Trans Women Living with HIV

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Table of Contents

- Bearing a Huge Burden
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Living with HIV

Across the globe, transgender women (trans women) are affected by HIV [3] to a much greater degree than other groups. The World Health Organization (WHO) estimates that the proportion of trans women living with HIV is 49 times higher than in the general adult population. This is true whether trans women are living in low-, middle-, or high-resource countries. Worldwide, the prevalence of HIV among trans women is about 19 percent; this means that 19 out of 100 trans women in a given population will be living with HIV. By comparison, the global estimate of HIV prevalence among female sex workers is 12 percent, and the estimate for men who have sex with men is 13 percent. The overall global estimate of HIV prevalence is 0.8 percent.

The US Centers for Disease Control and Prevention (CDC) reported that transgender people are diagnosed with HIV three times more often than the general population. As in the cisgender (non-transgender) population, transgender people of color [4] are many times more likely to be living with HIV than their white counterparts. From 2009-2014, 84 percent of new HIV diagnoses in the transgender community occurred among transgender women. CDC estimates that over half of African American transgender women live with HIV, compared to a quarter of all transgender women.

Click above to view or download this fact sheet as a PDF slide presentation [5]

Not being seen or served

Despite bearing such a high burden of HIV, trans women have been historically underserved as part of the response to the HIV pandemic. Often, transgender women are not even ‘seen’ because they are combined incorrectly into other categories, such as men who have sex with men. Existing data systems often do not ask the right questions about people’s sex and gender and therefore do not count transgender individuals. It can also be challenging to ‘see’ transgender women because, due to past negative experiences or fear of discrimination, many trans women choose not to identify as transgender when they seek services.

The good news

In the past few years, organizations have become more aware of how ill-served the transgender population has been by the global response to the HIV epidemic, and changes are (slowly) being made. WHO conducted a study and published guidelines on HIV prevention and care that included specific recommendations for transgender people. It also issued a policy that encourages countries to establish laws that decriminalize nonconforming gender identities, protect against discrimination, and work toward legal recognition for transgender
people. According to Kate Montecarlo, founder and chair of the Association of Transgender People in the Philippines, the WHO made a "remarkable imprint on history when it comes to transgender health and HIV advocacy among transgender women — in particular separating transgender people from men who have sex with men" and acknowledging the specific health needs of transgender people.

**Issues Common to Trans Women**

There are many intersecting issues common to transgender women that can make life challenging and make it more difficult for them to access the care they need. These include a range of social and structural inequalities that negatively affect the health outcomes of trans women living with HIV. As the National Center for Transgender Equality (NCTE) explains, "transgender and gender non-conforming people face injustice at every turn: in childhood homes, in school systems that promise to shelter and educate, in harsh and exclusionary workplaces, at the grocery store, the hotel front desk, in doctors' offices and emergency rooms, before judges and at the hands of landlords, police officers, health care workers and other service providers." For more information on some of these issues, see below.

**Stigma, Discrimination, and Violence**

The stigma and discrimination faced by people living with HIV is fairly well documented and understood. Studies have shown that stigma and discrimination — or the fear of them — keep people living with HIV from getting tested for HIV, getting linked to or having access to care, staying in care, getting HIV drugs, and taking their HIV drugs correctly (adherence).

In a 2011 survey of 6,400 transgender people, 63 percent reported having experienced discrimination serious enough to affect their ability to support themselves financially and emotionally. Transgender women of color, especially African-American trans women, bear the heaviest burden of discrimination. This is probably so because the combined effect of anti-transgender bias and structural racism is greater than the sum of their separate effects.

Serious discriminatory events can often be traumatic, leading to lasting negative effects on a person’s ability to function in the world — physically, mentally, emotionally, socially, and/or spiritually.

"In Peru, before making the transition, I was the victim of much bullying for being a queer person and quite feminine. And the police attacked me. Once I was leaving a nightclub and a policeman stopped me. He took me to a parking lot far away, on the beach, put a gun to my head and sexually abused me. Then he left me on the beach. There were other incidents." ~ Arianna Lint, Real Trans Latina History

The negative feelings and sense of rejection that come from experiencing discrimination can also lead to low self-esteem, social isolation, depression, and even thoughts or acts of suicide. The survey reported that an astonishing 40 percent of survey participants had attempted suicide.
If you are thinking of hurting yourself or committing suicide, please tell someone immediately. In the US, you can call 1-800-SUICIDE (1-800-784-2433) or 1-800-273-TALK (1-800-273-8255). To find a suicide hotline near you, try http://www.suicide.org/suicide-hotlines.html; this website lists US hotlines by state as well as hotlines by country (click on the "International Hotlines" link at the top of the main page).

Transgender people worldwide face extraordinary levels of physical and sexual violence. The National Coalition of Anti-Violence Programs reported that, in the US in 2013, severe hate-based violence against transgender people, people of color, and HIV-affected people was alarmingly high. Trans women were six times more likely to experience physical violence when interacting with police than survivors of violence in general. Violence, like stigma and discrimination, can result in trauma and lead to lasting negative effects on a person’s ability to function and remain healthy.

Importantly: if you are feeling threatened right now, call 911 or the National Domestic Violence hotline in the US at 800-799-SAFE [1-800-799-7233; or 1-800-787-3224 (TTY)]. You can also search for a safe space online at Domestic Shelters. If you live outside the US, please go to the Hot Peach Pages to find help near you. You can also search for shelters and services at SAFE (Stop Abuse for Everyone).

It is important to remember that, if someone threatens you, it is NOT your fault. You deserve to be treated with respect and to be safe. Often, women who have been abused have been humiliated to the point where they believe that they deserve whatever abuse comes their way. This is NEVER true.

Socioeconomic Realities

According to the NCTE, one in six transgender people have lost a job because of their gender identity, and more than three out of four took steps to avoid mistreatment, such as hiding or delaying their transition, or quitting their job. Overall, transgender respondents to the NCTE survey reported a rate of unemployment triple that of the general population; among transgender people of color, the rate of unemployment was almost four times what it was in the general population.

Unemployment and poverty can have serious negative outcomes, leading trans women to be homeless, engage in sex or drug work simply to survive and to cope with the stress of their situation. Each of these factors can greatly reduce a person’s health and well-being; when acting in concert, these circumstances can be devastating.

"Dealing with the fact that I am Trans, I face ostracism at work… People whom I thought loved me and were truly my friends have repeatedly mis-gendered* me at my job, jeopardizing my livelihood. Arkansas is a state with no legal protections for transgender people in employment. People can deny jobs and housing based on religious beliefs, which in essence is targeted to members of the LGBTQ community. Losing my job would put me in a position of possibly losing my apartment and having to do what is necessary in order to survive. I am working hard to make my own path in this world, but I have people who hate me simply because I am Trans." ~ Tiommi Jenae Luckett, I Could Be Broken, but I'm Not Defeated
Mis-gendered means that the person is referred to by a gender with which they do not identify. For example, someone assigned male at birth continues to be referred to as "he" even after they let people know that their preferred pronoun is "she".

While an accepting response from a trans woman’s family can protect against many of these injustices, being rejected by one’s family can make things worse. For trans women living with HIV, social support (or lack thereof) is even more important. Social support from friends and family has been found to help people living with HIV avoid depression or cope better with it. It can be helpful to connect with others who share your situation. To read some of the inspiring stories of brave trans women living with HIV, please visit our online blog A Girl Like Me [19] and consider joining our community [20].

**Legal Barriers and Public Accommodations**

In addition to being rejected by family, transgender women living with HIV often face disrespect and denial of service as part of going about their public daily lives. According to the NCTE's survey, 31% experienced at least one type of mistreatment in a place of public accommodation, such as a restaurant, hotel, retail store, or government office in the last year. Among respondents who interacted with the police, more than half experienced some form of mistreatment. And being harassed by police, quite naturally, makes many trans women uncomfortable seeking assistance when faced by threatening or violent circumstances.

Transgender people often have trouble updating their official documents so that their documents match their new gender identity. Without appropriate documents, transgender women can have trouble applying for jobs, accessing bank accounts, getting medical care, traveling, immigrating, and getting into homeless or domestic violence shelters. And showing identification documents that do not match one's gender identity can lead to harassment and even assault.

**Health Issues**

Compared to cisgender people living with HIV, transgender people living with HIV access HIV care less often. Trans women living with HIV are less likely to be on HIV treatment, and when on treatment, are less likely to be adherent [9] to it. Researchers have shown that transgender women are more likely to report difficulty integrating HIV treatment into their lives and less likely to report having positive experiences with their health care providers. In fact, according to the NCTE’s survey, almost one in five transgender people have been refused medical care because of their gender identity at some point in their lifetime, and one third had at least one negative experience in a doctor’s office related to being transgendered, such as being verbally harassed or refused treatment because of their gender identity.

"Denial of health care by doctors is the most pressing problem for me. Finding doctors that will treat, will prescribe, and will even look at you like a human being rather than a thing has been problematic. Have been denied care by doctors and major hospitals so much that I now use only urgent care physician assistants, and I never reveal my gender history." (respondent to the National Transgender Discrimination Survey [21], p. 75)

The Positively Trans study conducted by the Transgender Law Center in 2015 reported that
anticipated discrimination in a health care setting was the most common reason given for not visiting a health care provider for the 41 percent of transgender people living with HIV who said they had gone six months or longer without seeking medical care. In fact, survey respondents listed "gender affirming and non-discriminatory health care" as their number one health concern.

Another factor affecting trans women’s health is the general lack of knowledge among providers about transgender health care. Many providers simply do not know about the hormones used for gender transition or about gender-affirming surgeries. Nearly one quarter of NCTE’s survey participants reported having to teach their providers about appropriate transgender care. And almost 90 percent of those surveyed by Lambda Legal in 2010 said that there were not enough adequately trained health professionals to care for transgender people.

There are many negative consequences of poor access to health care for trans women living with HIV. Perhaps the most obvious is that fewer trans women living with HIV receive and take the HIV drugs necessary for them to stay healthy. But the shortage of informed transgender care providers also leads trans women to access feminizing hormones through underground and unregulated channels. This can result in trans women buying hormones that are not safe (off the internet, from the veterinary supply, etc.) and giving themselves incorrect doses (often too much).

Similarly, trans women seeking to feminize their appearance by injecting their own soft tissue filler (e.g., silicone) run the risk of infection and scarring from an unsterile technique or contaminated syringes. Sometimes, incorrect injection technique has resulted in sudden death from emboli (getting an air bubble or bit of foreign material in the bloodstream).

Conclusion

Despite all of the very real, day-to-day obstacles faced by trans women living with HIV, many demonstrate amazing resilience. They have shown that they can face harassment and violence with determination and grit. And they have shown that it is possible for trans women living with HIV to thrive and contribute to their communities in the face of multiple injustices.

According to the NCTE discrimination survey, although transgender people had major barriers to accessing health care, over three quarters still got the hormone therapy they sought. Despite bullying that caused them to drop out of school, many later returned to complete their education. Despite having lost previous jobs or homes due to bias, the majority of trans people reported being currently employed and housed.

As one of The Well Project's A Girl Like Me bloggers explained:
"I am an African-American Transgender Woman Living with HIV, and sometimes I have to choose which battle to fight... Being Black is no easy feat. I recognize all kinds of systemic privilege at my job, and I do not benefit from any because I am Black. As hard as I work, I feel undervalued and overworked... I face chauvinism and unwanted sexual advances at every turn... So, as I am sitting here thinking about the intersections in my life, it [becomes] apparent how resilient I truly am. I'm well, having the knowledge that I am a conqueror through divine intervention. There are forces working together for my good." ~ Tiommi Jenae Luckett, *I Could Be Broken, but I'm Not Defeated* [18]

For more information on the following topics, please see our list of Resources for Trans Women Living with HIV:

- Terminology and FAQs [25]
- Violence (including intimate partner and domestic violence) [26]
- Youth [27]
- Stigma and Discrimination [28]
- Socioeconomic Realities [29]
- Legal Barriers [30]
- Health Issues [31]

**Tags:**

- transgender [32]
- Trans woman [33]
- trans women [34]
- Trans People of color [35]
- Trans African-American [36]
- Trans Latina [37]
- racism [38]
- Stigma [39]
- discrimination [40]
- Trans Trauma [41]
- Trans Violence [42]
- Trans Harassment [43]
- Trans Depression [44]
- Suicide [45]
- Social support [46]
- trans Legal barriers [47]
- Documentation [48]
- Trans Police [49]
- Resilience [50]
- Trans Employment [51]
- trans unemployed [52]
- trans Poverty [53]
- trans Jobs [54]
- trans Housing [55]
- trans Education [56]
- trans Health care access [57]
Additional Resources

Select the links below for additional material related to Trans Women living with HIV.

HIV Among Transgender People (US Centers for Disease Control and Prevention) [61]
The Center of Excellence for Transgender Health [62]
Positively Trans (T+) (Transgender Law Center) [63]
Policy Brief: Transgender People and HIV (World Health Organization, PDF) [64]
TransLatin@ Coalition [65]
National Center for Transgender Equality (NCTE) [66]
Trans Women of Color (GLAAD) [67]
National LGBTQ Task Force [68]
National Transgender Discrimination Survey (National Center for Transgender Equality) [69]
Lesbian, Gay, Bisexual, Transgender, Queer, and HIV-Affected Hate Violence in 2016 (National Coalition of Anti-Violence Programs, PDF) [70]
Transgender Resources (GLAAD) [71]
Transgender Europe (TGEU) [72]
New Federal Actions to Address HIV in the Transgender Community (April 2016, HIV.gov) [73]
Values and Preferences of Transgender People (World Health Organization, PDF) [74]
Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations (World Health Organization) [75]

Transgender People and HIV (World Health Organization, PDF) [76]