (Trans woman, Vancouver)</td>
<td>“I personally really like the [organization] model, which is run by just knowledge, it's lived experience too.” (Trans woman, Vancouver)</td>
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</tr>
<tr>
<td>Autonomy and choice for trans women in selecting sexual health services appropriate to their needs</td>
<td>“Now I do the tests with my family doctor. She is trans-friendly. She does the tests for my levels of endocrinology. Those tests too. She gets me the hormones, the gels and everything. She always gives me the test and all that I need. I just need to tell her and she's happy to help. She's a good doctor for trans women.” (Trans woman, Montreal)</td>
<td>“The way I try to approach all my patients, is that a recognizing like the part that the power and privilege are always given to the health care provider and how that's dis-empowering for the patient and how I have to be the active participant in deconstructing that and I can't just say I can't just think it I have to ask it and I think as providers who are providing care to folks, we have to acknowledge that trauma is an integral part of what makes a person story.” (Service Provider P9, Toronto)</td>
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<td>“For me, it's very important to feel welcomed, respected and not judged.” (Trans woman, Montreal)</td>
<td>“I would say they [HIV tests] are available and that I can access them pretty much everywhere: my local community service centre, the hospital, my family doctor.” (Trans woman, Montreal)</td>
<td>“And we had a nurse that comes in and does testing about quarterly I would say that happens...they've been briefed on how to provide sort of destigmatized testing practitioners.” (Service Provider P2, Vancouver)</td>
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<td>“And so this idea of prevention also needs to kind of come into that conversation and so it's not just like ‘Here take PrEP, here have a condom, here whatever’, it's like you're actually a human being and let's have a conversation about how like sexuality and all of these different things fit into the entirety of your life.” (Trans woman, Toronto)</td>
<td>“So accessing the experience with HIV is more accessible now that you can do a rapid test in 5 min than me waiting for the results for 2 weeks so that you can be scared and keep wondering and being traumatized. You can get access very fast.” (Trans woman, Toronto)</td>
<td>“We’re doing STI screening we’re starting to do just preliminary strategies that patients can do their own slabs. So that’s been awesome. I think that [self-testing is] a very positive move in the direction particularly for trans and non binary folks who may not be connected to the parts of their body that they currently have.” (Service Provider P10, Toronto)</td>
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<td>“There are several avenues that I could access to access sexual health and HIV information if I wanted to – with my, my GP, my general practitioner, my doctor that I see... they have pamphlets and information here and also that they have information like that down [community health center].” (Trans woman, Toronto)</td>
<td>“I think it’s like you say I think most of my patients have like poverty and difficulty, isolation, past trauma. Like a lot of my patients have that but they feel it just adds up...the trans aspect kind of adds onto all the potential stigmatizing situation that drug addiction, the sex work, the HIV infection, poverty.” (Service Provider P8, Montreal)</td>
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<td>Models for trans-affirming systems change</td>
<td>“I personally really like the [organization] model, which is run by and for people with HIV, because when you ask questions about the transition for example, you're talking to someone who has experienced the transition, you know that the information is not just knowledge, it’s lived experience too.” (Trans woman, Montreal)</td>
<td>“Well I have two physicians at my clinic who have done training in trans care and they have a lot of experience working with trans folks and so they do they’re very experienced with hormone therapy but they’re kind of usually a first go to for me...” (Service Provider P9, Toronto)</td>
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<td>“…And just say I can’t just think it I have to ask it and I think as providers who are providing care to folks, we have to acknowledge that trauma is an integral part of what makes a person story.” (Service Provider P9, Toronto)</td>
<td>“We have an HIV social worker that we work with closely is dedicated to working with LGBTQ and HIV positive folk in the practice. So that’s been particularly great working with her.” (Service Provider P10, Toronto)</td>
<td>“We refer people to [organization] which is a low barrier free clinic that is run by a lot of queer and trans folks and it's specifically for trans non-binary two spirit folks. They provide healthcare there's a doctor....” (Service Provider P2, Vancouver)</td>
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familiarity on the issues of trans women affected by and living with HIV. As one participant described:

Because most of the time the nurses, they don't have any experience. They can see you like weird, they laugh. And you feel kind of like you don't want to go back. (Trans woman, Montreal)

Other trans women commented on how limited provider knowledge impacts the quality of care received by trans women affected by HIV:

Yeah the PrEP knowledge is very important because trans people are taking the hormones as well. So they need to know them both, knowledge, regarding like hormones as well as the PrEP. (Trans woman, Toronto)

Alternately, service providers talked about the challenges of providing comprehensive and affirming sexual healthcare themselves and finding other service providers:

The majority would prefer to have it combined into one so having a provider that is competent and both HIV care and trans affirming care. It is a challenge finding someone who's comfortable in both of those roles at the same time. (Service Provider P10, Toronto)

### 3.2.3 Absence of trans-specific services and organisations

A number of trans women and service providers in our sample discussed the lack of organisations specifically mandated to address the sexual health issues of trans women, along with the scarcity of services designed specifically to meet the needs of this population. One service provider was quoted explicitly acknowledging this gap in care systems addressing sexual health: “[There are no organisations] that I know of that focus on HIV and STI specifically for trans folks. I do not believe so” (Service Provider P9, Toronto).

Some trans participants discussed how gay men’s health organisations occasionally assumed the role of providing HIV prevention...
and care services for trans women affected by HIV. Although, on the surface, this arrangement appeared to address the shortage of sexual health resources designed to meet the needs of this population, both trans women and service providers in our sample highlighted the frequent failure of these organisations to deliver programs and services that adequately account for the distinct sexual health concerns of trans women. Illustrating, one participant explained:

I think the gay men’s health organizations believe that they are, you know, that they are trans competent you know and believe that they are doing a good job for trans folks and that they understand the struggles whereas mainstream health organizations are a little bit more willing to acknowledge that they don’t have a fucking clue about you know how to deal with us. (Trans woman, Montreal)

3.2.4 | Cisnormativity in sexual health

Several participants described mainstream sexual health organisations as being shaped by structural conditions that create prominent barriers to the provision of trans-affirming HIV prevention and care services, consistent with cisnormativity, the normative privileging of cisgender (non-trans) bodies and identities (Pyne, 2011). Some trans women, for example, explained that providers would commonly fail to recognise them as women in intake forms and medical records, unless they had changed their legal documentation to reflect their transitioned identities, which in turn would compromise their ability to comfortably access available services. Illustrating this, one participant noted:

So now we see the impact that it has once the moment someone has proper IDs (identification). That accessing care becomes a lot easier just booking an appointment and speaking to the receptionist and forcing also health care providers to take the person’s identity seriously. (Trans woman, Montreal)

One provider described the bureaucratic and technical issues that often prevented frontline staff from providing correctly capturing trans women's identities:

Oh let’s say if their gender marker or their name on their health card doesn't match that their authentic name and gender marker...there have been issues. IT (information technology) issues that I have to deal with... (Service Provider P10, Toronto)

Cisnormativity also manifested in a lack of research specific to the sexual health needs of trans women (e.g. “There’s no study on the efficacy of PrEP on post-op trans bodies...” [Trans woman, Vancouver]), and through a lack of representation of trans people in leadership roles in healthcare organisations:

And, you know, the answer that I always got from health care providers when I tell them like why don’t trans people feel safe here because you’ve got an entire fucking clinical team of cis people on a trans health care program. You don’t actually have any trans people working here. (Trans woman, Vancouver)

3.2.5 | The provision of trans-positive trauma-informed care

The most prominent facilitator included the provision of trans-affirmative trauma-informed care. Often, this meant not only genuinely recognising and interacting with trans women as women but also accounting for the distinctive forms of violence, stigma and discrimination affecting trans women in the provision of direct care. For example, one trans woman attributed a positive relationship with her doctor to the physician's sincere affirmation of her gender:

I also found a more effective doctor...I am better received... Here, he talks to me as a woman. They are more understanding toward me. (Trans woman, Montreal)

Moreover, trans women described how affirming providers increased their comfort and ability to access HIV testing, as well as to discuss sexual risk practices that may otherwise be uncomfortable to discuss due to stigma/judgment:

I’d ask my doctor because I have, she makes you feel, she’s a friend, she hears you, everything that you need she’s always happy to help...I speak to my friends as well. We talk and share, talk about guys who are trying to make you do it without protection, and things like that. (Trans woman, Montreal)

A service provider emphasised the importance of contextualising the issues of this population by understanding them as potential products of exposure to gender-based trauma:

So yeah we talked also about trauma and making sure that anyone who interacts with trans women have a level of awareness that the level of violence experience[d] is something that a lot of people can and can’t even really conceive of or comprehend. And so that comes also with having a tolerance for people being aggressive for people being high when they come to the appointment. Those are things
that you do when you’re [sic] experience trauma and when the experience itself is traumatic. And that means also not being defensive. (Service Provider P5, Montreal)

3.2.6 | Autonomy and choice for trans women in selecting sexual health services appropriate to their needs

Several of the participants discussed the importance of measures that could maximise their autonomy and choice, and the significance of measures that would specifically enhance the ability of trans women to access a range of HIV prevention methods without having to go through specialty clinics known to broker these resources. One woman, for example, reflected:

And you can get tested anywhere, any doctor can do it now. Any walk-in clinic and test for HIV anywhere. So you don't need to go to some specific clinic to get it done. (Trans woman, Toronto)

Although participants, in general, did indicate a need for services mandated to specifically address trans-specific sexual health issues, the provision of universally accessible HIV prevention options, across mainstream health organisations, was deemed necessary to facilitate care for trans women interacting with mainstream health systems.

One service provider, highlighting the importance of enhancing choice for trans women in the context of HIV prevention and care, discussed the relevance of promoting practices that could safeguard their privacy and bodily autonomy:

The person will then go in the bathroom on her own and do the urine sample and swab and all of that. So, they never have to actually get naked in front of the nurse. So that makes a big difference in terms of getting people to be comfortable getting tested. (Service Provider P5, Montreal)

3.2.7 | Models for trans-affirming systems change

Service providers, in particular, discussed the central role of systemic changes that could improve the provision of HIV prevention and care for trans women, and also highlighted examples of catalysts of transformation in their respective settings. For example, one participant described making lists of trans-competent service providers from whom they could receive mentorship to address gaps in their own insight:

So again there are systemic challenges... there are like cool people to do these tests but also core specialists that are trans competent that I continue to [talk to] so

definitely we have of lists of those people and then on that mentorship call we talk about that... (Service Provider P10, Toronto)

Another service provider described the power of institutional trans competency training requirements for staff in making sexual health organisations gradually appear more viable to trans women:

I know that some trans women who have access to our space before generally will say that I've come here specifically because they've heard from other trans women...that we are we are strongly encouraged to participate in at least some kind of yearly training.... (Service Provider P7, Vancouver)

While trans women similarly discussed a need for trans-affirming care training, some participants also described the importance of trans-led services and peer support:

Yeah I think it's [peer support is] super important. Like. First-hand experience and just being able to hear from people who lived that providing more information. (Trans woman, Toronto)

However, peer models of care provision were rendered less useful as they relegated trans women to low pay and low positions of power:

I think peer support is important but I think we need to acknowledge the fact that in most organizations, especially health care organizations, peer physicians are like the lowest level of authority, the lowest level of you know pay, the lowest level of actual agency in the organization. (Trans woman, Vancouver)

4 | DISCUSSION

This study described barriers and facilitators to HIV care from the perspectives of both trans women and service providers. We identified barriers at individual/interpersonal (e.g. anticipated and enacted stigma and discrimination), provider/structural (e.g. lack of provider knowledge of HIV prevention and care needs for trans women) and organisational/structural levels (e.g. absence of trans-specific services and organisations and cisnormativity in sexual health care). Notably, we also identified facilitators to access that can mitigate the negative impacts of these ongoing systemic barriers. We discuss several recommendations for HIV and sexual health service providers and program developers, aligned with key themes (Table 3), consistent with a CBR approach of balancing both research and action (Israel et al., 1998; Travers et al., 2013).

We corroborate findings from numerous other studies that stigma and discrimination impede access to HIV care for trans women (Dowshen et al., 2017; Perez-Brumer et al., 2018).
Perhaps most importantly, we explicate how stigma and discrimination impede access for those experiencing intersecting forms of marginalisation, consistent with intersectional perspectives (Lacombe-Duncan, 2016; Logie et al., 2011; Turan et al., 2019) and, in so doing, offer insights that could be used to inform population-specific interventions. There are changes individual providers can make, such as utilising trans-affirming HIV screening strategies that have been created by leading trans health organisations (e.g. Fenway Health; Cavanaugh, n.d.). However, broader change is necessary to uproot the deeply embedded stigmatisation of trans women. At an organisational level, anti-discrimination policy that takes into consideration intersecting experiences may be useful to set a tone for the provision of affirming care (Ontario Human Rights Commission, 2001). Provider-level training to reduce biases, which specifically takes into account intersectionality, may be one example of a useful organisational strategy for reducing negative attitudes towards trans clients (Lelutiu-Weinberger et al., 2016).

Upstream interventions may include embedding additional training in medical school and residency programs (Coutin et al., 2018; Dubin et al., 2018).

Moreover, training for providers may take into consideration the substantial body of literature focused on provider–patient communication (e.g. Bientzle et al., 2016; Foronda et al., 2016). For example, studies have recognised disciplinary differences in how physicians and nurses are trained to communicate, the findings of which suggest that working in interdisciplinary teams whereby healthcare providers more trained on empathic responses (e.g. nurses, social workers) may prove most supportive to trans women accessing sexual healthcare (Foronda et al., 2016). Other literature has examined the effectiveness of patient-centred versus doctor-centred care, finding that patient-centred care (e.g. listening to patients’ perspectives and concerns, encouraging patient decision-making) can result in the provider being perceived as more empathic and competent (Bientzle et al., 2016).

At a policy level, funding is needed to newly develop trans-specific and trans-led services and organisations. For those trans-specific services already in existence, especially those being run from predominantly MSM-serving organisations and HIV service organisations (which have historically been predominantly cisgender MSM focused), trans leadership is critical. Another manifestation of cisnormativity evident in our findings was how organisational processes did not adequately attend to diverse legal identity situations, which constrained their ability to be affirming. Beyond identification, our findings also explored how cisnormativity was embedded within sexual health research (e.g. exclusion of trans women from PrEP research). Trans women should be included in all HIV research if they are to be confident that prevention and treatment approaches take them into consideration.

As service providers often need to recognise trans women as a population of marginalised women in order to sensitively account for the gender-based trauma, trans-positive and trauma-informed care may be considered necessary key features of affirming HIV prevention and care for trans women. The principles of trauma-informed care (e.g. maximise a woman’s choices and control over her recovery; create a positive relational collaboration and an environment of safety, respect and acceptance; Elliott et al., 2005) intersect with other barriers (e.g. anticipated and enacted stigma in the provision of direct care) and facilitators (e.g. autonomy and choice for trans women in selecting sexual health services appropriate to their needs) identified in this study.

Trauma-informed care should also be culturally appropriate and intersectional, meaning that interpersonal work with trans women should include examining how their multiple social locations shape both their experience of traumatic life events and their resilience to the trauma (Singh & McKleroy, 2011). Training is needed for service providers working with trans women in trauma-informed care, including how to understand trauma, how trauma may be embodied and externalised in the context of clinical interactions and how to optimise trans women’s well-being in healthcare settings, which are in and of themselves traumatising spaces for trans women.

In light of the many trans women in our sample who reported expecting and sometimes experiencing violence, stigma and discrimination in healthcare settings, innovative strategies warrant attention for highlighting examples of practices that could serve to mitigate some of the concerns of trans women seeking HIV prevention and care services. Specifically, trans women should be able to access HIV testing from multiple places and by multiple people who work from a trans-positive trauma-informed lens and/or self-testing (Lippman et al., 2016).

Finally, connecting staff in need of additional learning to those within their organisations who work from a trans-positive trauma-informed approach, and/or to staff at other organisations, is one mechanism to build sustained mentorship. Above all, our findings suggest the importance of trans-led and valued leadership in systems change.

4.1 | Strengths and limitations

This study has several limitations including that it is limited by the geography of the sample. Specifically, trans women and service providers were recruited from urban centres with historically better access to both LGBTQ+ and HIV-specific services. Trans women living rurally may have different – and likely more negative – experiences accessing HIV care (Blodgett et al., 2018). Nevertheless, we recruited a racial/ethnically diverse group of trans women, with a range of education, employment, immigration experiences and sexual orientations, allowing for a rich exploration of intersectional considerations. Given that in order to be interviewed providers had to respond to an email to express their interest, it is possible that we recruited providers who were already likely to be trans-affirming. It is possible that perspectives from providers who are less trans-affirming may have looked more different from the perspectives of trans women. Our use of intersectionality lent to an analysis of intersecting systems of privilege and oppression.
that influence the HIV prevention and testing experiences of trans women. Health behaviour and communication theories have also been applied to understand healthcare decision-making broadly (Gallagher & Updegraff, 2012; O’Keefe & Jensen, 2007), as well as with respect to HIV testing and PrEP (Ayodele, 2017; Bekalu & Eggermont, 2015; Sullivan et al., 2019). Future studies could consider utilising these theories to understand how trans women’s individual attributes (e.g. attitudes towards HIV testing, perceived behavioural control) are influenced by message framing, and intersect with social and structural factors to influence their uptake of HIV prevention and testing.  

The study also had several strengths; one of them being the use of CBR methods. As a CBR study, this study was developed from the outset with trans community members to understand community needs and to increase the potential impact of this research on improving care (Israel et al., 1998; Travers et al., 2013). While CBR has some inherent challenges, such as time and resource requirements (Flicker et al., 2007; Israel et al., 1998; Travers et al., 2013), by working methodically and in close collaboration with each other, we were able to create evidence-informed and community-driven recommendations. Moreover, drawing on both perspectives of service providers and trans women lends strengths the recommendations. Each theme had significant overlap, yet nuanced perspective, between trans women and service providers. For example, while trans women expressed frustration at having to educate their providers about their trans health needs, providers discussed the challenges they themselves faced with providing trans healthcare with little training and/or identifying other providers who could provide competent care.

5 | CONCLUSIONS

We identified multiple barriers to HIV care that are functioning interpersonally between trans women and service providers, but also organisationally in leadership and structurally in healthcare systems. However, we also identified facilitators to access that can promote systemic change – notably, trans-affirming trauma-informed care and trans-led and valued leadership for systems change. Implementing suggested recommendations may promote access to HIV prevention, treatment and support, promoting individual health and well-being as well as prevention, among this highly affected group. These findings can be used by administrators and service providers alike to work collaboratively with trans women to reduce barriers and facilitators to HIV care, and ultimately to achieve health equity for trans women.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

AUTHOR CONTRIBUTION

ALD, HK, CHL, YP, GL, KN, AS, TL, CH and ML conceived of the research. ALD, HK and KPT led the data analysis, and YP, GL and KN corroborated the findings. ALD, HK, CHL and KPT completed a first draft of the manuscript. All authors contributed to the final version of the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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