RETAINING TRANSGENDER WOMEN IN HIV CARE:
Best Practices in the Field

By Connor Volpi and Sean Cahill

THE FENWAY INSTITUTE
**Introduction**

In recent years we have finally started to reduce the number of new HIV infections in the US, especially among heterosexual women and men, and among people who inject drugs.\(^1\) Despite these advances, HIV remains an epidemic that disproportionately affects underserved and marginalized populations, especially Black and Latina transgender women and Black and Latino gay and bisexual men. Transgender women of all racial and ethnic backgrounds are 49 times more likely to be HIV-infected than the general population.\(^2\) Transgender women are underserved in HIV prevention and treatment.\(^3\) In the United States, 21.6% of transgender women are living with HIV.\(^4\) Racial and ethnic minority transgender women are particularly vulnerable to HIV infection. HIV prevalence is as high as 50% for Latina transgender women and 48% for Black transgender women, compared to 4% among White non-Hispanic transgender women in the US.\(^5\) Research conducted in San Francisco found that transgender women have the highest levels of HIV-related morbidity and mortality.\(^6,7\) This issue extends past national borders, with research showing higher rates of HIV for transgender women globally.\(^8\)

Transgender women living with HIV are less likely than other populations to adhere to their antiretroviral medications.\(^9\) Transgender women face a range of barriers that can prevent them from seeking and remaining in care. These include societal discrimination and victimization, poverty and homelessness,\(^10\) and lack of affirming and culturally competent health care. The purpose of this brief is to identify the barriers to HIV care and describe innovative approaches to providing transgender health care and other supporting services that can minimize those barriers. With an increased risk of transmission and lower rates of adherence to antiretroviral medication among transgender women, it is imperative that these barriers be evaluated and addressed so that transgender women living with HIV can achieve better health outcomes. This brief also examines current initiatives in the field that aim to engage and retain care adherence for transgender women living with HIV. Examining programs currently in place can provide insight into key components that should be considered for future initiatives. Successful interventions can improve transgender women’s ability to access and remain in care, thereby improving overall health outcomes for transgender women living with HIV.

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Barriers to care and suggestions for improvement

Discrimination and violence victimization

Transgender people experience high levels of prejudice and violence. The 2015 National Transgender Discrimination Survey found that 46% of its respondents were verbally harassed and 9% of respondents reported experiencing physical violence because of being transgender. Thirty percent of those respondents who had a job reported experiencing some sort of mistreatment in the workplace, including harassment, being fired, or being denied a promotion. Twenty-nine percent lived in poverty, compared with 14% of the U.S. population. They experienced three times the rate of unemployment than the general public (15% vs. 5%). Thirty percent reported lifetime homelessness, and 12% in the last year. Twelve percent reported lifetime sex work, and 9% reported sex work within the last year.

Transgender women are disproportionately the victims of hate violence, according to the National Coalition of Anti-Violence Programs. Of 28 reported anti-LGBT murders reported in 2016 (in addition to the 49 killed at the Pulse nightclub in Orlando, FL), 19 of these people murdered were transgender or gender nonconforming (68%), and 17 were transgender women of color (61%). Anti-transgender hate crimes are often the most violent of anti-LGBT hate crimes. Transgender people are also two and a half times more likely to experience physical violence at the hands of police.

Lack of trust with medical professionals and mistreatment in healthcare settings are central barriers to care for transgender women. The 2015 national transgender survey found that one-third of its 27,715 respondents reported experiencing at least one negative event in a healthcare setting as the result of their gender identity. Additionally, an earlier version of the survey found that 28% of participants reported being harassed in medical setting and 2% reported being subjected to violence in a healthcare provider’s office. Overall, transgender women report fewer positive interactions with healthcare providers and have less confidence in their abilities to integrate HIV-treatment into their lives.

A statewide survey done by the Fenway Institute in Massachusetts found that 65% of participants reported discrimination in one or more public setting with 24% reporting that setting being related to health care. Transgender people who reported discrimination in public accommodations such as public transportation, stores and restaurants were twice as likely to report negative physical and mental health symptoms, such as pounding heart, headache, and feeling sad, upset, or frustrated. Those who experienced discrimination in health care were less likely to seek care subsequently, both routine preventive care and emergency care.

13 Ibid.
The 2015 National Transgender Survey also found high rates of serious psychological distress among transgender people (39% in past month vs. 5% among the U.S. population) and nine times the lifetime attempted suicide rate (40% vs. 4.6%).

Addressing the discrimination and victimization faced by transgender patients is essential, as it can be a major influence on their health and decision to seek help from healthcare providers. Given that stigma is one of the primary reasons why transgender women avoid seeking medical treatment, providers should consider taking a trauma informed approach with their transgender patients. This approach places importance on the safety of the individual and attempts to cultivate a high level of trust and transparency with the patient, making them as comfortable as possible despite the prior traumas they have experienced both in and out of healthcare settings.

Structurally and interpersonally, transgender women may experience many negative events when accessing healthcare. Health providers using a trauma informed approach can alleviate some of the stigma faced by transgender patients that can begin right after the client walks into the door. While filling out the initial patient paperwork, a client may feel uncomfortable working with a practitioner if their intake forms are not inclusive of transgender identities. Asking patients to state their sex assigned at birth and their current gender identity allows patients to inform health professionals in a private and comfortable way of their gender identity. Asking for the name a client goes by is also important, as it may be different than their current legal name. Legally changing one’s name is both time and resource consuming. Asking a patient their preferred name and pronouns on intake forms and respecting their responses will help the patient feel more comfortable and affirmed with health professionals. Cultivating and strengthening that comfort can help in increasing the likelihood that transgender patients will come back for future visits.

**Representation**

It is important for health care clinics to have some form of transgender representation in their office. The waiting room should include visible physical illustrations showing that their medical practice acknowledges and provides for all gender identities. Illustrations can come in the form of brochures, LGBT recognized symbols such as a rainbow flag, or pamphlets that are specific to sexual and gender minority populations. Additionally, many transgender people state that they have noticed a lack of transgender representation in the clinical settings, with research finding that transgender women feel more comfortable with going to a clinic that had someone who is transgender on staff. There is also a need for more research with transgender people. More funding should be allocated towards working with transgender populations. This will provide additional visibility to the community and inform more healthcare providers about the unique health disparities that affect the transgender community. Further, communicating with transgender individuals on research topics that are most important to their community will help build rapport and strengthen trust between gender minorities, researchers, and healthcare providers.

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22 Ibid.
Financial barriers

As noted above, the National Center for Transgender Equality found that transgender people have higher rates of joblessness and poverty than those who are cisgender (i.e. not transgender). This results in many transgender people lacking insurance, restricting their access to health care. While many health centers work on a sliding scale, options are few and limit the amount of places an individual can access care. The issue is further complicated by employment discrimination and social stigma, which result in many transgender women engaging in sex work. Transgender women who engage in sex work may not be able to make typical office hour appointments. Transgender women living with HIV may push off seeking healthcare if they are unable to find a clinic that is conveniently located and can accommodate their schedule. Clinics should be mindful of these obstacles and offer appointments beyond traditional office hours. Further, clinics should consider providing transportation from a location frequented by transgender women to the clinic to help those without transportation access healthcare.

Hormones and antiretroviral medications

Many transgender women believe that antiretroviral therapy will negatively affect hormonal therapy, or vice versa. One study found that transgender women living with HIV may prioritize care related to their gender transition over HIV-related care, especially if there are concerns involving an antiretroviral-hormonal interaction. This finding was consistent with another study which found that transgender women who believe that HIV treatment affects the efficacy of hormonal therapy have a decreased adherence to their medication.

In 2011 the Center of Excellence for Transgender Health at the University of California, San Francisco reviewed the possible impact of antiretroviral medications on cross-sex hormone therapy and determined that there was no scientific reason why the drugs would interact:

There is no evidence or clinical studies of potential drug interactions between different classes and combinations of antiretroviral medications (ARV) and cross-sex hormone therapy (csHT) used by transgender women for gender transition and feminization.

These conclusions were drawn from several studies of potential interactions between antiretroviral medications and oral contraceptives (which contain estrogen and/or progestins). These studies showed that, because nucleoside reverse-transcriptase inhibitors (NRTIs)—the umbrella term for the type of drugs used in PrEP—and estrogens/progestins are metabolized through different pathways, it is unlikely that any interactions could occur. It’s important to note that the hormone drug levels in oral contraceptives are much lower than the hormone drug levels in feminizing hormone therapy.

The UCSF analysis found that some protease inhibitors decrease blood levels of synthetic estrogen (ethinyl estradiol), while others cause an excess. UCSF notes that:

...the key clinical indication is to monitor patients for evidence of estrogen excess or deficiency...Clinical surveillance for estrogenic symptoms will likely improve compliance and retention with ART [anti-retroviral therapy] and csHT regimens...
The importance of locating HIV care in a broader context of affirming, competent transgender health care

Offering the most promise in addressing the HIV epidemic in transgender women is the delivery of integrated health services that address both HIV care and gender-affirming healthcare for transgender people. Transgender women living with HIV have expressed the desire to receive co-delivered services for their hormonal and antiretroviral needs. This is a realistic goal and has the potential to be a highly successful approach. In fact, research has shown that integrating hormonal therapy with antiretroviral therapy improves engagement and retention in care. However, doctors may be more familiar with one therapy over the other and not feel comfortable managing both. Additional education and training for healthcare professionals is needed to minimize this knowledge gap. This will allow for implementation of integrated therapy to be more widely available.

The Special Projects of National Significance Initiative:

Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color, 2012-2017

The Special Projects of National Significance (SPNS) Initiative is a multi-site demonstration project that funds organizations to help them design, implement, and evaluate interventions for people living with HIV or at high risk of HIV infection. It is part of the Ryan White HIV/AIDS Program, administered by the Health Resources and Services Administration. The SPNS Initiative titled “Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color” seeks to address the barriers to care experienced by transgender women of color living with HIV. These interventions for this target population are crucial given that transgender women of color are disproportionately burdened by HIV infection compared to White non-Hispanic transgender women, and are less likely than most other demographic or risk-behavior groups to be in care and on antiretroviral treatment. An examination of these high impact initiatives will help researchers and healthcare providers better understand the barriers faced by transgender women of color living with HIV, and implement initiatives to improve retention in care and health outcomes for transgender women living with HIV of all racial and ethnic backgrounds.


The Brandy Martell Project - Fremont, CA

The Brandy Martell Project at the Tri-City Health Center in Fremont, CA is named in remembrance of a former peer advocate. Brandy Martell was a transgender woman of color who was murdered after a confrontation. This initiative addresses and reduces the structural barriers that prevent transgender women of color from engaging and remaining in HIV prevention and care services. All transgender patients are offered care according to their financial needs. This initiative includes marketing and outreach conducted by peer advocates who are transgender women of color. Advocates provide education, one-on-one counseling, and testing. Additionally, a trained lawyer works individually with clients needing legal assistance. The initiative offers monthly workshop sessions designed to remove the barriers to retention to care, which are led by transgender facilitators.44

The Infini-T Project - Brooklyn, NY

The Infini-T Project at the Research Foundation of the State University of New York in Brooklyn, NY is a multidisciplinary intervention aimed to retain young transgender women of color in HIV care. The initiative uses social work, case management, peer advocacy, mental health care, and engagement with medical providers. Prior to launching the intervention, the university hired a transgender health consultant to train project staff. This intervention added a transgender peer youth advocate, whose goal is to help patients link to HIV care and to facilitate adherence to medical appointments. A transgender youth services specialist was also hired to engage with the community at outreach events and provide local referral and linkage knowledge. This initiative created additional social work services for referrals, screening, and support groups, and enhanced transgender-focused mental health services to better serve their mental health needs.45

Transgender Women Engagement and Entry to Care Project – New York, NY

The Transgender Women Engagement and Entry to Care Project (TWEET) at the Community Healthcare Network in New York, NY is a peer-based model of outreach and engagement that offers quality health care to transgender populations. This intervention draws on Social Cognitive Theory, the Transtheoretical Model of Behavior Change, and the Motivational Interviewing Method. TWEET relies on trans-identified peer leaders to conduct outreach, engage with, and link HIV-positive transgender women into care. TWEET provides HIV testing, treatment, and hormonal care for its clients. For clients without health insurance or requiring additional support with their current insurance, TWEET offers financial support. The intervention relies on peer leaders to provide important information on health education to their clients. Additionally, TWEET offers group sessions which involve peer-to-peer interactions and health referrals.46

TransActivate - Los Angeles

TransActivate at Bienestar Human Services, Inc. in Los Angeles, California is an intervention designed for Latina transgender women to empower them to lead healthier lives. This multilingual intervention incorporates Spanish into their programs to serve a population whose primary language may not be English. TransActivate’s focus is to encourage clients to engage and stay in care. The initiative aims to increase the cultural competence and sensitivity of clinical staff that work with Latina transgender clients. To achieve this, TransActivate began to engage with social networks to identify individuals diagnosed with HIV but not in care. The intervention utilized motivational interviewing-based linkage to determine what barriers are preventing clients from engaging in care, using interviews to help remove these barriers. After understanding the barriers, the initiative relied on peer navigation to help clients remain in care and increase the amount of social support available. Additionally, TransActivate offers cultural competency training for providers in the community.47

TransLife Care – Chicago, IL

TransLife Care is an intervention at the Chicago House and Social Service Agency that uses a strengths-based, case management approach. The initiative provides transgender women of color with intensive short-term linkage to care services, connecting them to resources that address their needs to support long-term retention in care. TransLife also offers cultural competency training within the community. Staff participate in outreach events to bring visibility to their organization and recruit additional transgender women of color as clients. TransLife connects clients to HIV counseling providers and case managers. Additionally, TransLife has created more linkage-to-care services, offers legal assistance, and provides housing options assistance. This initiative has created Chicago’s first weekly drop-in center for transgender individuals dedicated to helping them navigate the city’s resources, and offers classes and workshops related to skills-building and health awareness.48

Féminas - Lima, Peru

In Peru, transgender women have the highest prevalence of HIV of any social group.49 The disproportionate risk of HIV infection in this population is due to high rates of drug abuse and sex work.50 Estimates of HIV prevalence range from 30% to 50% in Peru’s capital and largest urban area, Lima.51 Additionally, transgender women living with HIV in Peru have difficulty finding places to obtain healthcare. A recent Peruvian investigation found that identifying as a transgender woman was associated with lower access to care.52 Given this disparity, the Foundation for AIDS Research (amfAR) funded Féminas, a community-based HIV research project in Lima that combines HIV prevention and treatment with gender-affirming medical care for transgender women.53

50 Ibid.
Féminas relies on a task force of transgender women comprised of community leaders, health outreach workers, and activists, to guide the research team. The hiring of transgender women staff members, and the extending of clinic hours of operation to accommodate transgender women patients, were seen as key facilitators for engagement in health care. The research team involved with Féminas determined that many transgender clients were willing to integrate HIV services with hormone therapy. Based upon the program’s success, the Peruvian Ministry of Health has approved the first-ever policy to provide integrated feminizing hormone therapy and antiretroviral care for transgender women within government health centers.

**Conclusion**

Transgender women are disproportionately burdened by HIV, and they are less likely than other HIV-positive populations to adhere to their antiretroviral medications. Both of these facts should be cause for alarm and action, as these statistics display a staggering disparity that needs to be addressed. Féminas and the five initiatives from the Special Projects of National Significance Program are just a few of the currently active interventions in the field that aim to engage and retain transgender women in HIV care. Although each unique, these initiatives possess certain similarities, including: providing financial assistance to clients, hiring transgender staff, and relying on cultural competency training of staff to ensure affirming, competent care. When possible, the interventions integrate HIV care and gender affirming healthcare and provided clients with linkage to a transgender-friendly provider who could prescribe both hormones and antiretroviral therapy. Culturally and clinically competent and affirming transgender health care has been shown to be an effective context in which HIV care can be provided to transgender patients. Researchers and health professionals should examine the success of current interventions and attempt to replicate these initiatives with transgender women in their communities. This will ensure that transgender women living with HIV are linked to the care they need and ultimately achieve better health outcomes.

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55 Ibid.


Connor Volpi is a Research Fellow at The Fenway Institute and a Masters in Public Health student at Brown University’s School of Public Health.

Sean Cahill is Director of Health Policy Research at The Fenway Institute.

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