



HHS Public Access

Author manuscript

Curr Opin HIV AIDS. Author manuscript; available in PMC 2018 May 11.

Published in final edited form as:

Curr Opin HIV AIDS. 2014 March ; 9(2): 168–173. doi:10.1097/COH.0000000000000030.

HIV Epidemics among Transgender Women

Tonia Poteat, PhD, MPH,

Johns Hopkins School of Public Health, 615 N. Wolfe Street, Room E7138., Baltimore, MD 21205

Sari L. Reisner, ScD, MA, and

The Fenway Institute, Fenway Health; Department of Epidemiology, Harvard School of Public Health

Anita Radix, MD, MPH

Callen-Lorde Community Health Center

Abstract

Purpose of review—Recent data on the high burden of HIV among transgender women has stimulated interest in addressing HIV in this vulnerable population. This review situates the epidemiologic data on HIV among transgender women in the context of the social determinants of health and describes opportunities for effective interventions.

Recent findings—Transgender women experience unique vulnerability to HIV that can be attributed to multi-level, intersecting factors that also influence the HIV treatment and care continuum. Stigma and discrimination, lack of social and legal recognition of their affirmed gender, and exclusion from employment and educational opportunities represent fundamental drivers of HIV risk in transgender women worldwide.

Summary—Interventions to improve engagement in HIV prevention, testing, care, and treatment among transgender women should build on community strengths and address structural factors as well as psychosocial and biologic factors that increase HIV vulnerability and prevent access to HIV services.

Keywords

transgender; HIV; social determinants

Introduction

Transgender is a term used to describe a diverse population whose gender identity or expression differs from that associated with their sex at birth. Language about and concepts of gender vary widely by region and culture and dynamically change over time. For the purposes of this review, “transgender women” refers to people who were natal males and who have a feminine gender identity or expression.

*corresponding author: TPoteat@jhsph.edu, +1-404-484-1118.

Conflicts of Interest

There are no conflicts of interest.

In 2008, Herbst and colleagues [1] published the first systematic review and meta-analysis of HIV prevalence data among transgender women in the United States. This exhaustive review used five search strategies and included 13 years of data (1990-2003), yet identified only 22 studies that included HIV prevalence for transgender women. In these studies, the average prevalence was 11.8%. The four studies that included laboratory confirmation found an average prevalence of 27.7%; and the two studies with incidence data found 3.4 and 7.8 infections per 100 person-years, respectively.

In the same year, Operario and colleagues [2] published a systematic review and meta-analysis comparing the global epidemics of HIV among transgender women sex workers to transgender women not engaged in sex work, male sex workers, and female sex workers. They identified 25 studies from 14 countries published 1980 – 2007. Overall crude HIV prevalence was 27.3% among transgender women sex workers and 14.7% among transgender women not engaged in sex work, including both self-report and laboratory-confirmed HIV status.

Since those seminal publications, attention to HIV among transgender women has grown such that a search of the literature published within the last year alone resulted in more than 30 unique citations. Using a social ecological framework [3] and focusing on the continuum of HIV prevention, care, and treatment, this review summarizes recent data on HIV burden among transgender women, describes the contexts that contribute to disproportionate vulnerability, and discusses opportunities for intervention.

HIV Burden

Baral and colleagues [4] published a meta-analysis of studies from 2000 - 2011 that assessed the burden of laboratory-confirmed HIV infection among transgender women worldwide. The pooled HIV prevalence was 19.1 % across the 15 countries with available data. Compared to all adults of reproductive age, transgender women had more than 48 times the odds of HIV infection. Data were only available from middle and high-income countries with male-predominant, concentrated epidemics. No studies were available from regions with generalized epidemics, such as sub-Saharan Africa [5]. Pooled prevalence can mask significant intra-country variability, hiding “hot spots” of extreme HIV burden. For example, while the pooled HIV prevalence among transgender women in the United States was 21.7% in the meta-analysis, a recently published study estimated HIV prevalence among transgender women in San Francisco to be a staggering 39.5% by laboratory testing [6].

HIV Vulnerability

Transgender women experience unique vulnerability to HIV that can be attributed to multi-level, intersecting factors that also influence all stages of the HIV treatment and care continuum. Transgender women who have sex with men often, but not exclusively, engage in receptive anal intercourse – an efficient route for acquisition of HIV infection [7]. High rates of sexually transmitted infections (STIs) have been reported among transgender women, including syphilis and herpes [7, 8], both ulcerative genital diseases that increase risk of HIV acquisition. Transgender women who have undergone genital reconstruction surgery may be

at additional risk for HIV through vaginal intercourse and trauma of the neovagina. However, data on HIV acquisition via the neovagina are lacking [9]. While biologic risks are important, they are not sufficient to explain the elevated risk of HIV among transgender women.

Transgender individuals around the world face high levels of stigma and discrimination, lack of social and legal recognition of their affirmed gender, and exclusion from employment and educational opportunities [7, 10, 11]. In several countries, transgender women can be arrested for “cross-dressing” or vagrancy and they may also be prosecuted under sodomy laws [12, 13]. Legal and economic marginalization increase transgender women’s vulnerability to HIV infection by limiting their employment options to sex work which in turn results in further stigmatization and disenfranchisement. For many transgender women, sex with men – including paid sex – can provide important validation of their gender identity [14, 15]. Sex work thus provides both desired gender affirmation and economic stability, often with greater financial rewards for sex without a condom [14, 16].

Experiences of gender-based discrimination, violence, victimization, rejection, and social marginalization are pervasive among transgender women worldwide [12, 17, 18]. Gender abuse in the form of verbal abuse, harassment, and/or physical abuse based on gender identity or presentation is a powerful risk factor for HIV among transgender women and often begins at an early age. A longitudinal study in New York City found that gender abuse was prospectively associated with sexual risk behavior and with incident HIV and STIs among young transgender women [19]. Lack of parental support has also been associated with HIV risk. One study among young transgender women in Los Angeles and Chicago found that sex without condoms was reported by those without parental support while consistent condom use was associated with having at least one supportive parent [20]. Brennan and colleagues [17] have shown that low self-esteem, polysubstance use, victimization related to transgender identity, and intimate partner violence were additively associated with HIV-infection and sexual risk.

The intersection of multiple stigmatized identities [21, 22] contributes to HIV vulnerability, and stigma toward people living with HIV is common in transgender and other marginalized communities [23]. Thus, transgender women living with HIV face stigma based on gender and HIV status, even within transgender communities. Intersecting stigma has important implications for engagement in care and treatment as well as for HIV prevention.

Continuum of HIV Care and Treatment

Transgender women may experience multiple barriers when attempting to access both routine and gender-related health services. Barriers include refusal of care, harassment and violence, and a lack of competent medical providers [10, 24, 25]. Faced with a lack of access to appropriate care, many transgender women utilize hormones without medical supervision [26]. Body modification may be undertaken with soft tissue fillers, usually industrial silicone. Among 335 transgender women in Peru who reported having undergone any gender enhancement procedure, 40% had injected industrial silicone[7]. Illicit hormone injections as well as injected fillers may carry HIV risk through the use of contaminated needles.

Barriers to healthcare are also associated with delayed access to urgent and preventive care, including HIV testing, care, and treatment. HIV screening rates are very low among transgender women, despite a high burden of infection [27], leaving many transgender women unaware of their HIV status. In national study of transgender people in Canada, Bauer and colleagues found that 46% of the transgender women had never been tested for HIV [28]. More than 50% of the kathoey sex workers interviewed by Nemoto and colleagues in Bangkok had never been tested [18]. Also, data suggest that few transgender women know the HIV status of their sexual partners [29]. Lack of inclusion in HIV awareness and prevention campaigns as well as competing priorities in the lives of transgender women may contribute to low rates of HIV testing [30, 31].

Once diagnosed with HIV, transgender women may continue to avoid medical care due to fear of, or actual experiences of discrimination in healthcare settings. A survey among transgender women living with HIV in the United States identified fear of disclosure of transgender identity, poor treatment by staff, and providers' lack of awareness of transgender issues, as important barriers to engagement in care [32]. Qualitative research among HIV-positive transgender women in Canada revealed similar themes [31].

Receiving antiretroviral therapy and achieving an undetectable viral load are important components of the HIV care and treatment continuum. Few studies have evaluated these components among transgender women. However, one study found that transgender women with HIV were less likely to have received antiretroviral therapy compared to non-transgender participants (59% vs. 82%) [33]. In another study, transgender women were less likely to report adherence to their antiretroviral regimen, more likely to have difficulty integrating treatment into their daily lives, and less likely to report positive interactions with HIV care providers relative to non-transgender participants [34]. Among HIV-positive women (including 28% transgender women) enrolled in a U.S.-based study, a history of recent abuse and violence was associated with a four-fold increase in likelihood of antiretroviral failure, underscoring the need to identify and address psychosocial issues, including trauma, in order to improve HIV-related outcomes [35].

In San Francisco, transgender women living with HIV have been found to have higher HIV-related mortality and a higher community viral load than non-transgender persons [36], consistent with both a lack of adequate HIV treatment and late presentation of disease. A recent retrospective analysis found similar rates for retention in care and virologic suppression for HIV-infected transgender women and nontransgender people attending 13 clinics in the USA [37]. This study included only clinics within and HIV research network, suggesting that these research-oriented clinics may have developed effective strategies for retention and adherence that could serve as models for other health facilities. No published studies were found outside the U.S. that evaluated engagement and retention in care in this population. This gap in the literature highlights the need for further research among transgender women living with HIV.

Opportunities

Scale-up of HIV interventions for transgender women must take place in the context of improved surveillance, monitoring, and evaluation so that health facilities, communities, and governments can be held accountable. It's promising to note that HIV studies in the United States and Asia have increasingly including transgender women. However, these studies often combine data from MSM and transgender women for sample size and other reasons. In order to better inform interventions for transgender women, they should be included in HIV research with sample sizes large enough for substantive analysis [9]; and results of combined studies should be disaggregated by gender-identity. Despite growing awareness of transgender identities, many current studies refer to transgender women as “transgender males,” “transgender men,” “males by nature but appearing as women.” etc. [38] When collecting data with transgender populations, using language that is consistent with their gender identity may improve participation. Andraski et al. [39] recommend addressing barriers to research participation by transgender women through: (a) cultural competency training, (b) transgender-friendly environments, (c) true partnerships with local transgender-friendly organizations and health care providers, (d) protocols that focus on transgender-specific issues, and (e) data collection and tracking of transgender individuals.

Combination approaches that address biologic, psychosocial, and structural factors are most likely to have impact [40]. Important legal interventions include decriminalization of “cross-dressing” and “sodomy,” as well as repeal of other laws used against transgender women such as anti-prostitution and vagrancy laws. Legal recognition of gender identity, prohibition of discrimination in education, employment, and housing, as well as other positive legislation will promote an enabling environment for transgender women to access HIV services.

Ensuring that transgender women have access to respectful and appropriate health care, including gender-affirming medical interventions can be accomplished both by training health care providers and integrating gender care into routine and HIV related medical care. Such interventions have the potential to improve rates of HIV testing as well as engagement and retention in care for transgender women with HIV. The HIV/AIDS Bureau of the Department of Health and Human Services in the USA has launched a new initiative to develop effective models of care for engaging and retaining transgender women of color in HIV care and treatment [41].

While data on stigma, discrimination, and violence among transgender women are growing, resilience among this population has been less studied. Resilience is a dynamic process of positive adaptation within the context of significant threat or adversity [42, 43]. Not all transgender women who have experienced adversity engage in HIV risk behaviors. For example, among 112 kathoey sex workers in Thailand, 73% consistently used condoms with clients and 65% were willing to have unprotected sex with clients for extra money[18]. Among non-transgender marginalized women with HIV, resilient coping skills have been found to mediate the relationship between HIV-stigma and depression, a factor associated with poor adherence [44]. Understanding not only risks/vulnerabilities, but also resilience among transgender women is critical to the development of effective interventions that are

relevant to and sustained by transgender communities. A strengths-based approach is especially important for transgender women, given the high levels of stigma and marginalization the community often faces. One example of such an intervention is Life Skills, a peer-led group intervention designed by and for young transgender women [45].

Empowerment has been defined as “a social process for people to gain mastery over their lives and the lives of their communities” (p. 294) [46]. It typically involves developing skills, knowledge, and confidence in their own abilities to overcome obstacles. Supporting existing transgender community structures and social networks that empower and mobilize community members is one way to support resilience and catalyze community-led structural change. In many parts of the world, transgender people have formed their own community and family structures. For example, Akhtar and colleagues [38] found that only four individuals in a sample of 306 hijras in Pakistan lived with their families of origin. The majority lived together as a clan in all-hijra communities with a guru (group leader). Similar alternative family structures have been documented in the U.S. with house mothers or fathers in house and ball communities [47].

Transgender individuals and groups are actively involved in creating websites to disseminate resources and information that target and reach other transgender people[48]. Across geographic regions and cultural contexts, transgender social networks have been shown to be efficient at engaging other transgender people [7, 28, 49]. Engaging with existing social networks may be a way to reach transgender people and deliver HIV prevention interventions that address the broader social context while being grounded in everyday lived realities.

Pre-Exposure Prophylaxis (PrEP) – the use of antiretroviral medication to reduce risk of HIV infection among HIV-negative people – can be highly effective among MSM and transgender populations [50]. A modeling study by Gomez and colleagues [51] in Peru suggests that PrEP strategies that prioritize transgender women and female sex workers can be expected to have higher impact for the same cost compared to prioritizing men who have sex with women or MSM.

The use of topical agents, microbicides, for the prevention of HIV infection has shown promise for prevention of vaginal HIV acquisition [52]. In recent years, there has also been progress in the development of microbicides for rectal use[53]. Focus groups and consultations among transgender people in both the Thailand and the United States [54, 55] suggest that, in addition to ensuring access, low cost and mitigating stigma and discrimination, education and outreach that acknowledge differences between MSM and transgender women are needed to support the effectiveness of rectal microbicide implementation.

Conclusion

The scientific literature on HIV among transgender women is growing, but large gaps remain. Stigma and discrimination remain formidable barriers to effective HIV prevention, care, and treatment. Researchers are beginning to examine the role of new biomedical

interventions, such as PrEP and microbicides, for HIV prevention in this population. They are also beginning to examine the factors that affect HIV testing and engagement in care and treatment. An increase in research and a scale-up of combination prevention programs tailored for transgender women will be necessary to effectively address the HIV epidemic among transgender women [56].

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Key points

- Transgender women experience unique vulnerability to HIV that can be attributed to structural, psychosocial, and biologic factors that also influence the HIV treatment and care continuum.
- Stigma and discrimination, lack of social and legal recognition of their affirmed gender, and exclusion from employment and educational opportunities represent fundamental drivers of HIV risk in transgender women.
- Barriers to health care access, including stigma, discrimination, and lack of health care providers competent in gender-related care, contribute to low HIV testing rates as well as limited engagement in care.
- Interventions to improve engagement in HIV prevention, testing, care, and treatment among transgender women should build on community strengths and address structural factors as well as psychosocial and biologic factors that increase HIV vulnerability and prevent access to HIV services.