Challenges and Successes in Linking HIV-Infected Women to Care in the United States

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Women currently account for 27% of new human immunodeficiency virus (HIV) infections in the United States, the majority of which are acquired through heterosexual transmission. In the United States, black and Latino persons are disproportionately affected by the HIV epidemic, a disparity that is most dramatically present among HIV-infected women. Many of these women face significant discrimination as a result of race or ethnicity and sex, and they suffer disproportionately from poverty, low health literacy, and lack of access to high-quality HIV care. As a consequence, despite the availability of highly active antiretroviral therapy (HAART), women with HIV often have delayed entry into care and experience poor outcomes. This article reviews risk factors for HIV infection in women, barriers to engagement in care, and strategies to improve linkage to HIV-related medical and social care.

Since the 1980s the prevalence of women in the human immunodeficiency virus (HIV) epidemic in the United States has been growing [1]. In many regions of the world, heterosexual transmission plays a major role in HIV infection in women and is therefore greatly affected by sex-based power relations and sex disparities. In the United States, the percentage of AIDS cases among female adults and adolescents (aged ≥13 years) has increased from 7% in 1985 to 27% in 2007 [2]. Eighty-three percent of these cases in 2007 were attributed to heterosexual contact, 16% to injection drug use, and 1% to other or unidentified risk factors [2]. The Centers for Disease Control and Prevention (CDC) estimated that in 2006 there were 278,400 women living with HIV in the United States [3]. In the United States, black and Latino persons are disproportionately affected by the HIV epidemic, a disparity that is most dramatically present among HIV-infected women. In 2007, black/African American females made up 14% of the United States female population, but accounted for 66% of HIV/AIDS cases among females [2]. Hispanic/Latina females made up 11% of the female population but accounted for 14% of HIV/AIDS cases among females. For female adults and adolescents, the rate (HIV/AIDS cases per 100,000 population) for black/African American females (60.6) was nearly 20 times as high as that for white females (3.3) and nearly 4 times as high as that for Hispanic/Latina females (16.0) [2]. Many of these women face significant discrimination as a result of race or ethnicity and sex, and they suffer disproportionately from poverty, low health literacy, and lack of access to high-quality HIV care. As a consequence women living with HIV often delay entry into HIV care and experience poor outcomes.

It is important to recognize the particular challenge researchers face when studying such sensitive information as drug use and sexual risk taking behavior. There is a reliance on self-reporting, which can be fraught with bias, particularly with pressures of societal norms, social desirability, and recall [4, 5]. Many researchers have tried to overcome these difficulties by...
using questionnaire wording creating comfortable environments that ensure privacy as well as trying different questionnaire delivery methods [4, 6]. Some studies have shown that the use of audio computer-assisted self-interviews can reduce socially desirable answer bias and improve data collection [7–11]. In this article, we review data related to HIV disease in women and discuss strategies to improve linkage to HIV-related medical and social care.

**INCREASED RISK OF HIV INFECTION IN WOMEN OF COLOR**

Multiple factors contribute to the excess risk of HIV acquisition in women of color [12]. The major drivers of the epidemic among these women involve complex behavioral, cultural, and environmental factors that result in excess vulnerability to HIV acquisition. These factors have little to do with the biology of race or ethnicity per se but are the consequence of socioeconomic inequality, lower health literacy, inadequate access to high-quality health care [13–15] and high-risk environments that result from racial and sex biases in the United States [16].

Although much of the discussion of HIV disease risk focuses on individual “high-risk” behaviors—for example, multiple sex partners or drug use, many women acquire HIV as a result not of their individual behaviors but of their sexual partner’s behaviors and of their membership in a social network where HIV infection is common among potential sexual partners. This is particularly true for black women, because the prevalence of HIV in black men has increased to as high as 6% in some urban areas [17, 18]. The high prevalence of HIV among black men results in increased HIV transmission risk for black women whether or not they engage in high-risk behaviors; that is, simply starting a new monogamous relationship puts black women at substantial risk of encountering HIV.

The vulnerability of monogamous black women to HIV is well illustrated in a case-controlled study of African American women with heterosexually acquired HIV in North Carolina which examined risk behaviors in HIV-positive and HIV-negative women [19]. Importantly, 27% of the HIV-infected women had no discernable high-risk behaviors. Independent risk factors for HIV acquisition among these women were food insecurity, less than high school education, and non-monogamous sex partners. Poverty and the reliance on men for economic support compound the risk of HIV infection in women [20]. Financial and material dependence on men often makes it difficult or impossible for some women to take control of their sexual relationships, and lack of education and access to information, compounded by low self-esteem, may contribute to their emotional vulnerability. Black and Hispanic women are more likely than white women to live in environments with elevated rates of poverty, crime, incarceration, and illicit drug use. Many of the same factors that place women of color at increased risk for HIV infection also place them at risk for delayed HIV diagnosis, delayed entry into HIV care, poorer treatment outcomes, and excess mortality [16, 21–23].

Within the National Institutes of Health–funded Women’s Interagency HIV Study (WIHS), of 961 women beginning HAART, African American women were more likely to use cocaine, crack cocaine, or heroin, and Hispanic women were more likely to be depressed, to have an annual income of ≤$12,000, and/or to not have completed high school. Depression was associated with poorer virologic response, increased risk of immunologic failure, and increased risk of developing of AIDS-defining illnesses [23]. Among the women in this study who continued to receive HAART, there were no differences by race in any of the outcomes [23].

In addition to experiencing disproportionate HIV incidence and prevalence, women of color also suffer from greater HIV-related mortality. Overall, AIDS-related mortality decreased significantly after the introduction of HAART in 1996 [24]. However, the decrease was smallest for HIV-infected black persons, particularly black women, who experienced a 44% decrease, compared with a 79% decrease among white men [25].

**KEY BARRIERS TO DIAGNOSIS AND ENGAGEMENT IN HIV CARE**

**Barriers to HIV Testing**

Although the asymptomatic nature of early HIV infection may contribute to some delays in testing and care, other social and behavioral factors also create barriers to testing. Most of the delay in accessing medical care is caused by a delay in undergoing testing by at-risk individuals, possibly because of denial or misperception of risk due to lack of education regarding risk factors [26]. Fear of stigma associated with the diagnosis of HIV infection and discrimination in the health care setting also contribute to some delays in testing and entry into care. A study of 203 patients (one-quarter of whom were women) tested in Boston, Massachusetts, and Rhode Island found a mean duration of HIV infection of 8.1 years (95% confidence interval [CI], 7.5–8.6) before subjects entered care [26]. Sixty-six percent of the patients were aware of their HIV risk before testing, but the remaining third were unaware of their risk for HIV infection. Heterosexual intercourse was the most significant risk factor in those with decreased awareness of HIV risk [26].

Many women with a diagnosis of HIV infection do not access health care until they become pregnant or experience symptoms of HIV disease; one reason is the belief that their family responsibilities take precedence over self-preservation [27]. Other factors including perceived barriers to accessing to HIV care, poverty, and lack of health insurance coverage,
also prevent many women from being tested and entering care [28, 29].

Violence, and the fear of future violence, can also play a major role in an individual’s reluctance to know his or her HIV status, receive testing for HIV, seek HIV care, and subsequently receive appropriate treatment [30]. In one study, 20.5% of women, 11.5% of men who reported having sex with men, and 7.5% of heterosexual men interviewed reported physical harm since diagnosis, and nearly half reported HIV-seropositive status as a cause of violent episodes [29]. In a study of HIV-positive women seeking care in Boston and Rhode Island, 68% had histories of physical or sexual abuse. These women were more likely to have episodic medical problems, sexually transmitted diseases, and chronic pain syndromes than did those who did not experience domestic violence [31]. Posttraumatic stress can affect self-esteem and lead to the development of chronic mental illnesses such as depression [32]. Studies have explored how negative self-images growing out of abusive relationships create barriers to self-care [16, 32]. Women who were victims of abuse were more likely than women who were not abused to consider their providers as judgmental, annoyed, and disrespectful and to find it difficult to discuss private and emotional issues with them [33].

**HIV-Infected Subjects Not Receiving Care or with Delayed Entry to Care**

Despite advances in antiretroviral therapy (ART), numerous patients with HIV infection are not receiving care. Among persons with known HIV infection, up to one-third are not receiving care [34]. In a study from the University of Alabama, 160 of 522 patients failed to attend a new patient visit within 180 days of their scheduled appointment [34]. Failure to establish care in a timely fashion was highest among white women (odds ratio [OR], 2.72; 95% CI, 1.3–5.68), closely followed by minority women (OR, 2.39; 95% CI, 1.27–4.52) and patients lacking private health insurance [34]. A significant proportion of patients wait >1 year before entering into HIV medical care [35], which may be due to denial of the diagnosis in addition to problems in the nature of the referral to primary HIV care. One-third of women with HIV infection in the United States present with AIDS at the time of their diagnosis or progress to AIDS within 12 months [2]. Key barriers to entry into care for HIV-infected women include lack of transportation [16], child care issues [28, 36], economic factors [22], symptoms of clinical depression [37], history of drug or alcohol abuse [16, 38] or physical or sexual abuse [16], nonwhite race [16, 38, 39], private insurance or lack of insurance [28, 38, 39], not receiving specialist care [40], inability to take time off work [28], and being too sick [28].

In a study of 316 HIV-positive adults who were not receiving medical care, 28% were women [41]. Most had an income of <$10,000 per year, and 84% did not have health insurance. Corroborating the findings of the WIHS cohort that HIV-infected women have high rates of poverty and unemployment [23], another study of 291 women with a diagnosis of AIDS, conducted between 1990 and 1992, found that 90% were unemployed and 83% had an annual income of <$10,000 [42]. In comparison, only 8% of HIV-infected men in the Multicenter AIDS Cohort Study had an annual income of <$10,000, and 14% were unemployed [43]. Going without care because of limited money for food, clothing, or housing; postponing care because of not having transportation; not being able to leave work for medical appointments; and being too sick were all associated with significantly greater odds of visiting an emergency room without being hospitalized and with never receiving prescriptions for ART [22]. In the WIHS cohort, African American women with a history of injection drug use, and those currently using alcohol and illicit drugs were less likely to report initiating HAART [38].

In the study by Rudy et al, 55% of patients not receiving medical care who were questioned reported that they had not been referred to a case manager, and 27% stated that not enough time was spent with them [41]. Twenty percent reported that they were told not to receive care, and 7% stated that they were not treated with respect. The researchers identified deficiencies in HIV counseling services, particularly in jails, private physician offices, and emergency departments and hospitals as important factors associated with inadequate medical care. These represent missed opportunities to link patients to appropriate HIV care. This particular study highlights how poor counseling can affect a person’s care-seeking behavior and motivation to seek care. Referral to case management may increase the numbers of patients receiving medical care [41].

Many women living with AIDS are from rural or smaller metropolitan areas, which creates additional potential barriers to high-quality care, such as the presence of fewer expert HIV care providers. Limited access to expert care may also contribute to poorer outcomes and increased disease progression [44]. Women with AIDS receiving care in highly experienced clinics survived longer after AIDS diagnosis than those in clinics with less experience [45]. Women who are incarcerated may not be tested, because many penal programs do not have guidelines for routine testing (especially in short-term facilities, eg, jails), even though the prevalence of confirmed AIDS diagnoses among those who are incarcerated is 2–5 times higher than in the general population [46].

**Late Initiation of HAART**

Several studies have found that compared with men, women are more likely to delay starting ART, are less likely to begin HAART, and have more visits to the emergency department and hospitalizations than men with similar CD4 cell counts [47,
Factors that have been associated with a lower likelihood of starting ART include being African American, having less education, using injection drugs, and being depressed [39, 49]. In a study from the WIHS cohort, of 889 women eligible for ART (CD4 cell count <350 or a viral load >50,000 copies/mL, as per guidelines at the time), 28% reported receiving no ART and, in comparison to white women, a significantly lower percentage of African American women received ART [16]. Women with a history of past and current use of crack cocaine or heroin were more than twice as likely to not receive ART than women who did not use these drugs, and women with a history of physical or sexual abuse and those with hepatitis C were also less likely to report receiving ART [16]. Women with high levels of depressive symptoms were less likely to receive ART, but those receiving mental health treatment were more likely to report receiving ART [37]. HIV-infected depressed patients were also twice as likely to die as those with mild or no depressive symptoms [50].

Recently, Losina et al [51] published a study using a state-transition model to estimate the life expectancy loss due to HIV disease, HIV-associated behavioral risk, late presentation to treatment, and early discontinuation of HIV care and to compare these survival losses by race and sex. The researchers estimated that HIV-associated survival loss, treatment discontinuation rates, and their consequences were highest among black and Hispanic women.

Another recent study of treatment outcomes among HIV-infected persons at Vanderbilt University HIV clinic (Nashville, Tenn) demonstrated that black subjects and women had lower survival rates and significantly shorter duration of HAART than white subjects and men, respectively. After adjustment for duration of HAART, the survival difference between black and white subjects was eliminated, but the difference between men and women persisted, suggesting that duration of HAART is not the only important factor contributing to poorer treatment outcomes in women [52].

Mistrust of Care Providers
Lack of trust in health care providers and the medical community may contribute to decreased use of health care services, particularly in the African American community [53]. The legacy of the Tuskegee Syphilis Study, in which treatment was withheld from African American men with syphilis, and ongoing disparities in health care quality and access only lend support to conspiracy theories regarding new medications and research in general and for HIV/AIDS in particular [54, 55]. Attitudes toward HIV, particularly HIV/AIDS conspiracy beliefs, may contribute to patients knowing they are HIV-infected but not accessing care [54]. The Coping with HIV/AIDS study in the southeast United States reported that nearly 25% of all minority respondents (and 11% of nonminorities) strongly believed that the government created AIDS to kill minorities; when asked if they were uncertain if the government created HIV, fully 45% of minorities and 23% of nonminorities agreed. Nearly half of all respondents believed that information about HIV was being withheld [53]. In a recent study of 500 randomly selected African Americans, Bogart and Thorburn found that a substantial proportion endorsed the beliefs that HIV was an artificially made virus (48%), that information and a cure for HIV were being withheld from the poor (59% and 53%, respectively), and that those who take HIV medications are guinea pigs for the government (44%) [54]. HIV-infected individuals who are not receiving care have common reasons for avoiding care. These include denial and disbelief about their HIV serostatus, beliefs about illness and culturally appropriate health care, and negative experiences with and distrust of the health care system [56]. In a study of HIV-infected persons in New York City, women were significantly less likely to report optimal utilization of HIV health care services, including less use of HIV primary care services and greater use of the emergency department. Several other risk factors were associated with suboptimal utilization of HIV health care services, including less use of HIV primary care services and distrust of the health care system [57].

Substance Use
A recent study of HIV-infected persons admitted to Jackson Memorial Hospital (Miami, Fla) or Grady Memorial Hospital (Atlanta, Ga) found that 20% of these individuals had never received HIV care despite knowing for >5 years that they were infected. Forty percent had not seen an HIV health care provider in >6 months [58]. The primary risk factors for not receiving care were alcohol abuse and crack cocaine use. Active crack cocaine use has also been associated with poorer treatment outcomes. A study examining women in the WIHS cohort who initiated HAART therapy found that drug use was associated with greater risk of AIDS-defining illnesses and AIDS-related death [23].

Steps Toward Improved Linkage to Care for Women

Increased HIV Testing
The CDC currently recommends routine opt-out HIV testing for all persons aged 13–64 years [59]. That is, patients should be informed that HIV testing will be performed during a routine visit or medical encounter unless they refuse to undergo it. This strategy has been in place for pregnant women for many years and has been effective at identifying HIV-infected women who become pregnant but who have no symptoms that would otherwise prompt an HIV test to be offered. Increased
implementation of this more proactive testing strategy may help to identify more HIV-infected individuals at earlier stages of disease and thus provide an opportunity for earlier linkage to care and treatment. Enhanced education of primary care providers, gynecologists, urgent care center providers, and emergency department staff could help increase the uptake of this recommendation.

Further increased targeted testing in areas with known higher prevalence of HIV infection can be an effective strategy as well. A recent study done by the CDC-funded National HIV Behavioral Surveillance Program evaluated a sample of 750 Washington, DC, residents believed to be at risk for HIV infection owing to their connection with geospatial areas of high HIV prevalence and poverty. The study found that 5.2% of all individuals tested and 6.3% of women were HIV positive [60]. Similar testing initiatives should be implemented in all US geographic areas with high rates of poverty and substance use and in other high-prevalence settings, including correctional centers and mental health facilities, to identify persons with undiagnosed HIV infections. However, it is critical that increased testing go hand in hand with active, direct linkage to care.

**Active Linkage to Care**

A recent study examining hospitalized HIV-infected patients found that patients who were not being “helped into care” after an initial diagnosis of HIV infection were less likely to engage in subsequent HIV care [61]. The diagnosis of a patient’s HIV infection should be seen as an opportunity to link individuals directly into care. Providing actual appointments rather than general referral information may be useful. Referrals for active case management may also increase the number of patients who access care [41, 62, 63]. Reduction in the number of patients who do not receive follow-up care may be possible with programs that focus on addressing barriers to care, such as lack of health insurance coverage, housing, or transportation, as well as perceived barriers to care, such as fear of medications, stigma associated with HIV, and death. Counselor training that focuses on interpersonal skills is needed, with a focus on patients’ needs and appropriate follow-up. Finally, women with AIDS receiving care in highly experienced clinics survived longer after AIDS diagnosis than those in clinics with low experience [45].

**Systematic Follow-up of Missed Visits**

It is critical not only that patients be linked to care but also that they be retained in care. A recent study of patients in HIV care at a clinic in Alabama showed that missed clinic visits were more common among women than men, and that missed visits were associated with greater likelihood of virologic failure and higher mortality rates in the first year of treatment [64]. Systematic follow-up of missed visits (either initial or follow-up) can help decrease missed visits by reminding patients of appointments, providing information or reassurance regarding the need for consistent adherence to ART, and addressing new challenges (eg, loss of insurance coverage or transportation). This type of follow-up also enhances the patient-provider relationship by reminding patients that the provider cares about their well-being and misses them when they are absent.

**Improving Trust with Culturally Competent Care**

Given the fact that the majority of HIV-infected women are women of color, it is imperative to create treatment environments that are woman-friendly, racially diverse, and culturally competent [12]. Woman-friendly environments offer child care and access to multiple resources including case management, social workers, and gynecologic care, at a minimum. Further, the clinic should have literature and educational materials directed toward women as well as regular programming (e.g., support groups) that focus on the needs of women. Culturally competent care requires health care providers to have knowledge of and comfort with cultures and beliefs that may be different from their own. Some of the key components of culturally competent care are linguistic competency, maintenance of open lines of communication, and understanding another person’s history and beliefs (e.g., cultural, religious) [12].

Strong patient-provider relationships are critical to linkage to and retention in care for all HIV-infected patients, but women in particular may be more challenged by competing priorities of providing and caring for families. These added challenges make it even more important that providers create environments in which women can get their needs met.

**Screening for Violence and Mental Illness**

Gielen et al [65] reported that 63% of 287 HIV-infected women reported having been physically or sexually assaulted at least once as an adult and that a history of child abuse was significantly related to mental health. Their study noted that women with larger social support networks who practiced more self-care behaviors (healthy diet and vitamins, adequate sleep and exercise, and stress management) reported better physical and mental health and overall quality of life. These are potentially modifiable behaviors that could be addressed at health care visits. Activities that put women at risk for HIV infection, such as injection drug use and high-risk sex, also put them at risk for violence and a lack of social support. Women who use injection drugs often rely on exchange of sex for drugs or money and have few female friends and strained family support [66].

**CONCLUSION**

In conclusion, strategies to improve linkage to HIV care for women must include increased community awareness of HIV,
increased HIV testing in general and in high-prevalence environments, in particular, and aggressive direct linkage to HIV care clinics. However, efforts must also go beyond these to include policies that address unstable housing, poverty, unemployment, and substance use in minority communities, because these challenges create competing priorities that impede successful treatment of women infected with HIV.

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