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HIV testing and entry to care among trans women in Indiana

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Abstract

Trans women in the United States are disproportionately affected by HIV infection. To improve HIV services for this population, more information is needed about their experiences in early stages of the HIV Care Continuum. Trans women in states such as Indiana, which has moderate HIV incidence but little public health investment in HIV prevention and treatment, experience special challenges. Our qualitative descriptive study describes the circumstances influencing HIV testing and entry to care by 18 trans women living with HIV in Central Indiana. In-depth interviews regarding participants' HIV care experiences were analyzed using standard content analysis. Participants discussed three main topics: (a) HIV testing circumstances, (b) facilitators and barriers to entering care, and (c) motivators for entering care after a delay. Findings indicate that social relationships play a significant role in trans women's care experiences and that stigma, discrimination, and adverse life circumstance are powerful deterrents to care. Practice and policy implications are discussed.

Keywords

entry to HIV care; HIV Care Continuum; HIV testing; HIV treatment; trans women

Transgender women (trans women), especially those of color, are disproportionately affected by HIV infection in the United States (Centers for Disease Control and Prevention [CDC], 2015; White House Office of National AIDS Policy, 2015). About 1.4 million or 28% of all trans women in the United States are living with HIV (Flores, Herman, Gates, & Brown, 2016). HIV infection rates are two times higher in transgender people than in sexual gender

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minorities, including lesbian, gay, and bisexual persons (CDC, 2015; Institute of Medicine, 2011). Rates of new HIV infection among Black transgender people is 24.9% compared to 0.6% in the general United States population (Human Rights Campaign, 2016). Moreover, Black trans women are more likely to be living with HIV (56%) than are White (17%) and Hispanic/Latina (16%) trans women (CDC, 2015).

Stigma, isolation, and discrimination are chronic sources of stress for trans women (CDC, 2015; Hendricks & Testa, 2012). Trans women also experience high rates of mental health problems, substance abuse, commercial sex work, incarceration, and homelessness (Dowshen, Lee, Castillo, Hawkins, & Barg, 2016; Hines & Ryan, 2016). Discrimination against trans women within health care settings and mistreatment by health care providers can impede access to HIV prevention, testing, and treatment services, and contribute to HIV-related health disparities (Golub & Gamarel, 2013; Lee et al., 2015; Logie et al., 2016).

The HIV Care Continuum, depicted in Figure 1, *Implementation Cascade for the Continuum of HIV Care*, the recommended trajectory of care for individuals living with HIV in the United States. Research has indicated that trans women living with HIV have more difficulties than other sexual minorities at each stage of the HIV Care Continuum. For example, rates of early diagnosis, engagement in care, treatment with antiretroviral therapy (ART), and viral suppression are low among trans women (Sevelius, Carrico, & Johnson, 2010 & Sevelius, Patouhas, Keatley, & Johnson, 2014). More than half of all HIV testing of transgender people occurs in non-clinical settings where follow-up medical, diagnostic, and/or treatment services are often not provided (CDC, 2015; 2016).

Theoretical Model and Research Focus

The Network Episode Model (NEM) provided an orienting lens for our study. The NEM is a sociological health utilization model that depicts how social, psychological, cultural, economic, and medical factors influence an individual's health and health behaviors over time (Pescosolido, Gardner, & Lubell, 1998). Two tenets of the NEM in particular guided our study. The first tenet was that people enter care through a variety of means including making an active or rational choice to enter care, enter care because of the coercion of others, or by just "muddling through" without actively seeking or resisting treatment (Pescosolido et al., 1998). The second tenet was that social influences exerted through social networks and communities play a central role in determining if, when, and how individuals receive care (Pescosolido et al., 1998). The NEM thus provided a foundation for our study as we focused on the means by which trans women living with HIV entered care and the social factors that influenced their experiences in the early stages of the HIV Care Continuum.

Entry into care has been an especially significant issue for trans women in Indiana. Indiana has a moderate incidence of HIV with a low level of public health investment in HIV prevention and care (Meyerson, Navale, Gillespie, & Ohmit, 2015). As a result, HIV testing delays have been common in publicly-funded Indiana testing sites, and only 45% of people living with HIV (PLWH) in Indiana have been linked to health care (Meyerson et al., 2015). In 2010, less than 1% of the 17,459 HIV tests administered in Indiana were administered to transgender people (Indiana State Department of Health, 2012). In addition, the majority of

research on trans women living with HIV has been conducted in major coastal cities (Edwards, Fisher, & Reynolds, 2007; Golub & Gamarel, 2013; Nemoto, Operario, Keatley, & Villegas, 2004; Nemoto, Operario, Keatley, Han, & Soma, 2004; Schulden et al., 2008). Findings from these studies, therefore, may not apply to trans women living in areas where fewer resources exist for PLWH, such as Indiana.

Given that trans women are at high risk for HIV and encounter many barriers to HIV testing and care, there is an urgent need to understand the circumstances that prompt HIV testing and influence linkage to care, especially in noncoastal regions such as Indiana. Such information would help nurses and other health care providers develop prevention and treatment strategies that target trans women. The purpose of our study was to describe the circumstances influencing HIV testing and entry to care among transgender women in Indiana.

Methods

Research Design

A qualitative descriptive approach was used in this study. Qualitative description is used to produce a low-interpretive, but practically useful, description of events (Sandelowski, 2000). Qualitative descriptive methods are often used to describe the day-to-day experiences of understudied groups to inform care practices (Morse, 1991).

Recruitment Procedures

Participants were recruited from seven agencies in central Indiana that provided primary medical and supportive services to trans women living with HIV. The agencies were chosen because they served communities with high HIV incidence. The first author sent introductory letters to care coordinators and program managers at each agency describing the purpose of the study and requesting assistance in recruiting eligible trans women. All seven agencies agreed to serve as recruitment sites.

The first author formed a community advisory board (CAB) to enhance recruitment efforts. The CAB was composed of three trans women (2 of whom were living with HIV), a cisgender (i.e., persons whose gender assigned at birth matches the gender with which they identify) woman, a commercial sex outreach worker, and an outreach worker. CAB members designed palm-sized recruitment cards to distribute to trans women who they knew were living with HIV. The palm cards included a brief description of the study and contact information for the first author.

Inclusion criteria were: (a) 18 years of age or older, (b) living with HIV, (c) identified as transgender, and (d) received services at an agency within the previous 12 months. Staff at the recruitment sites notified prospective participants about the study by phone. Interested participants were given the option to either contact the first author or to have the first author contact them. Once phone contact was made, the first author provided a verbal description of the study, emphasizing that all participation was entirely voluntary. The first author obtained verbal consent from those persons who agreed to participate and scheduled a face-to-face

interview. A total of 21 trans women were screened for eligibility; 3 were ineligible because they were not living with HIV; 18 were eligible and participated in the study.

Data Collection

Data were collected between November 2011 and July 2013. Prior to beginning the interview, the first author reviewed the purpose of the study, asked potential participants to read a study information sheet, and obtained verbal consent to participate in a digitally recorded interview. A waiver of signed consent had been obtained via the investigational review board at Indiana University to protect the identities of the participants. To minimize the risk of emotional distress, participants were told they did not need to answer questions they found uncomfortable or distressing. If participants became unduly upset during the interview or expressed suicidal ideation, procedures were in place to refer them to a local mental health service provider. Although several participants became tearful during the interviews, none required a referral.

The first author, an African American, cisgender woman, who was associated with the Ryan White HIV/AIDS Services program in Indiana, collected all data. The first author met participants at settings where privacy was ensured, including their homes, private offices at the recruitment sites, and study rooms at a local library. A brief paper-and-pencil questionnaire was used to collect the following sociodemographic information: age, gender at birth, current gender, sexual orientation, education, race, ethnicity, zip code, and residential area (urban vs rural), number of children, relationship status, and employment status and type. The questionnaire was also used to obtain health information such as insurance status and type and history of major health conditions and surgeries. Participants completed the questionnaires, and the first author reviewed them for completeness.

An in-depth interview was then conducted with each participant. Based on the NEM (Pescosolido et al., 1998), the participants were asked how they came to get tested for HIV, how they entered care, and what social factors influenced that process (Table 1). Examples of questions included: *Tell me about the time when you first learned that you were HIV positive. Tell me about your experiences with getting into care after testing positive. Tell me about your experiences with continuing or discontinuing HIV care. Tell me about the nurses, doctors, care coordinators, and other support people that you have encountered throughout your time of living with HIV.* Follow-up questions were used to probe for additional relevant information. Some interview questions were modified as data collection and analysis progressed in order to explore important issues that emerged in prior interviews in more depth.

The interviews lasted approximately 90 minutes and were digitally recorded. Participants were given a \$50 gift card in appreciation for their time. A professional transcription service transcribed the interviews verbatim. To ensure reliability of the data, transcripts were checked against audio recordings to ensure that no mistakes were made during transcription.

Data Analysis

The first author and two senior nurse researchers who were experts in qualitative research analyzed the data. Conventional content analysis (Miles, Huberman, & Saldana, 2013) was

used to analyze the participant narratives. The transcripts were read multiple times by all members of the research team to obtain an understanding of the participants' overall experiences. The research team met regularly during all phases of analysis to discuss the emerging findings. The first author kept a detailed audit trail comprised of memos that chronicled all major method and analytic decisions.

The first author identified and highlighted all text units (i.e., relevant words or phrases) related to participant experiences with any of the first three steps of the HIV Care Continuum: HIV testing, HIV diagnosis, and linkage to HIV care. She then coded each text unit with a short, meaningful label to capture its essence (Miles et al., 2013). For example, the phrase "I didn't want medication. I wasn't ready for that decision, especially not in prison," was assigned the label *feeling unready to start care*. The other team members reviewed, discussed, and modified or verified the codes (Creswell, 2013).

The codes were compared for similarities and differences. Data display tables were then used to organize similar codes into categories and to display the emerging categories for further discussion and refinement by the research team (Miles et al., 2013). For example, the tables allowed the team to develop categories of conditions under which participants were tested and categories of barriers and facilitators to care. The tables also allowed researchers to organize categories according to one of the first three stages of the HIV Care Continuum and to identify relationships between categories. For example, the tables revealed the social circumstances of the participants (e.g., family relationships, substance use, incarceration) that were commonly associated with barriers and facilitators of care.

The first author then wrote detailed narrative descriptions of the codes, categories, and relationships between them and supported these descriptions with quotes and examples. The narrative descriptions were discussed, reviewed, and refined by the research team (Creswell, 2013). The descriptions provided the basis for the results discussed below.

Results

Demographics

The sample consisted of 18 urban-dwelling trans women ranging in age from 21 to 60. Ten participants reported their race/ethnicity as African American or Black, 4 as White, 2 as multi-racial, 1 as Latina, and 1 as Native American/Asian Pacific Islander. Half of the participants completed high school ($n = 9$). Eight were employed in various settings including the entertainment industry, retail, health care, and warehousing, and the others were unemployed. More than half ($n = 10$) of the participants reported their sexual orientation as heterosexual, most ($n = 16$) reported their relationship status as single, and the majority ($n = 16$) reported never having gender reassignment surgery. Seventeen participants were insured through private insurance, state-funded insurance programs, and/or federal programs such as Ryan White Parts A and C.

Seven of the participants reported a history of mental health problems such as anxiety, depression, suicidal ideation, low self-esteem, schizophrenia, and bipolar disorder. This information emerged during interviews as participants recalled various circumstances related

to their transgender identities and their HIV diagnoses. Many participants described these conditions as persistent problems that they struggled with intermittently. More than half ($n = 11$) engaged in high-risk behaviors such as substance abuse ($n = 11$) and sex work ($n = 9$). In addition, more than half ($n = 11$) had experienced forms of violence and abuse such as physical assault and harassment, rape, intimate partner violence, and childhood sexual assault. Seven had been incarcerated.

At the time of initial HIV diagnosis, 16 of our participants had been living as trans women. Two were living as gay men; one had been living as a trans woman but had temporarily returned to living as a gay man after being raped and beaten and the other had privately identified as female since childhood. All participants had a female gender identity starting in childhood and, thus, well in advance of the HIV diagnosis.

At the time of the interview, more than half ($n = 12$) of the participants had been living with HIV from 1 to 5 years, and nearly half ($n = 8$) had been diagnosed with HIV between the ages of 20 and 29. The majority ($n = 15$) of participants were taking ART; one was not taking ART, and two did not provide this information. See Table 2 for additional participant demographics.

Participant narratives contained detailed and rich information about their experiences with the first three stages of the HIV Care Continuum. Participants addressed three main topics: (a) they identified three circumstances under which they received HIV testing and diagnosis, (b) they identified several facilitators of and barriers to timely entry into care, and (c) they identified several factors that motivated seeking care after having delayed care for a significant period of time following diagnosis. These topics are described below.

Circumstances of HIV Testing and Diagnosis

The participants identified three circumstances in which they received HIV testing and diagnosis. Most participants were HIV tested during a routine screening ($n = 10$), a few initiated HIV testing on their own ($n = 4$), and a few initiated HIV testing at the advice or urging of another ($n = 4$). Testing occurred in HIV counseling and testing centers ($n = 4$), prisons/jails ($n = 4$), private physician's offices ($n = 4$), hospital/emergency departments ($n = 4$), and plasma donation centers ($n = 2$).

Routine screening—Ten participants were tested during a routine health screening procedure rather than actively seeking HIV testing. The routine screenings occurred during a prison or jail intake procedure ($n = 4$), a hospitalization for an illness other than HIV ($n = 4$), or a pre-plasma donation screening process ($n = 2$).

Four participants were tested for HIV while in jail or prison as part of a routine intake health screening procedure following arrest. For most of the participants, HIV testing was optional (opt-in testing). For one participant, however, testing was mandatory and had some elements of coercion. She said,

I caught prostitution [charge] and part of the plea agreement was I have an HIV test before going to the reception diagnostic center (RDC). I went to RDC, they drew blood...and my first introduction to HIV was when I tested positive.

Because these participants had not sought HIV testing, most were caught off guard with the diagnosis and had difficulty absorbing it due to incarceration and lack of privacy.

Four participants were tested for HIV while they were in the hospital being treated for other problems. Participants had been admitted to the hospital for pneumonia, dehydration, seizures, swollen lymph nodes, and pain. In some cases, they had been hospitalized multiple times for these problems before being tested for HIV. Although most participants were shocked by the diagnosis, at least one suspected that she might have had HIV long before becoming ill or getting tested. She said,

The first time I found out that I had HIV I was in the hospital. I think I had HIV for a long time... [and] didn't feel that I needed to get it checked...I wasn't having symptoms...I just thought I had a cold...I went to the hospital and they told me that they needed to admit me, but I couldn't stay ...I was taking some antibiotics and stuff and nothing was helping. That next day I went back to the hospital and I passed out. I don't remember anything else...They had to put a thing down my throat...When I woke up [from the coma], they knew I had HIV.

Two participants were tested for HIV in plasma donor centers as part of institutional infectious disease pre-donor screening procedures. Both donated plasma “just to make a little extra money” and were thus not prepared to learn they had HIV.

Self-initiated testing—Four participants initiated HIV testing on their own because they were concerned they were at high risk due to having had unsafe sex, using drugs, being gay or transgender, knowing someone who was living with HIV, and/or having started a new sexual relationship. Some who had lived with HIV for many years at the time of their interviews had sought testing during the early years of the HIV epidemic because they had seen many friends die from AIDS. A few participants sought testing because of symptoms they experienced. One participant said, “I just didn't feel right and I decided to go get tested. [At the time] I could hardly get up [and] was not as spunky...I just wanted to find out.” Because these participants believed themselves to be at high risk, they were distressed but not necessarily shocked when they were found to have HIV. One participant, however, was surprised and confused when hearing her diagnosis:

As I get in relationships, we get tested. So we got tested several times together, both of us negative. And I will never forget the time we got tested, and it said, “Positive.” I couldn't understand. He was the only person I had been with...I didn't understand.

Recommended testing—Four participants initiated HIV testing at the recommendation or urging of another person who believed the participant to be at high risk because she had engaged in unsafe sex, identified as gay, or had sex with someone who was living with HIV. The people who recommended the HIV test were often former partners or health care providers. Most participants were thrown by this advice, even when it came from a health care provider. The physician of one participant, who was living as a gay male but identifying as female, recommended that the participant get tested for HIV. She said,

It was 1987 and I was living in Austin. Austin had a bigger gay community that was more supportive than what I was used to... There was a gay doctor there who talked me into getting tested. I was taken aback. I was afraid to get tested. I didn't have any symptoms... I got tested, I was positive, and I was hysterical.

Barriers and Facilitators to Early Linkage to Care

Most ($n = 11$) participants in our study linked to HIV care within 3 months of the initial diagnosis. This was the previously recommended standard of time for entry to care, and we thus referred to these participants as having experienced early entry to care. The other participants ($n = 7$) did not obtain care during this time, and we referred to these participants as having experienced delayed entry to care. Due to our study criteria, there were no participants who had not entered care. Participants identified several factors that were facilitators of or barriers to early entry to care.

Facilitators—Participants attributed early entry to care to several factors that facilitated the process. These factors included psychosocial support, direct referrals from a provider, and guidance from a friend.

Psychosocial and emotional support of others often facilitated early entry to care. For example, some primary care providers who delivered the diagnosis of HIV to the participants answered questions about the new diagnosis and reassured them that they could survive with HIV, thereby encouraging them to take the next step and receive care. Participants described these providers as “real nice and sweet to me,” “handling me with kid gloves,” and “being very accepting of who I was.” One participant said,

When I first found out [that I had] HIV, my mind was just racing and I was on the verge of [giving] up. I started going to counseling and the doctor [started] talking to me and telling me that having HIV doesn't mean that I'm going to die soon... He encouraged me to work through it and then I just started going to get treatment, my mood started changing, and I started accepting what I had.

Similarly, another participant who tested at an HIV Counseling and Testing Site entered HIV care right after receiving support from a care coordinator. The participant said,

I didn't have insurance when I found out that I was HIV positive. I was scared and thought I would need disability. The care coordinator told me that I could continue working and that she could get me the help that I needed. She helped me apply for insurance and set me up with an HIV clinic for my first appointment.

Several participants received direct referrals for HIV care from primary care physicians, staff persons at HIV Counseling and Testing Sites, hospital-based providers, and care coordinators at AIDS service organizations. Receiving a direct referral to a specific HIV care provider or agency was more helpful than being given a list of providers from which to choose and contact independently. One participant, who entered care soon after being diagnosed with HIV, said, “I got discharged from the hospital and they [referred] me to a primary care doctor and [then] he referred me to one of his colleagues who was an infectious

disease doctor.” Care coordinators not only made direct referrals but also helped participants obtain insurance to cover the cost of HIV care.

Several participants credited early entry to care to the helpful guidance they received from friends or partners. Friends who were transgender and living with HIV, and who were often “like family,” were especially helpful because they could provide information about HIV and good advice about seeking care. Friends provided guidance on choosing a health care provider and helped participants keep track of their medical appointments. One participant said,

I went to work and talked with another [transgender] girl. She guided me along because she was HIV-positive as well...After talking with her I went to care coordination, where I learned all the ins and outs [of HIV care], getting a good doctor, staying safe, and not infecting other people.

Barriers—Conversely, participants identified several factors that served as barriers to early entry to care. These factors were reluctance to face a diagnosis of HIV, concerns about lack of privacy and confidentiality, and lack of support.

Some participants did not seek early entry to care because they were reluctant to face or “deal with” the diagnosis. They were so shocked and angry upon hearing the HIV diagnosis that they “went into denial” despite others’ attempts to help them confront the illness. This was particularly problematic for participants diagnosed in prison. One participant said, “The [health care providers] kept calling me [to start me on treatment], but I wanted them to leave me alone. I didn’t want medication, especially not in prison.”

Some participants delayed entry to care because they did not want others to know that they had HIV, and they believed that HIV care services could be indiscreet. Several feared being seen at the clinic or agency providing care. One participant who wanted to keep her diagnosis “a secret” said,

[The clinic] was one them places where everybody who is positive goes. I didn’t want no one to see me. I just wanted to be so discreet about it and everything. I wanted everything to be done and taken care of, but I wanted it to be discreet still... I felt like everybody in the office would be staring at me and know that I am positive.

Lack of privacy and confidentiality was especially problematic for participants who tested in prison. One participant who tested in prison in the 1990’s said,

There were these huge, red signs that said medical deadlock on them, and everybody knew that these people were HIV positive. So the first time I dealt with HIV, it was a bad thing. You were a bad person and nobody wanted to be around you and you couldn’t be around people.

Another participant who tested in prison more recently said,

If [the test] comes back positive, they come get us and take us down, and tell us... It’s like putting your business out there because most people who went through the

orientation know that a callback after blood work [means] something's not right. It puts a label on you [and] the people in there look for that call back... When you get called back it's embarrassing...you come back and you're trying to deny it. You don't want it to be true and you don't want the people to start spreading rumors and gossip.

Participants were deterred from seeking early entry to care if they felt alone, had no one to talk to, were uncomfortable talking about their diagnosis with others, or blamed themselves for the diagnosis. Participants without supportive family members or friends had a particularly hard time. Some participants who felt isolated even contemplated "ending it all." One participant said, "I just ran from it...you know? I just wanted to die. My mom was gone [had died]. I didn't have no brothers, no sisters. I didn't have no family."

Several participants delayed entry to care because they were experiencing other adverse life circumstances that they found to be more pressing or that impeded them from seeking care. These adverse circumstances included drug use, homelessness, and incarceration. One participant said,

I just wanted to die. Everybody that was around me was around me for hustling and I just felt horrible. I was using meth and awful drugs, enough to kill me. I don't think I really cared if I would have died or not. [When] I went to the doctor and I broke down saying the reason why I do this stuff is because I'm depressed, I have low self-esteem, I felt alone. I was messing with heroin. I overdosed a couple of times. It was depression and self-medicating with drugs.

For some participants, the adverse life circumstances that impeded entry to care started after the diagnosis. One participant who delayed care for almost 1 year said, "I tried to overdose and everything. I started binge drinking and getting in marijuana." For other participants, such adverse life events intensified after diagnosis. One participant said,

I always had alcohol issues and was a crying drunk...I [was] sent to prison multiple times and was smoking crack multiple times. I was on drugs and couldn't stay consistent to HIV. That's why I became resistant to some of the different drugs.

In grappling with these adversities, participants had little "time to worry about meds and stuff like that."

Motivators for Entry to Care After a Delay

The participants who had delayed entry to care did eventually access care and described several factors that motivated them to do so. These factors overlapped somewhat with facilitators of early entry to care but came later. The factors were psychosocial support, education or information support, provider persistence, seeing others die from HIV, and substance abuse treatment.

Psychosocial support—Some participants attributed their entry to care after a delay to support from family, friends, or health care providers. These persons gave participants the message that everything would be okay, volunteered to escort them to medical visits, and

provided recommendations for places to go for HIV care. One participant who was incarcerated on several occasions after being diagnosed with HIV said,

When I finally got out of prison I met some people that helped me understand what HIV care was...They would tell me about viral load and CD4 counts and all of this stuff. They did not judge me and they loved me until I could learn to love myself... They [also] introduced me to a very private doctor who all of the [transgender] girls went to.

Another participant, who had not received HIV care for many years, credited her case manager for her eventual entry to care. She said,

I connected with her [case manager] quickly. I was still in denial and was also taking meds...She made me realize that I can still live and outlive most people that don't have HIV. [She said it was] all about taking care of [myself]. It was the major turning point in my life that made me realize [I had to get] out of denial.

Education and information support—Some participants eventually entered care after reading brochures about HIV treatment, receiving education and counseling about treatment options, and receiving HIV care coordination services. One participant who delayed entering care for about 9 months said,

[I] remembered the pamphlets and education and everything that said if it [HIV] was caught early that it was a good thing and they can get you undetectable. So, I told myself it's time to stop all the crying and get some help.

Provider persistence—Some participants eventually entered care in response to persistent urging from a health care provider. These participants often ignored early recommendations that they get HIV care, especially if they did not feel ill, but the providers firmly persevered in pressing the participants to confront and acknowledge their illnesses and obtain treatment. One participant said,

I was in denial for a long time, from 1992 to 2003. My numbers [HIV viral load] started going up...I was still feeling healthy, putting on weight, and doing the things that I normally do...They kept calling me and kept calling me [to start treatment]. The pressure helped the denial stage end...I gave in and told them that I would do it, so they started me on the [HIV] regimen in prison.

Another participant said, "They did my blood work and told me that if I don't get on medication now that it would turn into AIDS. It stuck in my head – death or life. So I started the one pill Atripla."

Seeing others die from HIV—Some participants entered care only after seeing loved ones die from HIV-related complications. For these participants, this was a stark reminder of their own mortality. One participant recounted the moment when she realized that she needed care:

I buried two brothers and was working on burying a third. All three of them had HIV. As my brother was lying on his deathbed he told me not to let anything stop me from living my dream. [Afterwards] I made a call and wanted help.

Substance abuse treatment—For some participants, substance abuse treatment prompted eventual entry to care. While receiving treatment for substance abuse problems, participants were encouraged to confront their HIV status as well. One participant said:

Our Narcotics Anonymous (NA) meeting was always a safe place. My friends [who were also in rehab] would also talk to me about viral loads and CD4 counts. It was at NA that I first learned that it was my inability to accept my personal responsibilities on a deeper level. My friends at NA were instrumental in my first introduction to care outside of prison.

Discussion

We examined the circumstances by which trans women in Indiana experienced HIV testing, diagnosis, and entry to care. The findings revealed three basic circumstances under which trans women received HIV testing: routine screening, self-initiated testing, and referred testing. Moreover, the findings revealed a wide variety of factors that facilitated or hindered early entry to care and a variety of factors that motivated entry into care after a significant delay.

Our findings resonate with the findings of other studies. For example, we found that the circumstances and settings that provided the context of testing influenced how the women experienced it, raising the question of what venues were optimal for testing in this population. Another study that focused on testing venues revealed that trans women may prefer self-testing to clinic-based testing in order to avoid stigma and discrimination in clinical settings (Lippman et al., 2016).

As with our study, other studies have identified factors that facilitated early entry into care or that motivated individuals to access care after a delay. For example, just as the trans women in our study sought testing for HIV because they engaged in risk behaviors, a cross-sectional survey study of trans women in Ho Chi Minh City revealed that higher rates of HIV testing were associated with reported sex with casual partners in the previous month, alcohol use, and post-traumatic stress symptoms (Bao et al., 2016). Similar to our findings that testing often occurred at the recommendations of others, a cross sectional study conducted in Lima, Peru indicated that the desire to check one's health, having sex without a condom, receiving a recommendation for testing from a health care provider, and having a partner recommend testing were factors that increased the likelihood of HIV testing (Lee et al., 2015). Our findings were also consistent with those of Dowshen et al. (2016) who reported that social support from family, friends, and health care providers facilitated engagement in services for young, transwomen across the HIV Care Continuum.

Our findings regarding barriers to entry to care also aligned with findings discussed by other researchers. Several other studies have revealed that mental health challenges, substance use, and other social problems impeded access to HIV testing and treatment for trans women

(Dowshen et al., 2016; Hines & Ryan, 2016; Logie et al., 2016). Our findings that barriers to testing and entry to care were often associated with the fear of stigma related to HIV infection have also been reported by researchers who found that trans women often avoided getting tested to prevent further stigma, isolation, and discrimination (Golub & Gamarel, 2013; Lee et al., 2015; Logie et al., 2016).

Limitations

Our findings should be considered within the context of several limitations. First, participants needed to have accessed HIV care within the previous 12 months to be eligible for the study. Therefore, our findings do not provide information on barriers experienced by trans women who have never accessed care. Second, our sample was limited to trans women living with HIV in Indiana, and thus our findings do not extend to women living in other geographical regions where available HIV services and attitudes regarding HIV and gender identity may vary. Third, most of the participants in the study were insured and thus our findings do not reflect the experiences of women who have no insurance coverage, which would affect their treatment experiences in a significant way. Fourth, health-related data, such as disease progression and time to entry to care, were self-reported and thus might have been over- or under-reported. Finally, the updated National HIV/AIDS Strategy (NHAS) for 2020 now recommends that at least 85% of people newly diagnosed with HIV be linked to care within 1 month of the initial HIV diagnosis (White House Office of National AIDS Policy, 2015), whereas we based our analysis on 3 months as the point of early entry to care. Therefore, it is unclear if the facilitators and barriers that we identified would be relevant for the 1-month as opposed to 3-month time frame.

Practice and Policy Implications

Despite these limitations, our findings have several practice and policy implications. Our findings underscore the importance of health care providers and care coordinators helping trans women successfully navigate the first three stages of the HIV Care Continuum. Health care professionals who provided ample emotional and information support, ensured confidentiality, avoided stigmatizing practices, and provided direct personal referrals as opposed to standard referral lists, did much to facilitate early entry to care. Our findings also suggested that professionals should remain acutely aware of how intersecting aversive life circumstances often faced by trans women, including homelessness, substance abuse, mental health problems, and incarceration, played a major role in this population's HIV care experiences. Our findings suggested that social and treatment programs that addressed these issues remained essential components in HIV prevention and treatment efforts.

Because our study was conducted in Indiana, our findings have implications for state-wide policies. As mentioned earlier, federally-funded testing sites in Indiana have reported low rates of trans women who test for HIV. Given that it was relatively easy to recruit trans women living with HIV infection for our study, we suspect that trans women in Indiana may seek testing at non-federal sites or that trans women who tested at federal sites may be identified as "women" instead of as "transgender women." Fear of stigma and discrimination in federal testing sites may explain why transgender people seek HIV testing in non-traditional settings (CDC, 2015; Golub & Gamarel, 2013; Poteat, German, &

Kerrigan, 2013). According to the Indiana Jurisdictional Plan (Indiana State Department of Health, 2012), federally funded HIV testing is routinely provided at HIV Counseling and Testing Centers and county hospitals, but not in physician offices, prisons/jails, and plasma donation centers. Therefore, offering federally-funded testing services in a variety of venues may increase uptake of HIV testing by trans women in Indiana.

The state of Indiana receives Ryan White HIV/AIDS funding, Parts A, B, and C, to support the provision of core medical and social support services for PLWH (HIV/AIDS Bureau [HAB], 2015). In June 2015, HAB released a crosswalk highlighting the specific core medical and support services most directly impacting and supporting improved outcomes across the HIV Care Continuum (HAB, 2015). HAB has encouraged Ryan White grantees and their associated planning bodies to assess services and gaps along the HIV Care Continuum in their respective jurisdictions and to fund specific services to facilitate improvement along specific HIV Care Continuum stages. For example, outpatient substance abuse care was listed as a core medical service that directly supported linkage to care (HAB, 2015). Because some of our participants were motivated to enter care because of substance abuse treatment experiences, this portion of the crosswalk aligned with our findings. By comparison, psychosocial support services were omitted from the crosswalk as a service that directly supported linkage to HIV care (HAB, 2015). Psychosocial support was instrumental to our participants receiving testing and diagnosis and to early and delayed entry to care. Our findings thus suggested that Indiana may need to tailor their crosswalk to include psychosocial services as a service that also directly supports entry to care.

Recommendations for Research

Because studies that have examined uptake of HIV testing have typically focused on men who have sex with men, have had minimal transgender representation, and/or were conducted outside of the United States (Chow et al., 2016; Frye et al., 2015; Liu et al., 2015; Logie et al., 2016), a wide range of studies are needed to understand the HIV care experiences of trans women throughout the United States. While our study provided a beginning understanding of these experiences, we recommend future research that employs larger and more geographically and socioeconomically diverse trans women. Longitudinal studies to obtain contemporaneous rather than retrospective accounts of these experiences would add to our body of knowledge related to this population. Such studies would also help obtain objective measures of time between first diagnosis and first visit with an HIV health care provider and would collect physiological measures of CD4+ T cell counts and HIV viral loads to measure stage of HIV disease at initial diagnosis. By integrating narrative, objective, and physiological measures, a robust description of how trans women experience the early stages of the HIV Care Continuum could be obtained.

Conclusions

Trans women in Indiana who are living with HIV experience the early stages of the HIV continuum in complex and varied ways. Many, however, identify similar factors that help or hinder their early care experiences. In our study, trans women consistently reported that their social relationships, be it with health care providers, friends, family, or current or former

partners, played a significant role in the care they received and that stigma, discrimination, and adverse life circumstances remained powerful deterrents to care. In order to meet new federal guidelines that suggest entry to care should occur within 1 month of diagnosis, HIV programs should comprehensively address challenges specific to this population and provide resources that can provide meaningful support and ameliorate significant barriers to care.

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Key Considerations

- HIV testing as part of routine health screenings is an effective strategy for identifying trans women who are living with HIV infection.
- Fear of being newly diagnosed with HIV, concerns about lack of privacy and confidentiality, not having anyone to talk to about a new HIV diagnosis, and adverse life events delay entry to HIV care.
- Psychosocial support from family and friends (especially those who are living with HIV infection), direct referrals to HIV care, and guidance from a friend or romantic partner on where to access HIV care facilitate timely entry to HIV care.
- Trans women who delay entering HIV care could benefit from health care providers offering ongoing psychosocial support, education, and persistence to initiate treatment.
- Treating substance abuse problems and addressing issues with homelessness can also facilitate entry to HIV care.

Implementation Cascade for the Continuum of Care

Table 1**Interview Questions**

Tell me about the time when you first learned that you were HIV positive.

Probes: (a) How did you cope with the news? (b) How are you coping now? (c) Who or what was helpful to you during that time? (d) What about now? From where do you get the support that you need?

HIV Care Continuum Step: HIV testing and diagnosis

NEM Components: Social support system and treatment system

Please tell me about your experiences of getting into care after first learning that you were HIV positive.

Probes: (a) Did you seek care right away? (b) Did anyone encourage you to seek care or is this something that you did on your own? (c) Can you describe for me what was happening in your life at the time you decided to seek care? (d) What led you to seek care the first time? (e) If you were not getting care at first, but then did, what led you to that point?

HIV Care Continuum Step: Linkage to care

NEM Components: Social support system and treatment system

Talk to me about your transition into care.

Probes: (a) Some people first see an HIV care coordinator or support person before seeing a doctor or nurse. If you met with a support provider first, please start with that experience and then move on to when and if you have ever seen a medical provider. (b) Did you enter care right away or was there a delay? (c) Can you explain more about what happened and what it was like for you? (d) How is it for you now? (e) In thinking about your experience of entering or getting connected to HIV care, can you describe for me what went well? (f) What did not go well, if anything? (g) How did you get connected to your current care coordination site? (h) What about your HIV doctor or nurse? (i) How did you get connected to them? (j) Were there other medical providers or conditions that affected your decision to seek care?

HIV Care Continuum Step: HIV Care

NEM Components: Social support system, and treatment system

Note. NEM = Network Episode Model.

Table 2

Participant Demographics (N = 18)

Race/Ethnicity	Number of participants
African American	10
White	4
Hispanic/Latino	1
Native American/Asian Pacific Islander	1
Multiracial	2
Number of years living with HIV at the time of interview	Number of participants
1–5 years	12
6–10 years	1
11–15 years	1
21–25 years	3
> 25 years	1
Age at time of HIV diagnosis	Number of participants
18–19 years	5
20–29 years	8
30–39 years	4
40–49 years	1
Sexual orientation	Number of participants
Heterosexual	10
Gay	3
Bisexual	2
Sexual	1
Transgender	1
Asexual	1
Gender reassignment surgery	Number of participants
No	16
Yes	2
Relationship status	Number of participants
Single	16
In a relationship	2
Highest completed level of education	Number of participants
High school	9
Some college	5
College graduate	2
Never completed high school	2
Employment status	Number of participants
Unemployed	10
Employed	8

Race/Ethnicity	Number of participants
Insurance status	Number of participants
Insured	17
Uninsured	1
Adverse life events	Number of participants
Substance abuse	11
Sex work	9
Forms of violence (physical assault, harassment, rape, intimate partner violence, childhood sexual assault)	11
Incarceration	7
Other chronic health conditions	Number of participants
Mental health problems (anxiety, depression, suicidal ideation, low self-esteem, schizophrenia, bipolar disorder)	7
Cancer	3
Hypertension	4
Diabetes	1
Asthma	2
No other health concerns	7