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Authors

Sevelius, Jae M
Patouhas, Enzo
Keatley, JoAnne G
et al.

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ORIGINAL ARTICLE

Barriers and Facilitators to Engagement and Retention in Care among Transgender Women Living with Human Immunodeficiency Virus

Jae M. Sevelius, Ph.D. · Enzo Patouhas, M.A. · JoAnne G. Keatley, M.S.W. · Mallory O. Johnson, Ph.D.

Abstract

Background Transgender women have 49 times the odds of human immunodeficiency virus (HIV) infection compared to other groups, yet they are disproportionately underserved by current treatment efforts.

Purpose This study aimed to examine culturally unique barriers and facilitators to engagement and retention in HIV care and strengthen efforts to mitigate health disparities, guided by the Models of Gender Affirmation and Health Care Empowerment.

Methods Through 20 interviews and five focus groups ($n=38$), transgender women living with HIV discussed their experiences and life contexts of engagement in and adherence to HIV care and treatment.

Results Our participants faced substantial challenges to adhering to HIV care and treatment, including avoidance of healthcare due to stigma and past negative experiences, prioritization of hormone therapy, and concerns about adverse interactions between antiretroviral treatment for HIV and hormone therapy. Receiving culturally competent, transgender-sensitive healthcare was a powerful facilitator of healthcare empowerment.

Conclusions Recommendations are offered to inform intervention research and guide providers, emphasizing gender affirming HIV care that integrates transition-related healthcare needs.

J. M. Sevelius · E. Patouhas · M. O. Johnson
Department of Medicine, University of California, San Francisco, San Francisco, CA, USA

J. G. Keatley
Department of Family and Community Medicine, University of California, San Francisco, San Francisco, CA, USA

J. M. Sevelius (✉) · E. Patouhas · J. G. Keatley
Center of Excellence for Transgender Health, Center for AIDS Prevention Studies, University of California, San Francisco, San Francisco, CA 94105, USA
e-mail: jae.sevelius@ucsf.edu

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Transgender women are one of the most highly impacted groups in the human immunodeficiency virus (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 [1]. Disparate prevalence rates of HIV are particularly pronounced for African-American transgender women when compared with transgender women of other races and ethnicities [2].

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. The importance of early initiation of antiretroviral therapy and optimal adherence to promote health and reduce transmission is widely recognized [3, 4]. Active engagement in clinical care and high levels of adherence to antiretroviral therapy are critical to allow people with HIV to live longer, healthier lives. However, 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 [5]. 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 had fewer positive interactions with their healthcare providers [6]. From a public health perspective, HIV+ transgender women have an almost threefold higher viral load than non-transgender HIV+ adults in San Francisco (64,160 vs. 22,376) [7] and likely elsewhere. HIV-related mortality and morbidity rates have also been found to be higher among transgender women [8]. These findings warrant investigation of the barriers to treatment among transgender women.

The cascade of missed opportunities for treatment begins with lack of HIV testing and moves to lack of linkage to care, poor retention in care, and low initiation and adherence to antiretroviral therapy [9]. It is likely that the factors that put transgender women at heightened risk for HIV infection also increase the risk of treatment failure at each of the points along this continuum. Giordano and colleagues documented that inconsistent engagement and retention in care (as measured by appointment keeping over time) were associated with increased morbidity among a large cohort of HIV+ adults [10], as those with low CD4 counts not on treatment represent an at-risk population for AIDS-related illness and death.

Marginalized populations such as transgender women, racial and ethnic minorities, substance abusers, those with mental illness, and those with unstable housing are more adversely impacted by the challenges associated with accessing and adhering to care [11–13]. These factors can result in late presentation (or no presentation) to HIV medical care and can consequently lead to poorer health outcomes than if they had sought care earlier in the disease process [14]. Adherence to antiretroviral therapy can be difficult due to factors such as the complexity of the regimens, side effects, HIV-related stigma, and competing priorities and demands [15]. However, disparities exist along social, economic, gender, and racial/ethnic lines, and there is evidence that some providers do not offer antiretroviral therapy to members of certain groups, such as racial and ethnic minorities, due to preconceptions that they would be less adherent [16, 17].

In addition to the health outcomes of the individual patient who has not initiated appropriate pharmacologic treatment, there are substantial associated public health outcomes. Transgender women who are not on antiretroviral therapy (or if on antiretroviral therapy, not adherent) are at increased risk for transmission of HIV to others. This heightened risk for new infections may result from risk factors demonstrated to be at higher prevalence in this population, including substance use, high number of sex partners, and trading sex for money, drugs, and shelter [18–20]. Second, those not on antiretroviral therapy or who are not adherent are likely to be more infectious due to uncontrolled viral load than those whose virus is controlled by antiretroviral therapy, thus multiplying the risk of transmitting HIV to uninfected individuals. Understanding patterns of HIV healthcare utilization, including treatment refusal, ambivalence, and/or low adherence rates in addition to facilitators to engagement in care among transgender women living with HIV may lead to different strategies to help patients make more informed treatment decisions and to improve health outcomes.

Due to the disproportionate burden of HIV on transgender women of color (particularly African-American transgender women), it is important to frame this area of inquiry with an intersectional perspective. Intersectionality research considers the escalatory effect of multiple inequalities experienced by marginalized groups [21]. This framework posits that social inequalities are the result of the intersection of differences related to race, class, gender, etc. Transgender women of color are likely to experience multiplicative effects of marginalized social identities, with evidence that African-American transgender women are particularly vulnerable to experiencing social marginalization and its negative consequences [22]. For example, African-American transgender women are more likely to report a history of incarceration [23], homelessness [22], being uninsured [22], experiencing discrimination [24], engagement in sex work [22, 25], and are less likely to be employed full time than other transgender women [26]. Identities may intersect in ways that support positive outcomes as well. For example, African-American transgender women may also be more likely to report having a spiritual practice that may promote resilience [27, 28]. In this study, we considered the impact of intersecting identities on participants' experiences seeking and adhering to HIV care and treatment.

Theoretical Framework

In developing this study, we approached the topic from a perspective informed by the Models of Gender Affirmation and Health Care Empowerment. The Model of Gender Affirmation is a transgender-specific theoretical model developed to examine the role of gender affirmation in risk-taking, self-care, and healthcare-seeking behavior [29]. "Gender affirmation" is the process by which individuals feel socially validated in their gender identity through interpersonal interactions, such as interactions with a healthcare provider. 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. The Model of Gender Affirmation posits that when a transgender woman's need for gender affirmation is high but her access to this type of affirmation is low, she will seek out opportunities to receive this affirmation, sometimes in ways that might pose risks to her health, such as having sex to affirm her femininity [29, 30]. The model accounts for the role that psychosocial factors play in transgender women's need for and access to gender affirmation. For example, transphobia, or the stigma associated with being transgender, can be experienced as enacted by other people and it can also be internalized. Experienced (or "enacted") transphobia limits transgender women's access to gender affirmation while internalized transphobia increases the need for gender affirmation. Similarly, other psychosocial factors, especially experiences of trauma, and varying levels of social support, life stability, and substance use can all affect transgender women's access to and need for gender affirmation. The Model of Health Care Empowerment posits that vulnerable populations will experience improved health outcomes through engagement and retention in HIV care when they are informed, committed, collaborative, and engaged in their healthcare [31–33]. We were interested in how, taken together, these models create a conceptual framework for the examination of factors that affect engagement in healthcare from a transgender-specific perspective.

The aim of this study was to examine the barriers and facilitators that may be unique to transgender women in order to elucidate the observed disparities in engagement and retention in HIV care. Through this examination, we hope to provide insight and guidance to those wishing to better engage and serve this population and contribute to efforts to understand and mitigate the forces that result in disproportionately poor health outcomes.

Methods

This study explored HIV+ transgender women's experiences, perspectives, and life contexts of engagement and retention in HIV treatment and antiretroviral therapy initiation and adherence through focus groups and in-depth individual interviews. Including both individual interviews and focus groups with HIV+ transgender women was important to obtain depth and breadth of content. Individual interviews reduce participant concern about peer acceptance and confidentiality, which results in detailed content and context to the data acquired. Focus groups foster broader topic exploration through group members' exchange of ideas and responses, opening the possibility for dialogue and debate among different members of the group. Focus group discussions are especially well suited to the assessment of inter-subjective cultural norms within groups [34]. Through these combined approaches, we aimed to gain a thorough understanding of individual, social, and contextual issues associated with HIV treatment engagement and adherence.

Participants

Participants for the focus groups and individual interviews were purposively sampled based on HIV status from a cross-sectional survey of transgender women in the San Francisco Bay Area; snowball sampling and street-based recruitment were also used. Community-based agencies that serve transgender women also assisted with recruitment by posting flyers in their common spaces. Eligibility criteria were assigned "male" gender at birth and currently identifies as "female" or "transgender" or some variation indicating the person does not identify with her birth sex (i.e., transsexual, gender variant, male-to-female, MTF, etc.), 18 years of age or older, currently living with HIV (by self-report), and able to provide informed consent.

Procedures

The Models of Gender Affirmation and Health Care Empowerment served as our conceptual framework, guiding the study design and analysis [35]. The interview and focus group guides were shaped by this conceptual framework through its use as a starting point for generating questions that explored how needs for transgender-specific healthcare and gender affirmation might facilitate or hinder engagement and empowerment in healthcare.

Individual Interviews

The individual interviews ($N=20$) focused on experiences of HIV testing and first learning of HIV+ diagnosis, social support around their diagnosis, accessing treatment, treatment regimens, experiences of and concerns about adverse side effects, access to and relationships with providers, issues and concerns around treatment, adherence, and retention in care. Questions focused on transgender-specific aspects of healthcare-seeking behavior, including questions about aspects of healthcare-seeking behavior that pertain to the role of gender affirmation, such as seeking transition-related healthcare, and on how informed, committed, collaborative, and engaged the participant was in her own healthcare. Sample items from the individual interview guide include "Tell me about when you tested positive for HIV" and "Tell me about your most recent visit to a doctor for HIV related reasons." Sample questions related to hormone use included: "Are you currently seeing a doctor for your hormones? How do you feel about him/her?" Two trained interviewers conducted the in-depth individual interviews; both are male, one is transgender and one is non-transgender. Participants were informed that they were being asked to participate because they are a transgender woman living with HIV and that the study was being conducted to help us learn more about ways to increase HIV+ transgender women's access to HIV treatment and help them adhere to their treatment. Interviews lasted approximately 1–1.5 h on average. Participants were compensated US$40 for their time.

Focus Groups

We conducted five focus groups ($n=38$) with transgender women living with HIV in the San Francisco Bay Area. Focus group guides elicited content related to experiences seeking or avoiding healthcare (e.g., HIV-related care, gender-related healthcare, mental healthcare, substance abuse treatment, etc.), housing, food, experiences of and challenges with accessing, engaging, and adhering to HIV care, and other content related to services. Sample questions from the focus group guide include “Have you received any type of HIV-related medical care? If so, what has been your experience with this care?” and “What do you see as the biggest obstacles to getting the services you need?” Four focus groups were held in English ($n=33$) and one in Spanish ($n=5$); two transgender women of color extensively trained in focus group facilitation led both groups. Participants were informed that we were interested in learning about the health service needs and experiences of transgender women living with HIV. Focus groups lasted approximately 1.5 h on average. Participants were compensated US$30 for their time. All procedures were approved by the UCSF Committee on Human Research.

Data Analysis

Interviews and focus groups were digitally recorded, transcribed verbatim (the Spanish focus group transcript was professionally translated prior to analysis), and entered into Atlas.ti software for data management and analysis. Transcripts were analyzed using template analysis, a standard qualitative technique for identifying and organizing themes through the development of a coding template [36]. In this case, the a priori themes were based on the primary research question, that is, “what are the unique barriers and facilitators of engagement and retention in HIV care faced by transgender women living with HIV?” Initial coding of the data consisted of reading the transcripts and identifying sections of the text that correspond to the a priori themes. Each interview was read and analyzed by two team members, one primary (second author) and one secondary (first author). The primary analyst coded each interview using the thematic codes developed based on the apriori themes. Then, the secondary analyst read each coded interview while inserting additional codes and commentary to contribute a dissenting viewpoint or expand the interpretation of the primary analyst. While this technique allowed both coders to confirm the accuracy and interpretation of themes, it precluded the use of a quantitative measure of interrater reliability due to the potential for over-inflation of the estimate [37]. Any differential use of codes or interpretation of data was resolved through discussion. No major differential interpretations were noted, indicating a high level of agreement between coders. As the data highlighted issues that were not included among the a priori themes, existing themes were modified or a new theme was created in an iterative process. Once all interviews were discussed and coded, we conducted searches as relevant to our analysis. We searched single codes across the data set or subset to compile all of the passages associated with this code, an analytical approach that identifies patterns of experience and permits comparisons of the experiences of different participants. We also searched for the overlap of multiple codes, which identifies associations between different themes. Final analysis and interpretation was guided by the Models of Gender Affirmation and Health Care Empowerment and organized thematically [9].

Results

Participants

Participant characteristics are listed in Table 1. Participants in both the individual interviews and the focus group were predominantly African-American (85 and 71 %, respectively). Latinas and Native Americans were relatively well represented in the focus groups (18 and 11 %) but were not represented among the individual interview participants. The majority of both individual interview and focus groups participants were between the ages of 40 and 59, had some college, and endorsed the statement “I barely have enough money to get by” when asked about their current financial situation. Additional information was collected from individual interview participants about HIV and hormone therapy care and treatment status as well as self-reported adherence to both hormones and antiretroviral therapy. All individual interview participants reported that they were receiving some type of HIV care at the time of the interview.

Thematic Findings

To provide consistency in the use of qualitative terms, findings are presented by indicating the proportion of participants who discussed each theme according to the following classification system: “none” 0 %; “a few” 1–20 %; “some” 21–40 %; “about half” 41–60 %; “many” 61–80 %; “almost all” 81–99 %; and “all” 100 % [38].

Gender Affirming Healthcare Is Critically Important to Engagement and Retention

Gender Affirmation in HIV Testing and Care Settings

Participants stressed the importance of gender affirming healthcare at all stages of the HIV continuum of care, from testing to full engagement in care. The cultural competency of the provider was described as extremely important to engagement and retention by all participants. About half of the participants also mentioned the clinic environment and staff, emphasizing that both should be welcoming to and respectful of transgender patients. Gender affirming healthcare meant that providers were knowledgeable about trans-related medical issues, ideally able to provide and integrate both hormone therapy and HIV care, and all staff members were respectful and sensitive to issues that may be difficult for transgender patients. Focus group participants reported that they were reassured about seeking care when they received referrals

Table 1 Participant demographics

	Individual interviews, *N* (%)	Focus group participants, *N* (%)	Total, *N* (%)
Race/ethnicity[a]			
African-American/Black	17 (85)	27 (71)	44 (76)
Latina	0 (0)	7 (18)	7 (12)
Pacific Islander	1 (5)	3 (8)	4 (7)
Native American	0 (0)	4 (11)	4 (7)
Multiracial	1 (5)	3 (8)	4 (7)
Caucasian	1 (5)	3 (8)	4 (7)
Other	0 (0)	1 (3)	1 (2)
Age			
20–29	0	1 (3)	1 (2)
30–39	2 (10)	7 (18)	9 (16)
40–49	7 (35)	10 (26)	17 (29)
50–59	10 (50)	18 (47)	28 (48)
60–69	1 (5)	1 (3)	2 (3)
Did not respond	0 (0)	1 (3)	1 (2)
Educational level			
Some high school	3 (15)	13 (35)	16 (28)
High school diploma or general educational development	5 (25)	3 (8)	8 (14)
Technical or vocational school	0 (0)	2 (5)	2 (3)
Some college	10 (50)	18 (49)	28 (48)
College degree	2 (10)	1 (3)	3 (5)
Did not respond	0 (0)	1 (3)	1 (2)
Financial situation			
I do not have enough money to get by	3 (15)	7 (20)	10 (17)
I barely have enough money to get by	13 (65)	19 (54)	32 (55)
I have money to get by	4 (20)	9 (26)	13 (22)
Did not respond	0 (0)	3 (8)	3 (5)
Human immunodeficiency virus treatment status			
Currently on antiretroviral therapy	16 (80)		
Previously but not currently	0 (0)		
Never on antiretroviral therapy	4 (20)		
Self-reported adherence to antiretroviral therapy			
Excellent	5 (25)		
Very good	6 (30)		
Good	3 (15)		
Fair	2 (10)		
Poor	0 (0)		
Very poor	0 (0)		
Not applicable	4 (20)		
Self-reported viral load			
Undetectable	14 (70)		
Detectable	5 (25)		
Do not know	1 (5)		
Hormone treatment status			
Currently on hormones	15 (75)		
Previously but not currently on hormones	4 (20)		
Never on hormones	1 (5)		
Self-reported adherence to hormones			
Excellent	2 (10)		
Very good	7 (35)		
Good	2 (10)		
Fair	1 (5)		
Poor	0 (0)		
Very poor	0 (0)		
Not applicable	5 (25)		
Did not respond	3 (15)		

[a] Participants were permitted to choose more than one race/ethnicity; therefore, total percentage is more than 100

from other transgender women who reported positive experiences at certain clinics or from trans-specific agencies who endorsed certain providers.

> "It's how the doctors—it's about respect and it's about the knowledge that they have, and it's about sensitivity." (African-American interview participant, age 54)

Some participants reported that before they received their diagnosis, they avoided HIV testing sites because they were perceived as not trans-friendly. In particular, HIV testing sites that serve gay men were generally not perceived as transgender friendly or sensitive. Participants described resentment that they continue to be classified as men who have sex with men and refused to engage in services that were not respectful or inclusive of their gender identity. When testing sites acquired reputations as not being sensitive to transgender women, participants reported that word spread quickly and they would avoid those sites.

> "[A local HIV testing agency] serves gay men…They might think they are for me too but they are not for me… I am not a man. I don't want to be treated like one." (Focus group participant)

Some participants reported that when they were first diagnosed, they similarly avoided seeking medical care due to past negative experiences and transphobia. They reported that they were reluctant to access services where they were not sure whether the providers would be familiar with treating transgender people, and they worried about having to deal with clinic staff that might be transphobic or refuse to use the correct name or pronoun. For instance, many transgender women have identification documents that list their birth name and birth sex, but they expect that clinic staff will address them by their preferred name and female pronouns. Focus group participants discussed the importance of clinics documenting their preferred name and pronoun in their medical charts so that they are not called for their appointment by a male name or pronoun.

> "I go by [female name], but my ID still says [male name]. With me looking like I do, if they call me [male name] in front of the other patients I might just walk out." (Focus group participant)

Access to transition-related healthcare, specifically hormones, from their HIV provider was also cited as an important facilitator of engagement in HIV care. A few participants mentioned that it was important that their HIV care provider was supportive of additional gender affirming procedures the patient was interested in pursuing or, alternatively, choosing not to pursue.

> "I don't know why they couldn't handle it. All I know is—she asked me—she was doing a physical exam on me of the full body and she was just like, why haven't you had this sex change yet? Like I wasn't a person yet." (White interview participant, 39)

Focus group participants also emphasized the benefits of integrating HIV care and hormone therapy to make these services more accessible and integrated. One focus group participant described how she switched her HIV care provider because the HIV clinic was not familiar with transgender care. When she switched to a doctor that was more familiar with proper hormone dosages, she learned that she was previously prescribed a dose that was too high, which caused the erratic mood swings she had been experiencing.

Control over One's Body/Medication Regimen

Participants reported feeling that they needed to be in charge of their medication regimen and described strong feelings of protectiveness and ownership over their bodies. This was often related to experiences that occurred for some participants early in their transition when they felt they had to take control of their own transition process and make decisions about hormones without the support of an informed provider. All participants in the individual interviews reported that they felt they had to educate themselves about hormones and that they learned most of what they know from the Internet and from other transgender women in their community. Many interview participants described themselves as the primary decision maker when it comes to their HIV care, whether they were fully engaged in care or not.

> "I do an off and on thing myself, which I know, it's not recommended. It's a personal choice. But, usually when it gets to a scary position, when T-cells are too low, or the viral load is too high, then I start taking my medicine again and bringing it back." (Focus group participant)

HIV-Related Stigma Affects Decisions About Testing and Care-Seeking Behavior

Concerns About Confidentiality

While access to peer navigation and transgender staff at service agencies were reported as important at other stages of the HIV treatment continuum, at the testing stage, the presence of transgender peers raised concerns about confidentiality. Participants expressed concern that their results may not be held in confidence if they had an HIV test counselor who was also part of the transgender community, and this was especially important for those who reported that they were engaged in sex work when they received their diagnosis. Focus group participants also described not wanting to access HIV care at agencies known for providing such services because they feared being seen entering or leaving the building or running into people they knew. Many individual interview participants reported that prior to their diagnosis, they avoided HIV testing due to concerns about confidentiality and HIV stigma, which resulted in delays in diagnosis.

> "Someone telling your business like that, you know, with me having psych issues as well as being HIV positive, that could send me in a downward spiral until I want to kill myself or do some harm to myself." (African-American interview participant, 39)

Fatalism and Avoidance

Some participants reported that they knew they were at high risk for HIV and felt that their infection was inevitable. This was compounded for African-American participants due to the high rates of HIV associated with both their race and gender. Some participants described negative experiences in the healthcare system in the past due to transphobia and thus were reticent to test and then receive a stigmatized diagnosis that would require them to access additional healthcare. Four participants reported that they were diagnosed in mandatory HIV testing sites due to avoidance of public testing sites, and one was diagnosed in a housing facility.

> "I got arrested and in [that state], if you get arrested for prostitution or any type of sex crime, it's mandatory that you take an HIV test, and basically…I was handcuffed and forced to take an HIV test, and strapped down

> because I refused." (African-American interview participant, age 48)

Reduction of HIV-Related Stigma Over Time

A few interview participants as well as participants in the focus groups discussed the perception that because HIV is so prevalent in the transgender community, and especially the African-American transgender community, they are much less concerned about confidentiality than when they were first diagnosed. They indicated that as they adapted to their diagnosis over the years, learned more about the epidemic, and received support from HIV+ peers, they were more comfortable living openly as an HIV-positive person. In fact, a few of the participants in both the individual interviews and focus groups discussed being actively involved in speaking and volunteering efforts on behalf of the HIV+ transgender community. They described the rewards of being a role model to younger transgender women who may be early in their treatment process and struggling to adjust to their diagnosis and participating in HIV-related and transgender activism.

> "Now that I'm clean and sober, I'm definitely on the right path. I'm proactive and I'm outspoken, and I'm an activist for HIV and AIDS. I'm an activist for transgender rights, you know, as a transgender woman, I should be afforded every right that someone else is afforded. But I know I'm not." (African-American interview participant, 54)

Competing Priorities Are Barriers to Antiretroviral Therapy Initiation and Adherence

Prioritizing Transition-Related Care

When participants described being in medical care but not HIV care, it was always in relation to receiving hormones from a provider. Hormones were often described as a primary motivator for participants to seek medical care, and other types of care-seeking behavior were usually described in relation to their transition. Focus group participants described how, especially early in their transition, they prioritized transition-related medical care over their HIV care. If forced to choose (due to time, money, transportation issues, etc.) between attending an appointment to receive their hormones or an appointment with their HIV care provider, they would choose to get their hormones first. Fears about drug interactions between hormones and HIV medications led some participants to forego antiretroviral therapy in favor of staying on hormones. This seemed to be especially true when they were early in their transition and believed that antiretroviral therapy would slow down the desirable effects of hormones.

> "I got so many appointments, I got to go to different pharmacies for my meds. I make sure I get my hormones though cuz I gotta stay on track." (Focus group participant)

Participants reported that this was less common for them as they got older, were further along in their transition, and became better informed about the importance of antiretroviral therapy. Most of the HIV providers that participants saw early in their transition were perceived as lacking knowledge about hormone therapy and were thus not well informed about possible interactions between hormones and antiretroviral therapy. However, focus group participants expressed appreciation that there are now more providers in the San Francisco Bay Area who are knowledgeable, able to provide both hormones and antiretroviral therapy to their patients, and can answer questions.

One interview participant (African-American, 38) described intense frustration early in her HIV treatment over her HIV care provider withholding hormones because she was having unexplained side effects when she began taking antiretroviral therapy. When she switched providers, it was discovered that she had a sulfa allergy that meant the antiretroviral therapy regimen she was on was contraindicated. She was able to resume her hormone regimen under this new provider but expressed ongoing resentment that this situation delayed progression in her transition.

A few interview participants reported that having primary care providers withhold hormones until their CD4+ cell count had increased encouraged them to be more adherent to their antiretroviral therapy regimen so they could resume hormone treatment. However, other participants reported that if their provider refused to prescribe hormones they would get them from somewhere else, such as a different clinic, the street, or the Internet, indicating that withholding hormones to increase antiretroviral therapy adherence may have dangerous unintended consequences. Focus group participants discussed the perception that earlier on in their transition, they were more likely to seek hormones without a prescription, but currently, it is relatively easy to get legitimately prescribed hormones in the San Francisco Bay Area.

Life Instability

Almost all participants reported that, especially when they were early in their transition and/or recently diagnosed, they experienced significant instability in their day-to-day lives, such as the unpredictability of their housing situation, health, income, food sources, and personal safety. This led to the prioritization of concerns they felt were more pressing than HIV care and contributed to difficulty managing the complex medication regimens and simply forgetting to take their medication. Those in the focus groups particularly emphasized that it was hard for them to manage complex pill regimens and the need to travel to several pharmacies for their medications. One interview participant described how the complexity and demands of her daily life often interfere with her ability to remember to take her medications, "Sometimes I mean to take them but I don't take them because I forget." (White interview participant, age 39)

Some participants noted that the time and energy it took to navigate complicated systems of care did not seem worth it to them when they were making money by engaging in sex work. The lifestyle of sex workers also precluded waking up early in the day for appointments when they had been up late working the night before.

> "[I am not currently using any of the services] because they cut back on a lot…you standing in line to get some services, you know, and it's not even anything compared to what you can really make yourself on the street or wherever. You know, so it's a waste of time." (African-American, 39)

Drug and Alcohol Use

Many women reported using drugs and alcohol to cope with transphobia and/or avoid dealing with the reality of their diagnosis, and many cited substance use as having interfered with their engagement in care and adherence to medications. A few discussed the importance of their recovery from drug and alcohol use and described themselves as currently "clean and sober."

> "[When I received my diagnosis] I went off the deep end and just went on a rampage and I was getting high because I never was really an alcohol drinker so mine was crank. It took 11 years for me to get myself together, to finally hit rock bottom two or three times." (African-American interview participant, age 46)

Participants in the focus groups discussed their frustration that culturally competent substance abuse treatment was not readily available, and treatment programs that segregate patients by gender alienate transgender people. The discussion focused on their experiences trying to access appropriate treatment. They discussed the fact that even when they were permitted to attend women's substance abuse treatment support groups, their issues were often so different and the women in the group so resistant to their presence that it was very difficult to stay, let alone receive the benefits of support from the group.

> "I personally feel that it's hard to concentrate on my recovery when I have to protect myself from things that people are saying to me. If there was another substance abuse program that would only focus on trans people, it would be great." (Focus group participant)

Unmet Service Needs Are Barriers to Optimal Engagement in Care

Housing

Housing was the number one service priority indicated in the focus groups, followed by medical services, mental health services, oral health services, substance abuse treatment, and peer support. Focus group participants discussed their perception that housing for those living with HIV is temporary, and that there were few low-income housing options available to them. They also expressed the need for transitional housing post-incarceration and a desire for trans-specific housing to protect them from the transphobia they often encounter from other residents. HIV-specific housing came with concerns about confidentiality.

> "Discrimination is a big barrier in obtaining housing… especially if you've never worked… People see you dressed and think 'Oh, hooker'. I'm a church girl and I do everything I'm supposed to do…but I can't get a job and I can't get housing." (Focus group participant)

Social Support

About half of the interview participants described profound isolation, particularly early in their transition and/or when they were first diagnosed, often attributed to early family rejection and loss of community when they transitioned. Many focus group participants described some connection to other transgender women in the community who they relied on for various forms of support, including housing, financial support, information about transition-related issues (e.g., hormones, dress), and guidance related to engaging in sex work. However, they reported that when they received their HIV diagnosis, they often did not feel able to rely on this same network for support related to their status. They feared the ramifications of HIV-related stigma, including possible loss of confidentiality and rejection by potential sex partners.

> "I don't have friends. I'm a loner. I have acquaintances. I have people that I choose to talk to about certain things and share. I have maybe one person that I can trust, you know." (White interview participant, age 39)

Some interview participants reported being close to at least one of their family members and a few described having at least one close friend at the time of their diagnosis. Having at least one supportive person to whom they felt they could safely disclose their diagnosis seemed to serve as a facilitator to accessing treatment earlier in the disease process. Focus group participants discussed the importance of peer support when accessing and staying engaged in care. In contrast to their fears about confidentiality when they were first diagnosed, they noted that once they were engaged in care, services such as peer navigation were useful and important. Focus group participants also expressed a desire for support groups led by transgender facilitators, and African-American focus group participants in particular discussed their preference for ethnicity-specific support groups when available.

> "There's nothing for the African American transgenders, specifically. If they do anything that's for the Black population they want to open it up to the men. The Black gay men….we need specifics, we need Black transgenders leading groups for us…[peers who are] working at these agencies." (Focus group participant)
>
> "We need to sustain our existence here in San Francisco which is geared more for White gay men. We're not White gay men. " (Focus group participant)

Mental Health Services

About half of the interview participants reported currently using or having used some form of mental health treatment, including psychotropic medications. Focus group participants discussed the need for more readily available mental health services aside from psychotropic medications. One focus group discussion of this issue was centered on the perception that medications to address their mental health problems were more readily available than therapy, which participants viewed as a problem.

> "I don't take medicine for my mental health but I do like to talk to someone. The thing is that right now I don't have that option. I have to write my name in a waiting list right now. I have to wait between 1 to 1 years before I get a therapist." (Focus group participant)
>
> "We as Black trans women don't want to address mental health because we think it's an ugly thing. But yet, we transition and we still have anxiety and we still have PTSD; we still have domestic violence issues; we still have all that. But yet, it's not being addressed. We're so busy addressing the hormones and the trans thing and the HIV that we're leaving out everything else. We're not dealing with the total package, the total person." (African-American interview participant, age 49)

Discussion

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, were reported as barriers to care among transgender women as well, but our participants described additional transgender-specific barriers as a result of transphobia and needs for gender affirmation and transition-related healthcare. This finding corroborates and expands upon the growing literature that documents the associations between access to gender affirmation and improved quality of life, mental health, and self-care behaviors [29, 39–42].

To better understand the observed disparities in health outcomes experienced by transgender women living with HIV, the transgender-specific findings will be the focus of the discussion here. Furthermore, the majority of our participants were African-American. This is reflective of the HIV epidemic among transgender women, and the perspectives of those who are African-American are predominantly reflected in our findings. From an intersectional perspective, while our sample was fairly homogenous in terms of other social variables (i.e., SES, age), it is important to consider the multiplicative impact of race and racism in the lives, social context, and healthcare experiences of transgender women of color in our sample.

Gender Affirmation in HIV Care Increases Engagement and Retention

Gender affirmation was of paramount importance to participants at every stage of the HIV engagement in care continuum. Our theoretical model integrating the Gender Affirmation Model and the Model of Health Care Empowerment clarifies how experiencing gender affirmation in healthcare settings may represent a necessary precondition for achieving healthcare empowerment for many transgender women. Gender affirming healthcare includes interactions with supportive providers who are knowledgeable about transgender health and affirming of their gender (i.e., being addressed by the proper name and pronoun, having supportive interactions in discussions related to their transgender status), as well as access to transition-related healthcare (i.e., hormones and/or surgery). For our participants, transgender sensitivity and knowledge on the part of providers and clinics were a crucial barrier when absent and a powerful facilitator when present. Negative experiences can result in avoidance of healthcare settings altogether [43–45]. Our findings corroborate other studies that 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 [46]. Diminished trust subsequently affected participants' decisions to initiate antiretroviral therapy as well as their adherence behaviors. When a provider has low levels of sensitivity and/or knowledge of transgender-specific healthcare, patients may assume they must make their healthcare decisions without the support of an informed provider. For our participants, this led to delayed initiation of antiretroviral therapy, taking drug "holidays," and impaired patient–provider communication. As described by our theoretical model, gender affirming healthcare supported engagement and retention in HIV care among transgender women by increasing patient–provider trust, fostering positive interactions, and supporting a collaborative relationship.

Currently, few formal medical education programs include transgender-specific medical care in their training of providers [47]. Training providers to conduct thorough yet respectful health assessments, including mental health and sexual health, and the creation of safe clinic spaces will help build trust and rapport with transgender patients. For example, intake forms should permit patients to self-identify as transgender, records should identify their preferred name and pronoun, and this documentation should be handled as sensitive and confidential health information. Efforts are currently underway to allow for the identification of transgender patients using electronic medical records [48] and guidelines are available [49].

Integration of Hormone Therapy and Antiretroviral Therapy in Primary Care Settings

Transgender women living with HIV are often juggling 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 initiated antiretroviral therapy, our participants often experienced barriers to integrating the regimens into their daily lives. This substantiates our team's previous quantitative findings that transgender women reported significantly lower self-efficacy in this area than non-transgender people [50]. Our participants reported that 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 [51–53]. Seeing the same provider (or at the very least, being seen at the same clinic) for both hormones and antiretroviral therapy made it easier for our participants to manage their appointments and medications, increased the likelihood that they kept their appointments due to their high level of motivation to adhere to their hormone regimen, and increased trust in their provider. Several resources are available to guide the provision of hormones for primary care providers who are new to treating transgender patients [54, 55].

Meeting Transgender Women's Service Needs

Our participants reported that they often feel most comfortable with outreach and program staff who are also transgender. However, when testing for HIV and in the stage of early diagnosis, confidentiality was of extreme importance. The need for peer support and the need for assurance of confidentiality should be carefully balanced. Concern about HIV-related stigma among our participants decreased as they described becoming more comfortable with their diagnosis over time. This was especially true for our African-American participants who reported that they perceived HIV to be so pervasive in their communities that HIV-related stigma was not of much concern, particularly after they had lived with the diagnosis for many years.

Transgender staff who already have established relationships with the community that the program seeks to serve can be indispensable in terms of engagement and retention. Our participants reported placing a great deal of trust in the recommendations of their peers in terms of where to seek culturally competent services. In addition, our participants reported that 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.

Our participants reported that when seeking social services, they preferred transgender-specific services when possible, but at minimum wanted reassurance that the services they sought would be transgender friendly. Programs such as a transgender-specific portal to a larger health clinic, use of peer health navigators, and holding transgender-specific clinic hours are models that have been successful [51]. Our African-American participants further preferred ethnicity-specific services whenever possible. They reported the perception that HIV services tend to be geared toward White gay men and felt that even those HIV-related services that were geared toward African-Americans tended to then cater to gay men. In addition, services that increase social support and build community may help to reduce HIV-related stigma and support transgender women in coping with life stressors related to transphobia.

Theoretical Model: Gender Affirming Care as Powerful Facilitator of Healthcare Empowerment

Based on these findings, we propose a theoretical model that integrates the Models of Gender Affirmation and Health Care Empowerment [29, 32]. Getting one's needs for gender affirmation met may serve as a pathway to healthcare empowerment for transgender women. Our participants reported that when their gender affirmation needs are met, they are more likely to be engaged and collaborative in their healthcare due to increased trust in their provider and more committed and informed due to increased motivation to engage in self-care behaviors. This model may be useful in the development of interventions, policies, and future research aimed at optimizing HIV treatment engagement and retention among transgender women.

Limitations

The current findings are drawn from a convenience sample of transgender women living with HIV in the San Francisco Bay Area, and most participants were either already connected to our research through a cross-sectional survey or were connected to an agency. These findings may not generalize to transgender women who are more isolated or significantly different from our sample in other ways. Our sample had a mean age of 49; younger transgender women may report different barriers to care. The interviewers who conducted the individual interviews were both male, while the focus group facilitators were both transgender women. This may have affected some participants' ability to be as open and honest as possible in their responses, and face-to-face interviews may increase participants' motivation to provide socially desirable responses. Some aspects of the interview were retrospective, and recall about early experiences may not be as accurate as recall about more recent experiences. All of our individual interview participants were receiving HIV care services in the San Francisco Bay Area at the time of data collection. As this area is comparatively rich in resources dedicated to serving the transgender community, transgender women living with HIV in other areas may experience additional or more intense barriers to care that are not reflected here. Our methods did not permit a quantitative assessment of interrater reliability [56, 57]. Thus, the analysis conducted by the primary coder may have influenced the analysis of the secondary coder. We compensated for this possibility by having the secondary coder provide dissenting viewpoints and/or expanding upon the analysis of the primary coder.

Conclusion

Engagement and retention of transgender women 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 women's lives and address the multiple barriers to healthcare engagement, treatment adherence, and empowerment that serve to create, maintain, and deepen HIV-related health disparities among transgender women living with HIV.

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