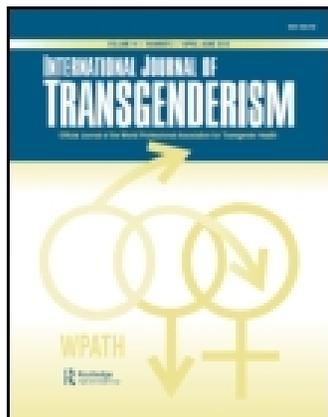


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Access to HIV Care and Support Services for African American Transwomen Living with HIV

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ABSTRACT. Low access to HIV care and support has led to survival rates for transwomen that are half that of other populations at risk for HIV. Within the population, HIV disproportionately impacts African American transwomen. Interventions to increase access to HIV care and support are needed to better serve those most affected and vulnerable within the population. We conducted a study of barriers to care and support services for African American transwomen to fill a gap in the literature to improve access for this population. A total of 10 in-depth interviews were conducted with African American transwomen with HIV who lived outside the metro area of San Francisco. Three overarching thematic topics emerged—gender stigma, peer, and institutional distrust—giving insight into African American transwomen’s barriers to HIV care and support services. A number of factors within these themes impacted access, such as whether organizations offered gender-related care, the geography of organizations as it relates to safe transportation and location, confidentiality and trust of peers and organizations, and trauma. Specific instrumental, institutional, and emotional supports are recommended for increasing access to care and support services for African American transwomen living with HIV.

KEYWORDS. Culture/cultural competence, gender, ethnicity, HIV/AIDS, marginalized population, relationships, research, qualitative, stigma, transgender

Data from around the country and world suggest that transwomen may be the most disproportionately impacted group affected by HIV (Herbst et al., 2008; Poteat, German, & Kerrigan, 2013). In the San Francisco Bay Area, transwomen have the highest HIV prevalence of any risk population, the highest proportion of AIDS cases, and the fastest rate of death due to AIDS (San Francisco Department of Public Health [SFDPH], 2008). Of all HIV cases diagnosed in 2011, transwomen were more likely to be non-White, be injection-drug users,

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and have been diagnosed between ages 20 and 29 (compared with between 30 and 39 for other groups; SFDPH, 2011).

Within the population, evidence from numerous studies has suggested that ethnic/minority transwomen are at increased risk for HIV infection (Clements-Nolle, Marx, Guzman, & Katz, 2001; Herbst et al., 2008; Nemoto, Sausa, Operario, & Keatley, 2006). For example, African American transwomen in California have a substantially higher rate of HIV diagnosis (29%) than all other racial or ethnic groups (Rapues, Wilson, Packer, Colfax, & Raymond, 2013). A recent population-based study of HIV risk within the population also found that African American transwomen made up almost half of all HIV-positive cases in a sample of 341 transwomen and that race was significantly linked to HIV risk (Rapues et al., 2013). The same study found that despite a decade of focused prevention efforts, the HIV prevalence of transwomen in San Francisco has gone up and continually impacts African Americans more (Rapues et al., 2013; Rapues, 2012).

The burden of HIV in transwomen is exacerbated by low access to HIV care. Data from transwomen in San Francisco show they have a significantly higher community viral load compared to other populations at risk for HIV. This finding suggests that a greater proportion of the population are not receiving adequate HIV care, are not virologically suppressed, and/or are not engaged in HIV care (Das et al., 2010). Indeed, we have observed significant gaps in service delivery along the HIV care continuum for transwomen. Based on annual HIV surveillance data, antiretroviral therapy (ART) coverage among transwomen was modest (65%) relative to the overall San Francisco ART coverage (83%–89%; SFDPH, 2011). Similarly, Melendez and Pinto (2009) found inadequate HIV care and adherence for HIV-positive transwomen reporting less use of ART when compared to a sample of nontransgender HIV-positive patients.

Retention in care has been found to create dramatic improvements in health outcomes among people infected with HIV (Horstmann, Brown, Islam, Buck, & Agins, 2010). Although many marginalized populations may access care at

some point, retention in regular and consistent care is low (Rumptz et al., 2007). Support services have been found to have a positive impact on access and retention in HIV care services, especially among marginalized populations (Horstmann et al., 2010). Support services serve as a critical bridge to HIV care for socially marginalized HIV-positive people via outreach, education, case management, and social support (Rumptz et al., 2007). Services that support the multifaceted needs outside of medical care for HIV-positive transwomen may be critical to access and retention in HIV care services. Yet little research has been conducted to understand access to and retention in HIV care and support services for HIV-positive transwomen, especially those disproportionately impacted by HIV in the transgender community.

Providers have speculated that transwomen are deterred from ART due to concerns over masculine side effects (Carrico, Johnson, Colfax, & Moskowitz, 2009). There are also likely structural barriers to care that may be more important than individual decisions, such as a lack of transgender-specific services outside of major metropolitan areas like San Francisco, and related costs and time constraints of living in or traveling to San Francisco where services exist (Sevelius, Keatley, Iñiguez, & Reyes, 2008). For example, many transwomen cannot afford to reside in San Francisco where the average price for a studio apartment in 2011 was \$1,800, which is well above the average income in the population (Rapues et al., 2013). A more viable option may be to find services in areas outside of San Francisco for transwomen who reside elsewhere. However, research on access to care for transwomen at lesbian, gay, bisexual, and transgender (LGBT) community-based clinics and organizations in nonmetro areas has found that funding constraints often force organizations to encompass transgender services within those for men who have sex with men (MSM; Melendez et al., 2006). Since most transwomen do not identify as MSM, these services may not be appropriate for transwomen (Clements-Nolle et al., 2001; Operario, Soma, & Underhill, 2008).

This study was conducted to fill a gap in the literature about structural and individual-level barriers to care in a population most impacted

and with the least access to HIV care—African American HIV-positive transwomen outside San Francisco, in Alameda County, California. Findings from this study have direct implications for organizations seeking to increase access and retention in HIV care and support services for African American transwomen living with HIV, especially those in areas outside major metro areas, where care is more readily available for those in the transgender community.

METHODS

Data Collection and Participants

This study was conducted in collaboration with a local community-based organization that was interested in better serving transwomen in their social service agency, which at the time served HIV-positive, nontransgender women. The aim of the study was to specifically address access to support services and care for transgender women in Alameda County, which is 25 miles from San Francisco across the San Francisco Bay. Community leaders in HIV/AIDS and transgender health were engaged for their input on study instruments, recruitment, data interpretation, and dissemination.

Semistructured, in-depth qualitative interviews were conducted with 10 African American transwomen living with HIV. The first author (Erin C. Wilson) conducted all interviews and is an expert in qualitative research. All interviews were audio-recorded and transcribed verbatim. Field notes were also taken. Interviews focused on exploring transwomen's HIV story, exploring their support service and care experiences, and investigating barriers and facilitators to HIV care and support services. Participants were recruited through referrals from community-based organizations that serve transgender women living with HIV. All but one participant accessed publicly funded HIV care services. Participants were interviewed in locations that felt safe and convenient to them, including coffee shops, their apartments, community-based organizations, and on the street. On average, interviews took 2 hr to complete. Institutional Review Board approval was obtained from the University of California,

San Francisco, and all participants were given an information sheet and provided verbal consent.

Setting

Alameda County is located across the bay from the city of San Francisco, and Oakland is the major city in Alameda County with a population of a little less than 400,000 residents. Oakland has historically been a city with a large African American population. The 2010 census found that African Americans made up the second largest ethnic group and almost 35% of the overall Oakland population. As of December 21, 2010, there were 10,243 persons estimated to be living with HIV in Alameda and neighboring Contra Costa counties, with the majority of cases among African Americans (41.8%; Oakland Transitional Grant Area Collaborative Community Planning Council, 2012). The bulk of AIDS service organizations and HIV care providers serving Alameda County residents are located in Oakland. Relevant to those data, Oakland was recently ranked as having the 12th highest crime rate in the United States, and in recent years there have been a number of high profile murders of transwomen (CQ Press, 2012).

Data Analysis

Textual data were assessed iteratively in two main stages based on thematic content analysis. The primary author initially took a deductive approach to the first pass of the data by developing structural codes to identify the constructs of interest—namely, barriers and facilitators to support services and HIV care for transwomen living with HIV. The primary author then worked with additional authors to inductively code data and identify salient themes in the data that more holistically spoke to the multitude of individual and structural factors impacting access to support services and HIV care in the data. The most salient theme that emerged in the primary author's analysis was stigma and discrimination. Based on this finding, the second inductive codebook was developed collaboratively by all authors to capture stigma external to transwomen in this sample and that were experienced within the community.

Field notes, transcripts from audio files, and codes were used in the analysis. Patterns within and across categories were then identified and interpreted. Final data analysis for this study began with data reduction, then display, analysis, and conclusion drawing using a conceptual framework in which stigma and discrimination were the primary drivers of access to care among transwomen living with HIV (Denzin & Lincoln, 1998). Atlas.ti software was used to both code and develop data displays used in the analysis for this study.

RESULTS

The 10 African American transwomen living with HIV in Alameda County ranged in age from 28 to 55 years old. Three main themes emerged from these data to explain barriers to HIV care support services: gender stigma, peer distrust, and institutional distrust. The most salient facilitators to HIV care were people and organizations that provided instrumental, emotional, and informational support. Further in-depth analyses revealed why these factors emerged as salient barriers and facilitators to HIV care for transwomen living with HIV and how some women adapted to these constraints to find creative ways to maintain their care regimen. Quotes are provided to illustrate the main thematic topics.

Barriers

Gender Stigma

Gender-related stigma impacted HIV-positive transwomen's relationship to care. Transwomen in this setting reported being socially isolated and secluded due to the fear of violence while out in public. For many participants, their trauma from previous experiences with violence was related to their gender identity and/or gender presentation. For many, trauma and fear were also related to the reactions of others in the African American communities where they lived who were unaccepting of their gender presentation. The experiences the participants had related to their neighborhood and gender presentation

engendered a fear of societal reactions to them while in public. As one participant explained,

[a] lot of people are afraid of being ridiculed. A lot, a lot of people are afraid of people making them feel badder than they already feel, 'cause how society didn't already make them feel and now they just trying to crawl back up and then they go somewhere and then they get knocked down again.

Transwomen in this study faced the added burden of finding ways to navigate everyday life without being identified or stigmatized as transgender. For African American transwomen in this study, and specifically for those who did not present as women all the time or whose gender presentation was less gender conforming, taking public transportation, walking outside in their neighborhood during the day, and generally being visible was highly risky. A number of transwomen reported that they wanted to be accepted as they were, go unnoticed, or pass as women to avoid violence and harassment. However, one participant explained how the opposite usually occurred—transwomen were consistently noticed in public, which posed a threat to their safety and well-being. This participant attributed noticeability to the fact that some transwomen maintained some of their male gender dress and appearance, or as she put it best:

A lot has to do with a lot of them aren't 24/7, so, catching a bus in certain parts of the area, going to the doctor and all that, being humiliated on the bus because they look different and they're kind of a boy, but they're not, but they're kind of a girl and stuff like that . . . I guess they're not really comfortable being that way during the day time because they probably don't feel like they, you know look the part.

Transwomen considered the ability to be safe in public when determining how they were physically going to present. Transwomen who felt unhappy with their presentation may have only presented as women "part-time," while in safe spaces (e.g., clubs or transinclusive

social spaces) or at night. In this instance, the participant explained that public transportation, especially during the day, left transwomen vulnerable to violence and humiliation. Consequently, some HIV-positive transwomen reported being reluctant to travel to HIV care appointments, which would require taking public transportation during the day when appointments were offered. For some transwomen, going outside during the day at all was avoided, and they came out only at night, when they were less visible. According to some participants, this was associated with other risks for targeted violence. One participant explained,

Risks are high for those only out at night . . . I was out there all nights and all hours of the nights and I knew what went on there and I knew it . . . the trouble. And I got myself hurt a couple of times at those hours. So now I don't be out there and I don't do that. I ain't getting hurt no more. So I don't put myself in that kind of situation.

These examples of how stigma influenced HIV-positive transwomen's decisions to attend or miss their HIV care appointments were underscored by the socioenvironmental context of downtown Oakland, which is where many African American transwomen spent their time but also an area that was dangerous and lacking safe spaces where transwomen could socialize. One participant explained, "Nowhere out here in Oakland [for transwomen to go] 'cause Oakland they be saying they too much, they be starting too much stuff or troubles out here, too much fights and stuff." Another participant emphasized Alameda County as transgender-resource poor saying, "There's nothing out here [in Alameda County] for us. Nothing, but prejudice."

Peer Distrust

The participants in this study also described how social competition and HIV-related stigma from other transwomen caused distrust and impacted access to support services and HIV care in places where programs specifically targeting the community existed. Distrust was

characterized in numerous ways. One participant explained that transwomen are competitive, reacting with jealousy and anger because "you look better than them." One participant described how transwomen were known to "out" their transwomen peers who looked more like nontransgender women when they would "start spreading to everybody—[whispering] 'That's a man!'" This participant went on to say that she felt like she was put "underneath a microscope" by her peers who were always policing her appearance. Another participant characterized the transgender community as "cut-throat" explaining that she "prefers the gay boys more 'cause they treat [her] better than the queens do because they be cut-throating each other."

The competition transwomen experienced among peer groups of transwomen created distrust in their social networks. This distrust transwomen had of peers extended to a fear that peers whom they could not trust, if those people found out they were living with HIV, would disclose their HIV-positive status. Specifically, transwomen were fearful that people would assume they were HIV-positive simply because they were seen entering or being near agencies that were known to provide HIV care. One participant attributed the high likelihood of seeing the same people "at the club and at the hospital" to the small, interconnected social network in the community of HIV-positive transwomen—that is, most people knew each other and therefore, there was a lack of anonymity.

. . . because we know we don't have to be ridiculed . . . [referring to a local clinic], everybody was able to look in the window and see you over there and see you going there and they said, "Oh, she got AIDS. Psss, psss, psss." And then there was the whispering . . . where people was like . . . I was, you know, I was [labeled as positive] before I even knew I was positive. I was like scared to walk on that side of the street, like, "Oh no they not going to say I've got HIV!" you know, I was like that.

Hence, some transwomen were reluctant to attend care appointments at clinical sites that

were centrally located in Oakland where the possibility of seeing peers was high. One participant described being fearful of being outed as HIV-positive because she attended a clinic where her peers were also served. This high likelihood of running into other transwomen paired with the distrust within this community was an important barrier to her HIV care. As one participant explained,

[t]he main reason is, “I’m not going there [HIV care site], because I heard this person goes there, that person goes there,” or, “I don’t want to see anybody that know me.” . . . [I]f they come here it’s only, what? A couple of places to go, so you’re going to run into somebody. Just like at [x] Hospital, you go there you can see a whole . . . everybody you’ve seen at the club last night you see them at the hospital. And a lot of people don’t want that.

Institutional Distrust

Participants reported a number of different types of negative experiences with HIV care organizations that decreased willingness to access HIV care and support services. As a result, long-term engagement in HIV care was reportedly tenuous and intermittent, characterized by changing providers, switching HIV care organizations, and being further dissuaded to play an active role in their HIV care. One illustrative vignette came from a participant who discussed how an HIV care organization made her sign a contract promising that she could only seek her HIV care and support services there. This participant reported being fearful of losing access to HIV care altogether if she sought services elsewhere and so she complied with her contract, despite challenges with her HIV care services at this organization. After more than a year receiving HIV care services at the organization, she found out from another provider that the contract was not binding and she was free to access services anywhere she chose. Thus, her trust in providers overall was greatly reduced and she was reluctant to access care services at a new agency.

Others distrusted their providers because they were not treated as partners in their care, were treated coldly, and/or were not given accurate information about their health. For example, one participant described her providers’ services as rote and uncaring. Alluding to having higher expectations she said, “They just go through the format. I mean medication, blood draw, and uh, medication, blood draw, and check-up. That’s about it, that’s all I can expect from them.” Another participant described an early care experience and reported that “the people giving you the information go through it really fast because they’ve given it a hundred times. So as a new person, you don’t learn anything, and then when you ask questions, they make you feel small . . . like stupid.” In other instances, women experienced a loss of trust due to not being a full partner in their own HIV care. One participant described a time where she found out that her CD4 T-cell count was not what she had been told it was, leaving her feeling as if her HIV care organization had “let [her] down”:

When I was tested positive I was 146 [CD4] with 82,100 [viral load] and then a month and a half after I got on the meds, the first set of meds, they told me, this is what they told me, wrote down for my caseworker, “Your CD4 count is 700 and you’re almost undetectable. You’re at 40 so you’re really good.” When I started asking for copies of my medical records and, you know, just let me keep my own things just for my own benefit . . . I was going through my records and I noticed that in all of the months that I’d been there, not one of the lab reports says that I was over 700 [CD4]. The highest on my CD4 count was 265.

The distrust and negative experiences in the HIV care system were exacerbated by the transgender-related stigma participants experienced. One woman, for example, was referred to a number of support services from her provider, but the services were within substance use programs and organizations serving sex workers—two behaviors that she did not report to her provider. This participant stated that she felt that she was being stereotyped as being a sex

worker and drug user simply because she was a transwoman living with HIV:

[The HIV care organization] sent me to every prostitute recovery program that there is to get services. Well, there's nothing that they can offer me. You know, I was celibate for 4 years before I got raped, so I know about abstinence and long term relationships and being monogamous and being, you know, frugal with your body.

The participant expressed frustration at being referred to services she did not need. This participant reported leaving the organization that gave her the inappropriate service referrals, thus limiting her access to HIV care.

Another participant described a need for more complex, comprehensive health education and information from her HIV care provider:

Yeah, because I just recently found out that I had Hepatitis B. And I just recently, and all they gave me was a little bitty pamphlet with three pages, and that's it, you know what I mean? They didn't tell me nothing about it, you know, anything because they didn't have no time or whatever. But, you know, I just recently found out about that. That was a shocker, you know, I really don't know, I still don't know what it can do to me and how detrimental it is to my health. I still don't know, right now to this day I don't know how detrimental it is to my health . . . I'm just scared that it might progress to Hepatitis C, that's what I'm scared of.

This participant's lack of understanding of her comorbid HBV/HIV status demonstrates how unsatisfied she was with her HIV care and support services.

Some participants also had an expectation that there would be transwomen on staff at places where they sought care. Even at care organizations where transwomen served as staff, some participants questioned the extent to which transwomen played a vital role in the organization and were valued. One participant elaborated on this doubt in the following passage:

[Transwomen] shouldn't be discriminated like that, they should, they don't have jobs just like everybody else, you know what I mean? . . . They [employers] push you to the back, to the last burner, to the last end, you know what I mean . . . Most the trans[women], they do stuff like pass out condoms, pack condoms . . . you know what I mean? Stuff like that, which is low on the totem pole.

This participant emphasized the "low rank" jobs that she has observed transwomen having in HIV care and support service organizations. Suggesting that there is little value and not enough responsibility of front-line HIV prevention work such as outreach, this participant expressed sentiments that underscore the importance of strong visibility of transwomen in the workplace in positions of greater influence and higher status.

Facilitators

Instrumental, Emotional, and Informational Support

A consistent theme throughout these data was the importance of providing instrumental services, or those that are direct, tangible forms of assistance, in order to engage and retain HIV-positive transgender women in care. Participants in this study reported that organizations that provided instrumental support, providing services such as food, gift certificates, and a physical meeting space, had success in engaging transwomen in HIV care (see Table 1 for recommendations for increasing access to care). One participant explained why the provision of instrumental services is important to HIV care engagement and retention:

Well you just, you got to make it interesting, you've got to have something there for us, somebody, 'cause you see ain't nobody going to come if you don't have nothing there or they ain't doing nothing or to have something, some type of food or something there for them, you know. Something like that, you'll always keep them in, you know.

TABLE 1. Recommendations for HIV Care and Social Service Providers for Increasing Access to Care for HIV-Positive African American Transwomen

Barriers	Recommendations	Facilitators	Recommendations
Gender stigma	<p>Tailor clinic hours to HIV-positive transwomen's preferences; some women, for example, may be more likely to make the commute later in the day or evening.</p> <p>Locate clinic spaces at a hub of multiple lines of transportation; some HIV-positive transwomen may benefit from having more transportation options to maintain anonymity and safety.</p>	Instrumental support	<p>Provide hormone therapy and gender-related care which are extremely incentivizing of engagement in care.</p> <p>Offer transportation to appointments.</p> <p>Offer incentives that can be used for basic needs.</p>
Peer distrust	<p>Offer safe spaces for HIV-positive transwomen to convene and build a collective identity.</p> <p>Have clinic patients sign a confidentiality and nondisclosure agreement upon accessing services.</p> <p>Consider rebranding clinic names to omit stigmatizing terms (e.g., HIV clinic, AIDS clinic, transgender health clinic). This may minimize the number of unintended disclosures of HIV or transgender status simply by being near or at the clinic.</p>	Emotional support	<p>Provide staff training opportunities and strategies to effectively communicate and maintain rapport with patients.</p> <p>Integrate patient satisfaction assessments of provider interactions into regular quality-improvement initiatives.</p> <p>Offer accompaniment to clients to medical appointments (Higa, Marks, Crepaz, Liau, & Lyles, 2012).</p> <p>Provide opportunities for social connections through volunteer jobs at care agencies or give information out about other volunteer jobs available.</p>
Institutional distrust	<p>Develop and discuss standards of care and practices that emphasize quality, transparency and patient-centeredness in the clinical encounter.</p> <p>Assess patients for the quality of previous clinical encounters; some HIV-positive transwomen may be traumatized as a result of previous bad experiences.</p> <p>Develop a referral protocol that includes an assessment to determine the "goodness of fit" of specific health education or behavioral programs for each patient to avoid reinforcing stereotypes about HIV-positive transwomen.</p> <p>Discuss how to meaningfully involve patients or other HIV-positive transwomen in visible roles and responsibilities in the clinic infrastructure and operations.</p>	Informational support	<p>Discuss the role of trans-sensitivity at an institutional level and implement a series of continuing-education opportunities for staff.</p> <p>Actively involve the patient in their HIV care through increasing transparency and access to their medical record for informed decision making.</p> <p>Make information available in waiting rooms and exam rooms (Higa et al., 2012).</p>

Like we give the gift certificates to the girls here, that's why we always have girls come, 'cause a lot of the girls be needing that stuff.

Transwomen in this study were clear that they needed incentives beyond HIV care and support services, especially those that helped them meet their basic needs. The majority of participants was on SSI, general assistance, or other entitlement program assistance and lived on a fixed income, and most participants emphasized how important instrumental services became in their decision to seek care.

Another key component of instrumental support that facilitated participants' access to HIV care was access to gender-related care. Access to hormone therapy appeared to be as important as food for many participants. One participant's HIV care was provided through the same clinician who administered her hormones, and the hormone access was what motivated her to maintain her care regimen:

I go to my doctor's, because I'm also on hormone replacement therapy too. And see those run in the same, I get those from my same doctor, so therefore I must see my doctor, so I can get my hormone replacement therapy . . . [I] have to go in, because I'm not going to miss my hormones.

Access to care and support services was also facilitated by structural factors like transportation and anonymous or safe locations of organizations. One participant used the subway to get from place to place because she felt it was a more private and safe mode of public transportation than using the bus. As she stated, "[n]obody's really messing with nobody or bothering nobody or paying nobody no attention. But on the bus, there's a lot of kids on the bus laughing."

In terms of location, participants expressed strong preferences for San Francisco over Alameda County for a variety of reasons:

I love the atmosphere [of San Francisco]. People are more nicer too, much nicer, more openly and homey-like. But I'm talking about feelings, like, that good feeling vibe of being over there. I love

walking through the shops and everything. I don't even need no money. You can just have a look, and it just feels good.

. . . because people [in Oakland] still are homophobic and people will sometime bother you . . . San Francisco is the capital, it's the gay capital. You can be yourself; you can do whatever you want to. But in Oakland, you got to be ready to cut somebody, because they're going to try you. You know, if you don't bother people I figure that if I don't bother you, don't bother me, but people is not like that over here [in Oakland].

One participant mitigated the risks of exposure to peers and others who might assume she is HIV-positive and out her by using the back entrance of the HIV care clinic in Alameda County she attended, because having to walk through the busy front entrance was "like a stage."

The provision of emotional support by the service providers was also an important facilitator for some study participants. The mechanisms through which HIV care and support service organizations offered emotional support for HIV-positive transwomen were numerous. Feelings of support were very simple for some. A participant explained that "[t]hey all understand. They know my lifestyle, you know what I mean, they all understand and they know my lifestyle." Another participant also stated, "They [HIV-positive transgender women] need the space, they need space out of their space . . . they can just let their hair down and be who they are." For others, emotional support came from the honesty in peer-led interactions where a strong sense of altruism and gumption prevailed. One participant, for example, described interacting with a peer leader employed at her HIV care organization saying,

I was on drugs then when we met, and she was one of the girls that took me to go, to clean up, she was like, "Come on, let me take you over here." 'Cause she seen how it was and she fed me and stuff and helped me out. So when I got myself better

and clean off of drugs, me and her kind of connected again.

For this participant, a like individual was there for her in a time of need, making a strong positive impression. Another participant characterized ideal expectations of a relationship with providers, emphasizing the honesty associated with the caring role and which cannot be mass-produced or overworked. She explains,

You're going to have to let them know that you are truly there to help them and not just to do a job, you know. 'Cause some people are just doing their job, but some people put more of themselves into it, and this woman put more of who she was for me, out of her heart. And um, I really miss her too, I miss her, I really miss her.

Another participant described the caring relationship with her HIV care team as "trans-sensitive" saying, "I think the approach is very welcoming—a lot of private rooms where you can actually express yourself . . . The whole staff treats [you] with dignity and respect and they talk to you as though you are a person." The majority of participants in this study emphasized that the authenticity of "true" caring, as opposed to merely performing a job, was important.

Social connectedness was also a form of emotional support that may encourage access to care and support services for transwomen. In discussing their relationships with the communities they lived in, participants identified volunteerism as a means to not only structure their day but also increase their perception of self-worth. A participant explained the impact of volunteering for her HIV care organization: "By me being able to get up and go to work there, it gave me something to do . . . It made me feel good and I'll be there sometimes five in the morning 'til two, three o'clock in the afternoon." Another participant expressed a desire to volunteer but said she did not have transportation she needed in order to afford the commute. This reinforced the dual nature, patient and peer volunteer, at HIV care organizations, where HIV-positive transwomen were able to receive HIV care and give back to the community.

Participants also described the desire to better their relationships with their family and get family support to achieve life goals, like home ownership and having a family.

HIV care and support service organizations also offered comprehensive information to promote informed decision making, or informational support. Many participants described information about instrumental support services (e.g., insurance coverage, support groups, navigating social welfare services) as valuable types of informational support. However, informational support with regard to understanding one's medical prognosis and health status appeared to be especially highly valued. One participant explained,

My first doctor I had, he was a big impact on me too and he was a gay guy . . . he really brought my spirits up and helped me understand what I was facing and what I was going through and for me to start taking my medicine and stuff, what I'm going to be going through. It was a real big help.

DISCUSSION

Access to and retention in care has been found to create dramatic improvements in health outcomes among people infected with HIV. Findings from these data illustrate ways in which care and support service programs may better increase access to care for transwomen by providing wrap-around services, hormone and other gender-related care, opportunities for social connection to providers and peers, safety in the form of alternative appointment times when transwomen are more able to travel via public transportation, and organization locations that are safe and anonymous. However, substantial barriers persist that require larger policy and community safety efforts to address structural issues like community violence and stigma toward transwomen in order to increase access to care and support.

As transwomen in this study expressed, gender-related violence was particularly prevalent in their geographic locale, which created

trauma and fear that impacted access to care. One important example was fear of transporting themselves to care appointments via public transportation. In Oakland, the two high-profile deaths of transwomen and the burning of a gender nonconforming youth on a public bus last year are emblematic of the violence that encircles transwomen in the area (Anthony, 2012; Emslie, 2013; Guthrie, 2013). This fear seemed to be exacerbated by experiences of interpersonal transphobic violence that created fear of their neighborhood that was intimately tied to their gender identity.

In a study of transwomen and cisgendered women, trauma was the single significant factor in a list of behavioral, economic, and health-related factors related to ART failure (Machtiger, Haberer, Wilson, & Weiss, 2012). In this same study, reporting trauma was associated with a 4 times greater odds of ART failure, which speaks to the critical importance of trauma on HIV-care adherence for women overall. A local report from Alameda and Contra Costa health departments noted in their HIV services plan for 2012–2014 that violence is highly prevalent in areas where transwomen live and work, which is an added cost to providers, as street outreach and intensive case management are the ways in which organizations currently address this issue (Oakland Transitional Grant Area Collaborative Community Planning Council, 2012). Immediate efforts to raise awareness of violence against transwomen and get support from law enforcement and other entities are urgently needed to increase safety and access to care. In the longer term, more analyses and data are needed to explore ways in which bias and the intersections of race and gender impact access to care for ethnic/minority transwomen living with HIV, especially in high-crime locales where stigma may be exacerbated by the environment.

This analysis found that for transwomen living with HIV, the high level of distrust of other transwomen, even those who are also HIV positive, is a barrier to care. Anecdotally, reports of distrust within the transwomen community have been tied to competition over sexual and steady partners. We found that within this subpopulation of African American transwomen,

distrust of peers was due to a fear of disclosure of participants' HIV status; such distrust was also found to exist in another study of transwomen attending diverse transgender-specific programming (Parks & Woodson, 2002). Distrust was driven by past experiences of unwanted disclosure by peers and the ramifications to livelihood for those who were sex workers on safety and on the ability to find partners in the future. Distrust was operationalized as a barrier by increased wariness of going to organizations where participants' may run into other transwomen. This limited space reduced transwomen's ability to have anonymity, feel safe, and avoid fears of disclosure. Unfortunately, many of the organizations where this sample of transwomen accessed care were geared toward serving the transgender population, thus accessing care in places where participants would not encounter other community members proved difficult.

One possible solution to this problem of trust within the community is to have HIV care and support services provided in settings that are not dedicated to serving the LGBT population, as Melendez and Pinto (2009) suggested in their study of access to primary health care for transwomen. An interesting finding from San Francisco was that transwomen and women have low ART use in common. And compared to men, both groups of women also had no insurance or public insurance at the time of an AIDS diagnosis between 2003 and 2008 (SFDPH, 2008). These data point to overlaps in care needs that may reflect similar support service needs among HIV-positive transwomen and nontransgender women. Research is needed to assess barriers to access and retention in support services for HIV-positive transwomen and to explore the integration of HIV-positive transwomen into services for women. Participants from this study offered additional ideas for overcoming structural barriers such as offering alternative hours and delocating care venues out of central places where African Americans in the community congregate. Since HIV care organizations operate during the day, HIV-positive transwomen are required to be out during the day in order to access and maintain engagement in HIV care. Having night hours

for appointments and less centrally located care locations could help thwart the risk transwomen have of being visible during the day and in areas where disclosure of HIV is a threat due to the likelihood of seeing peers.

Yet an equally important problem remains related to distrust in the community that may impact HIV care and prevention. Research with gay men has found that community involvement counters the negative effects of anti-gay bias on sex practices among gay men through social support that stresses health and protecting oneself from risk (Ramirez-Valles, 2002). For many transwomen, one of the only known places to find community and social support is the sex work community, which is a risky social network for transwomen (Reisner et al., 2009; Sugano, Nemoto, & Operario, 2006; Wilson et al., 2009). Antistigma work is needed in all communities with support from the federal government, leaders, and media to increase the ability of transwomen to be visible and develop healthy relationships. Additionally, acceptance from the broader LGBT community may thwart some of this stigma and create spaces where transwomen can have more advocacy power and support (Kosenko, 2010).

Perhaps the most immediate findings that could be intervened upon involve challenges transwomen faced in interactions with the support services and HIV care institution staff. Transwomen reported interactions with staff who exhibited gaps in racial and gender cultural competence, did not treat participants as partners in their care, and did not give accurate health information. Research with ethnic/minority transyouth suggests that even in programs where providers are appropriately trained, some ethnic/minority transwomen may feel uncomfortable or unwelcome in LGBT clinics that are perceived as predominantly White (Garofalo, Deleon, Osmer, Doll, & Harper, 2006; Kenagy, 2002). Thus race cannot be ignored when addressing services for transwomen. Others reported broader transgender-related stigma enacted through, for example, assumptions about one transwomen being a sex worker because of her gender identity and another transwoman sensing workplace discrimination by seeing transwomen with what they perceived to be low-

level jobs in the organization. These negative experiences created a heightened sensitivity, skepticism, and distrust of institutions that provided critical care services, which ultimately led to inconsistent access to care for these participants. The expansion of training for medical providers and the requirement of LGBT health courses in medical and support service training programs may help prevent negative client-provider interactions and build better care and social service organizations (Obedin-Maliver et al., 2011). For transwomen with existing negative experiences, providers can help overcome the historical trauma by talking about those past experiences with their clients and trying to find ways to not make similar mistakes. Both of these recommendations complement work already underway but are likely to be years from full implementation. Thus, multiple explorations of barriers to care are needed so as to further refine efforts underway and ensure that region, race, and other subpopulation differences are accounted for in efforts to increase access to care for transwomen living with HIV.

In the meantime, facilitators to care such the provision of incentives to supplement income generated by SSI, general assistance, and other programs and jobs should be reinforced as successful ways to engage transwomen in HIV care. Access to gender-related care like hormone therapy was also an important draw for many participants. All programs that work with transgender women should consider providing access and referrals to gender-related care in order to enhance engagement in HIV care and support services. Informational support such as better provision of provider-relayed medical records, health information, and information that is relevant to transwomen can be available in waiting and exam rooms (Higa, Marks, Crepaz, Liau, & Lyles, 2012). Another important facilitator found in these data was the personalization of the care experience by staff people who got to know their clients and built relationships with them, which gave participants the sense that people cared about their health and well-being. Transwomen reported that when they felt as if someone truly cared about their health they were more likely to set and attend appointments and take care of themselves; it was mostly the front

office staff who took on the responsibility of developing those relationships but all staff could be encouraged to personalize care interactions to increase access. Having individuals who are available to accompany patients to medical appointments is an effective intervention with other populations, and based on these data, should be considered with transwomen as well (Higa et al., 2012). Additionally, having transgender staff, especially those who are qualified to hold positions of some power within the organization may serve to increase trust of an organization and providers.

There are a number of limitations to this study. These data are limited by the homogeneity within one racial/ethnic group and location in Alameda County, California, which may mean findings are not relative to the general transgender population. Despite this limitation, many of these barriers and facilitators may be useful in other settings where access to HIV care is available for transwomen. Additionally, these data are relevant for organizations considering providing HIV care to transwomen, especially in light of health care reform and the potential for dispersed care for HIV-positive individuals who may now access care from their primary care provider. Most important, these data may contribute to efforts to better services for transwomen of color living with HIV.

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