The HIV Epidemic Among Women in the United States: A Persistent Puzzle

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DESPITE THE SIGNIFICANT ADVANCES in the prevention and treatment of human immunodeficiency virus (HIV) in the United States, the story of the HIV epidemic among women has remained the same for the past 20 years. Women account for 23% of new AIDS (acquired immunodeficiency syndrome) diagnoses,¹ a proportion that has hovered around the same mark since 1999.² Heterosexual sex continues to be the predominant mode of HIV transmission, and significant racial disparities remain,¹ with the heaviest HIV burden on black women, as first noted in 1983.³ This lack of progress calls for new ways to study the HIV epidemic among women in the United States.

Specific behaviors, such as substance use and multiple sexual partners, are associated with sexually transmitted infections, including HIV.⁴ As a result, research and surveillance initially focused on women with risky behavioral characteristics in order to identify women at greatest risk of HIV acquisition.⁵ These approaches, however, did not always succeed,^{6–8} leading to a greater appreciation of the complexity of HIV risk among women in the U.S. Disparities in HIV infection are no longer viewed as driven by individual behaviors alone.⁹ Instead, place characteristics, such as poverty, violent crime, social disorder, incarceration rates, and male-to-female sex ratios are thought to be powerful drivers of HIV among U.S. black adults.^{10–13}

This appreciation has led to newer recruitment approaches that reflect the relationship between HIV risk and environmental and network characteristics. HIV surveillance evaluations, such as the Center for Disease Control and Prevention (CDC)'s National HIV Behavioral Surveillance among heterosexuals (NHBS), as well as HIV clinical research such as the HIV Prevention Trials Network (HPTN) 064 and the HIV Vaccine Trials Network (HVTN) 903 studies, recruited individuals from "hot spots" (i.e., geographic areas with higher HIV prevalence), using sampling methods designed to recruit individuals at higher risk of HIV acquisition.^{14,15} HPTN 064 used venue-based sampling (VBS),¹⁴ and HVTN 903 used a combination of VBS and network recruitment methods¹⁵ to recruit women into longitudinal cohorts to estimate HIV incidence. NHBS 2010 used respondent-driven sampling (RDS) to survey men and women living in metropolitan areas with high HIV prevalence and

poverty who reported having heterosexual sex in the past 12 months.¹⁶

These approaches to recruitment have succeeded in identifying women in the U.S. at high risk of HIV acquisition, as evidenced by the HIV incidence findings of HPTN 064 and HVTN 903 of 0.32%¹⁴ and 0.31%¹⁵ respectively, nearly five times the estimate of HIV incidence in the general U.S. population of similarly aged black women.¹⁷ These approaches have also uncovered the unexpectedly high prevalence of newly diagnosed HIV among black women in New York City, as reported by Reilly et al. in this issue of the *Journal of Women's Health*.¹⁸ NHBS researchers used RDS to recruit a cross-sectional cohort of 523 men and women who were 18–60 years old, resided in New York City, and who reported opposite-sex vaginal or anal sex in the prior 12 months. In this substudy of 153 black women from New York City who did not self-report a history of HIV infection, 10% of these women were newly diagnosed with HIV. Access to health care and HIV testing was good, with over 80% of participants reporting health insurance, a recent healthcare visit and prior HIV testing. Half of those newly diagnosed, however, had never had an HIV test before. Prior injection drug use (IDU) was identified as the only significant factor associated with HIV infection in multivariate analyses.¹⁸

The prevalence rate for newly diagnosed HIV of 10% is remarkably high and contrasts sharply with both HPTN 064, which found a 1.5% prevalence¹⁴ using similar criteria, and the 2010 NHBS, which found an overall HIV prevalence of 1.1% among women from 21 metropolitan areas in the U.S.¹⁶ Why do these prevalence rates have such striking differences?

Differences in study design and in recruitment methods may explain some of the observed differences. Cross-sectional and longitudinal designs are subject to different types of participant selection bias; highest-risk individuals may be willing to participate in a one-time interview but may be difficult to enroll and follow over time. Recruitment approaches, by necessity, depend on the desired target population and study objectives. VBS may be a particularly relevant method for reaching populations associated with a specific geographic place, such as a zip code.¹⁹ RDS is gaining popularity as a surveillance tool for "hard-to-reach" populations²⁰; however, the generalizability of RDS and its

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suitability for surveillance estimates are under debate.^{21–23} The feasibility and generalizability of RDS may depend on the density of social and sexual networks, how seeds are selected and identified, and sample variability.^{21–25}

Older age and former IDU also explain the difference in the prevalence of newly diagnosed HIV among the studies. Just over half (54%) of the participants in the Reilly study were over 40 years old, versus 20% in HPTN 064; of note, older age was associated with newly diagnosed prevalent HIV in HPTN 064.¹⁴ In the Reilly study, 18% had ever injected drugs, versus 3.9% in HPTN 064.¹⁸ Unlike the overall NHBS study, the Reilly substudy did not exclude individuals reporting prior IDU and therefore may have mixed IDU and heterosexual risk.¹⁶ HPTN 064 and HVTN 903 both included male sexual partner risks as possible eligibility criteria, which may have enriched the “heterosexual” nature of the sample.^{14,15} As the authors note, the selected seeds may have led to an oversampling of networks with current or former IDU members. It is also possible that former IDU is an underrecognized or emerging risk factor among U.S. women. Former IDU may connect women to higher risk sexual networks or be associated with different levels of behavioral risk, adding to the questions about how best to identify women in the U.S. who are at highest risk of HIV acquisition.

Regardless of differences in study populations and design, the results of HPTN, HVTN, and NHBS all underscore the extent of ongoing and undiagnosed HIV infections among U.S. women and highlight the need for continued HIV prevention and testing in this population. In the Reilly et al. study, black women in New York City with new HIV diagnoses reported low HIV testing rates, despite good access to health care. Even with the rollout of universal health care, significant barriers to HIV testing still exist, such as distrust of the medical system, perceived lack of risk, and stigma associated with HIV testing and diagnosis. These barriers may be even steeper for women of color and for women with former or current stigmatized behaviors, such as substance use. Moreover, older women may not be seen as a high-risk group by providers and as a result may not be approached for testing.

There are many pieces to the puzzle of the HIV epidemic in U.S. women. The results of these studies collectively suggest that HIV risk among U.S. women is not only complex, but also dynamic. Moving forward, a combination of strategies integrating individual, network, and environmental factors will be required not only to monitor the HIV epidemic among women, but also to ensure that prevention technologies reach those at greatest risk.

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