Transgender Issues in HIV

Providers need accurate, current information to provide optimal care

BY JAE SEVELIUS, PH.D.

AS AWARENESS ABOUT THE EXISTENCE OF TRANSGENDER PEOPLE GROWS in mainstream consciousness, so does our knowledge about their unique strengths, needs, and vulnerabilities. Providers of HIV care need accurate and current information about transgender people living with HIV, including potential barriers and facilitators to engagement and retention, as well as strategies for optimizing HIV care and treatment for transgender patients. ►

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Terminology

'Transgender' is an umbrella term for individuals whose gender identity differs from the sex they were assigned at birth.

'Transgender women', sometimes referred to as 'male-to-female' (or 'MTF') are individuals who were assigned male sex at birth, but who identify as women or as transgender women.

Similarly, 'transgender men' ('female-to-male' or 'FTM') were assigned female sex at birth, but identify as men or as transgender men. Some transgender people do not identify within the male/female binary at all.

Furthermore, current literature is moving away from the MTF and FTM terminology for a variety of reasons; a summary of selected common terms is provided in Table 1. Terminology used to describe transgender identities varies widely by geographic region, age, ethnicity, and other factors. When serving transgender patients, providers can build trust by asking for and using the terminology preferred by each patient and by ensuring that the patient's preferred name and pronoun is recorded in his/her medical record and used by every staff person who interacts with the patient.

Stigma and Discrimination

Transgender people often experience stigma and discrimination, resulting in social marginalization and negative health outcomes. Because their gender identity and/or presentation differs from the sex they were assigned at birth, transgender people challenge society's most basic assumptions about the binary nature of sex and gender and the stability of identity.

The discrimination, rejection, and violence experienced by transgender people are often referred to as 'transphobia'. Just as homophobia negatively affects lesbians and gay men, transphobia affects transgender people in a multitude of deleterious ways. Experiences of discrimination and victimization negatively impact mental health by increasing anxiety, depression, and suicidality.[1-3]

Transphobic discrimination, victimization, and lack of social support consistently are associated with attempted suicide, substance use, dropping out of school, and unprotected sex among transgender youth[4]. Transgender people have shockingly high rates of suicidal ideation and suicide attempts compared to the general population (31 percent vs. 2 percent),1 and often report using substances to cope with the intense stressors associated with the stigma of being transgender.[5]

HIV in Transgender Populations

Transgender women are one of the most highly impacted groups in the HIV epidemic to date, yet they are disproportionately under-researched and underserved by current treatment efforts. Transgender women have 49 times higher odds of HIV infection compared to other groups, a disparity that exists across race, culture, and socioeconomic boundaries.[6] Disparate prevalence rates of HIV are particularly pronounced for African American transgender women when compared with transgender women of other races and ethnicities.[7] Furthermore, HIV+ transgender women have an almost three-fold higher community viral load than non-transgender HIV+ adults in San Francisco (64,160 vs. 22,376),[8] and likely elsewhere. HIV-related mortality and morbidity rates have also been found to be higher among transgender women.[9]

In addition, there is evidence that current efforts to provide effective treatment to transgender women living with HIV are not as successful as with other populations. In the only study of its kind to date, transgender women living with HIV were less likely to be receiving antiretroviral therapy than a control group of non-transgender men and women.[10] Furthermore, transgender women living with HIV who were on antiretroviral therapy demonstrated worse adherence than non-transgender people, reported less confidence in their abilities to integrate treatment regimens into their daily lives, and experienced fewer positive interactions with their healthcare providers.[11]

To date, there are few studies of HIV incidence among transgender men in the literature. Transgender men at risk for HIV are those that report sex with non-transgender men (trans MSM), a subgroup that has only recently begun to receive attention in public health research. The few research studies focused on trans MSM to date have found relatively high levels of reported risk behavior, but lower levels of HIV prevalence (0-3 percent).[12] Some trans men who are on cross sex hormone therapy (i.e. testosterone, or 'T') self-report a link between testosterone use, increased sex drive, increased interest in engaging in sexual activity, and exploration of sexual behaviors that may include sex with non-trans men. For trans men on testosterone, the masculinization of the body may lead to increased access to non-trans MSM partners, and a willingness to take sexual risks that could potentially place trans MSM at risk for STI and HIV infection.

Engagement and Retention in HIV Care

Because transgender women are extremely disproportionately affected by HIV, and because the vast majority of HIV-related research has focused on transgender women, this discussion will focus on what we know about transgender women's experiences with seeking HIV care. Much of this information may be applicable to transgender men as well, but transgender men are likely to face qualitatively different issues as well.

Transgender women living with HIV face culturally unique and substantial challenges to adhering to HIV care and treatment regimens, such as limited access to and avoidance of healthcare due to stigma and past negative experiences, prioritization of gender-related healthcare, and concerns about adverse interactions between antiretroviral therapy and hormone therapy. Issues that affect other marginalized populations, such as mental health issues, substance use, and poverty, are barriers to care among transgender women as well, but additional transgender-specific barriers exist as a result of transphobia, as well as needs for gender affirmation and transition-related healthcare.

Importance of Gender Affirming Health Care

"Gender affirmation" is the process by which individuals feel socially validated in their gender identity through interpersonal

Table 1. Selected common terms used to describe transgender identities

Term	Definition
Transgender	An umbrella term used to describe individuals whose gender identity differs from the sex they were assigned at birth
Trans	Shorthand term for 'transgender'
Transgender woman/Trans woman	Transgender person assigned male at birth, identifies as female
Transgender man/ Trans man	Transgender person assigned female at birth, identifies as male
Transvestite/ Cross-Dresser	A person who dresses in gendered clothing that differs from their own identity for entertainment or sexual purposes but does not necessarily identify as transgender
Genderqueer	Gender nonconforming person, a term increasingly used by youth
Transsexual	A term that is sometimes used to refer to transgender individuals who have undergone medical procedures to affirm their gender; currently a less favored term in trans-related literature

interactions, such as interactions with a healthcare provider. The Model of Gender Affirmation is a transgender-specific model developed to examine the role of gender affirmation in risk-taking, self-care, and healthcare-seeking behavior.[13] It posits that when a transgender woman places a high level of importance on gender affirmation, she will seek out opportunities to receive this affirmation and avoid experiences in which she is not affirmed in her gender.

A gender affirming healthcare experience would include, for example, a transgender patient being called by the correct name and pronoun by all staff throughout the healthcare encounter without unnecessary attention being drawn to her transition status. Gender affirmation also includes having access to and support for transition-related health care, such as hormones and surgeries, as desired by the patient. Evidence of the associations between access to gender affirmation and improved quality of life, mental health, and self-care behaviors among transgender people is growing rapidly.[14,15]

Gender affirmation is of paramount importance to many transgender women at every stage of the HIV care continuum. Transgender sensitivity and knowledge on the part of providers and clinics can be a crucial barrier when absent, and a powerful facilitator when present. Studies have reported that when transgender women do seek healthcare, patients' trust in their provider is compromised when they encounter insensitivity and low levels of knowledge. Diminished trust subsequently impairs patient-provider communication and can affect participants' decisions to initiate and/or adhere to antiretroviral therapy.

Multiple negative experiences can ultimately result in avoidance of healthcare settings altogether. Gender affirming healthcare, however, can support engagement and retention in HIV care among transgender women by increasing patient-provider trust, fostering positive interactions, and supporting a collaborative relationship.

Intake forms should permit transgender patients to identify themselves and their records should correctly identify their preferred name and pronoun to all providers and staff that interact with them. This documentation should be handled as sensitive and confidential health information. This increases trust in the provider and clinic by ensuring that patients are not called by the wrong name and/or pronoun, an experience commonly reported by transgender people as highly detrimental to their health care experience.

Efforts are currently underway to allow for the identification of transgender patients using electronic medical records.[16] In the meantime, clinics should revise local systems to be inclusive and respectful of transgender patients. The UCSF Center of Excellence for Transgender Health's Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care, and Services offer guidelines for clinics and have been implemented by agencies across the US.[17]

Currently, few formal medical education programs include transgender-specific medical care in their training of providers. Providers who serve transgender patients should be comfortable with transgender people at all stages of transition. Training providers to conduct thorough yet respectful health assessments, including mental health and sexual health, will help build trust and rapport with transgender patients. In addition, creating a safe clinic space, including respectful front line staff, sends the message that transgender patients are welcome and is more likely to yield positive health care experiences.

Integration of Hormone and Antiretroviral Therapy

Transgender women living with HIV often juggle a variety of demands on their time and energy due to trauma, addiction, and the deleterious effects of transphobia in their day-to-day lives. Once they initiate antiretroviral therapy, transgender women often experience barriers to integrating the regimens into their daily lives.

One method for starting to address this barrier is the integration of hormone therapy and antiretroviral therapy in HIV primary care settings, a strategy that has been employed successfully and recommended by primary care clinics that serve transgender patients.[18]

Seeing the same provider (or at the very least, being seen at the same clinic) for both hormones and antiretroviral therapy may facilitate patient management of their appointments and medications, increase the likelihood that they keep their appointments (augmented by a high level of motivation to adhere to their hormone regimen), and increase trust in their provider.

Several resources are available to guide the provision of hormones for providers who are new to treating transgender patients. The UCSF Center of Excellence for Transgender Health has an online Primary Care Protocol for Transgender Patient Care that provides peer-reviewed guidelines and

additional resources for review.[19] In addition, the World Professional Association for Transgender Health recently revised its Standards of Care document that has long served as a resource for those wishing to increase their expertise and receive guidance in the provision of health care to transgender patients.[20]

Additional Recommendations

- **Increase visibility of transgender people in peer and professional support roles.** Transgender patients often feel most comfortable with outreach and program staff who are also transgender. Transgender staff who already have established relationships with the community that the program seeks to serve can be indispensable in terms of recruitment and retention. In addition, transgender staff who have personal experience with many of the same issues that clients face can offer unparalleled support, guidance, and mentorship. Transgender staff who are openly living with HIV can model disclosure about status to help reduce stigma and can serve as an invaluable resource in peer navigation programs.
- **Attend to transgender-specific needs.** Interventions specific to transgender patients are ideal. Programs such as a transgender-specific portal to a larger health clinic, use of peer health navigators, and transgender-specific clinic hours are exemplar models that have been successful. In areas where it is not possible to create transgender-specific services, explore aspects of existing programs that can be tailored to the transgender community, such as adding a transgender-specific support group to substance abuse treatment programs or housing programs.
- **Maintain current referral resources.** While some areas may not have many transgender-specific referral resources, identifying services that are informed and sensitive can help patients avoid negative experiences in the community. This may also increase the likelihood that they will access support services that may help them stay engaged in their treatment, such as complementary and alternative therapies that help alleviate side effects of HIV medications and spiritual and/or meditation groups that help promote healthy coping strategies. When possible, create a centralized, up-to-date, and comprehensive transgender resource guide that can be given to patients.

Conclusion

Engagement and retention of transgender patients in HIV care and treatment will be optimized by services that are gender affirming and integrate transition-related healthcare needs. Such interventions must fully attend to the social, economic, and psychological context of transgender patients' lives and address the multiple barriers to healthcare engagement, treatment adherence, and empowerment that serve to create, maintain, and deepen HIV-related health disparities, particularly among transgender women living with HIV. HIV

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