

# HIV Testing and Entry to Care Among Trans Women in Indiana

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*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.*

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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 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

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HIV-related health disparities (Golub & Gamarel, 2013; Lee et al., 2015; Logie et al., 2016).

The HIV Care Continuum is 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 nonclinical 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.

#### Implementation Cascade for the Continuum of Care

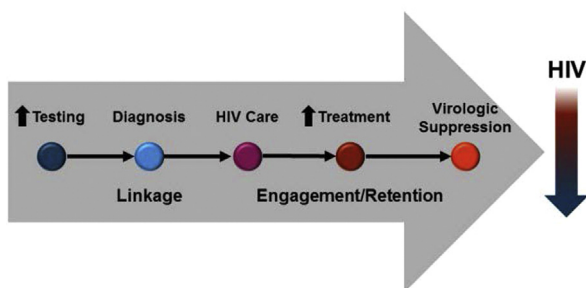


Figure 1. Implementation cascade for the continuum of HIV care. Image courtesy of Moupali Das, MD, MPH.

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