

Literature Review

on Issues Related to
Women with HIV/AIDS in
New York City



Women Living With **HIV** and **AIDS** in **NYC**

A MAPPING PROJECT
AND LITERATURE
REVIEW



Literature Review on Issues Related to **Women** with **HIV/AIDS** in **New York City**



INTRODUCTION

Half of the 34 million people living with HIV/AIDS worldwide are women (UNAIDS, 2007). In contrast, women in the United States are less likely to be infected than men: women comprise about 25% of the 1.2 million domestic cases of HIV (Kaiser Family Foundation, 2008). For many years the number of newly diagnosed cases of HIV hit a plateau at approximately 40,000 each year in the US and, in 2005, 27% of these cases were among women (Centers for Disease Control and Prevention, 2007). Employing new technology able to more accurately track new cases of HIV, the CDC issued revised numbers in 2008. The results were significantly higher, with approximately 53,600 adolescents and adults having been newly infected (Hall, Song, Rhodes; et al, 2008). The HIV burden among women in the US is not distributed equally across age, race, or socio-economic class. Young, African American and poor women are disproportionately infected with HIV: in 2005, over half of the women diagnosed with HIV in the U.S. were between the ages of 15-39, 66% were African American, and 64% of the women living with HIV have annual incomes below \$10,000 (Centers for Disease Control and Prevention, 2007; Kaiser Family Foundation, 2008). Most women with AIDS (73%) acquired HIV through high-risk heterosexual contact, the remainder were primarily infected through IV drug use (24%) (Kaiser Family Foundation, 2008).

New York State has the largest population of people with AIDS in the United States (Kaiser Family Foundation, 2008). The state also has the country's largest population of women, Blacks and Hispanics living with AIDS (Kaiser Family Foundation, 2008). The rates of HIV/AIDS among women in New York City approximate national averages but vary in terms of demographic distribution. In 2007, 30% of the 100,642 people known to be living with HIV/AIDS in New York City were women (New York City Department of Health and Mental Hygiene, 2008). While the percent of women with HIV in New York City who are African American reflects national figures (58% in 2006), there is a far larger representation of Hispanics: 31% of the New York City women living with the virus are Hispanic, versus 14% nationwide (Centers for Disease Control and Prevention, 2007; New York City Department of Health and Mental Hygiene, 2007). The female population of women with HIV/AIDS in New York is also much older than the national average: 83% were between 39 and 59 years old in 2006 (New York City Department of Health and Mental Hygiene, 2007). Still, AIDS was the leading cause of death among women in New York City aged 25-44 between 2000 and 2002 (Kerker, Kim, Mostashari, Thorpe, & Frieden, 2005). In terms of transmission categories, 39% of HIV-positive women report acquiring the disease through high-risk heterosexual contact and 21% attribute the infection to injection drug use (New York City Department of Health and Mental Hygiene, 2007). The remaining women report their transmission route as "unknown" (36%) and perinatal (4%) (New York City Department of Health and Mental Hygiene, 2007).

What challenges do women with HIV in New York City face? What are the needs of this population and what interventions have been successful in meeting these needs? In an effort

to answer these questions, this literature review summarizes the current research on women living with HIV in New York City and other major urban areas in the United States. Specifically, the review includes research that focuses exclusively on women or includes analysis based on gender. Academic databases were searched using the terms “woman/women” and “HIV” and “United States.” Because this summary focuses on women living with HIV, articles about prevention among high-risk women were not included unless they contain information about secondary prevention among women who are already infected (“prevention for positives”). Research was identified about the psychosocial issues (mental health, substance use, violence, abuse, spirituality, sexuality, stigma, family and children), medical concerns (co-morbidities, access to care, reproductive services) and structural factors (criminal justice systems, housing) to form a holistic picture of the issues that shape the lives of women and girls with HIV in New York City and beyond.

PSYCHOSOCIAL ISSUES

Mental Health

The literature reports high rates of mental health problems, ranging from distress to suicidal ideation, among women living with HIV/AIDS in the United States. For example, studies have found that rates of depression among women with HIV are four times higher than uninfected women (Morrison et al., 2002) and the general population (Simoni, Bu, Goodry, & Montoya, 2005). A 2005 study of HIV-positive women in New York City found that 26% had attempted suicide at least once since being diagnosed with HIV (Cooperman & Simoni, 2005). Studies have found that 50% of HIV-positive women experience some kind of psychiatric disorder (Dodds et al., 2004). Depression is experienced by about 15%, anxiety by 11%, and post-traumatic stress disorder (PTSD) by as much as 35% of all women with HIV (Dodds et al., 2004). Women’s identities as caregivers (versus people who receive care) and hesitation to disclose their HIV status are two gender specific barriers to mental health treatment (Schrimshaw, 2002).

Untreated, these mental health issues can interfere with women’s capacity to adhere to HIV treatment (Anaston et al., 2005; Cook et

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al., 2004) and access social support services (Catz, Gore-Felton, & McClure, 2002). However, interventions have been developed to help reduce mental health problems in this population. Surveys conducted with HIV-positive women in New York City found that women who feel a strong sense of belonging to a social network, have high levels of self-esteem, feel in control over their lives, experience low levels of social conflict, and believe social support is available to them and/or receive social support from friends and family are less likely to be depressed (Schrimshaw, 2002; Simoni et al., 2005). From this, support groups and efforts by AIDS service organizations to accommodate women have been effective in reducing mental health problems among HIV-positive women (Schrimshaw, 2002; Sikkema, Hansen, Meade, Kochman, & Lee, 2005; Simoni et al., 2005; Simoni & Cooperman, 2000). The high prevalence of mental health problems in this population suggests the need to more fully integrate psychiatric services into primary HIV care for women. The University of Miami reports on a successful project that locates mental health clinicians, including social workers and psychiatrists, directly inside the Obstetrics/Gynecology office that delivers care to women with HIV in order to facilitate client access to these services (Dodds et al., 2004).

While HIV-related medical problems and the unique bereavement, stigma, stress and anxiety issues among HIV-positive women certainly contribute to mental health problems in this population (amfAR, 2008; Cooperman & Simoni, 2005; Feist-Price & Wright, 2003; Sikkema et al., 2005; Simoni et al., 2005), many of their mental health problems relate to experiences of poverty, physical/sexual abuse, violence and substance use that are related, but distinct, from their HIV status. As Catz et al. (2002) explain, "The emotional effects of being HIV seropositive are compounded in these women, who may already be prone to high levels of anxiety and depression as a consequence of their low SES [socio-economic status]" (p. 58). Similarly, when researchers compared the psychological health of women in New York City before and after the advent of HAART they found was that the two groups of women had the same rates of mental health problems even though the women who had access to HAART had improved physical health outcomes (Siegel, Karus, & Dean, 2004). The authors explained the lack of difference in this way:

[W]omen in both samples, most of whom were socioeconomically disadvantaged, faced numerous other life stressors independently associated with depression (e.g. drug or alcohol addiction, violence,

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poverty, being the sole caregiver of 1 or more dependent children), some of which posed a more imminent threat to their psychological and physical well-being than did HIV. Indeed many women who are at risk of contracting HIV or who are already infected do not view the disease as the most challenging stressor they confront (p. 1131).

Violence & Abuse

In fact, a national study of HIV-positive women found that 66% had experienced some form of domestic violence in their lifetime and 31% had been sexually abused as children (Cohen et al., 2000). A survey administered to HIV-positive women in New York City found even higher rates of interpersonal violence: 50% reported childhood abuse, 68% reported abuse during adulthood, 7% had been physically assaulted or raped in the last 90 days (Simoni & Cooperman, 2000). One national study found that some incidents of violence are related to HIV status: half of the women who reported domestic violence since their diagnosis indicated that this post-diagnosis violence was caused by their HIV status (Zierler et al., 2000). While HIV-positive men also report abuse and violence, rates of abuse are higher among HIV-positive women (Henny, Kidder, Stall, & Wolitski, 2007; Zierler et al., 2000).

Interventions to help women with HIV cope with histories of abuse and reduce the violence in their lives are important to improving their mental health, increasing their access to antiretrovirals (Pence et al., 2007) and building their ability to negotiate safer sex practices, including condom use (Lang, Salazar, Wingood, DiClemente, & Mikhail, 2007). While the literature has documented high rates of violence and articulated the need for systems of care “to address the HIV epidemic’s shift into poor, minority, and female populations” (Pence et al., 2007, p. 1114), there are few programs that specifically address this intersection of HIV status and histories of violence and abuse (Pence et al., 2007; Sikkema et al., 2004; Simoni & Ng, 2000; Zierler et al., 2000). In one such intervention, HIV-positive women participating in group therapy for survivors of childhood sexual abuse in New York City experienced significant improvement in trauma symptomology (Sikkema et al., 2004). The researchers credited this improvement to the skills for coping with stress that were taught to the group and the social support that the group members conveyed to each other.

Substance Use

Similarly, there is a need for substance abuse treatment programs that specifically target HIV-positive women (Von Unger & Collins, 2005). Women with HIV report high rates of substance use. Nationally and in New York City, 20% of the women living with HIV were infected through injection drug use (Centers for Disease Control and Prevention, 2007; New York City Department of Health and Mental Hygiene, 2007). Interviews with HIV-positive women living in urban areas between 1997 and 2000 found that in the preceding five years, 23% had used crack, 42% had used other drugs and 35% had never used drugs (Sharpe, Lee, Nakashima, Elam-Evans, & Fleming, 2004). An HIV diagnosis has different impacts on female drug users. For



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some, the diagnosis can motivate them to stop using, for others, an HIV diagnosis will increase use, while others are too “caught up” in drug use to care about their HIV status (Von Unger & Collins, 2005). Medical professionals may be reluctant to prescribe antiretroviral medication to women who are actively using drugs because of concerns about adherence (Parsons, Rosof, Punzalan, & Di Maria, 2005; Sharpe et al., 2004). Research has found that HIV-positive women with histories of substance use are more likely to adhere to antiretroviral regimes when they are involved in drug treatment programs, irrespective of modality (Kapadia et al., 2008). From this, it is essential help HIV-positive women access drug treatment programs (Kapadia et al., 2008; Sharpe et al., 2004; Thorpe et al., 2004; Von Unger & Collins, 2005).

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Family & Children

Family can be a strong source of psychosocial support for women living with HIV (Latham, Sowell, Phillips, & Murdaugh, 2001). A study of HIV-positive women in a Midwestern city found that while friends were more supportive on a day to day basis, the women’s perceptions of family support – the extent to which they felt family support existed, even when family did not live nearby and did not provide actual assistance – was correlated more strongly with the women’s mental health (anxiety, stress, depression, loneliness) than the friend’s support (Serovich, Kimberly, Mosack, & Lewis, 2001). For HIV-positive women, disclosing their HIV status is the first step towards gaining family support. Studies have found that while women approach disclosure with high levels of trepidation, most experience little or no regret after disclosure (Serovich, McDowell, & Grafsky, 2008). Women are mostly likely to disclose to female relatives, especially mothers and sisters, who they see regularly, live close to and with whom they experience high levels of relationship satisfaction (Serovich, Craft, & Hae-Jin, 2007). Women who feel devalued and discriminated against are less likely to disclose (Letteney & LaPorte, 2004). Disclosure to children can be particularly difficult but is critical to their planning and care (Letteney & LaPorte, 2004; Simoni & Davis, 2000). HIV-positive women are more likely to have children than HIV-positive men (60% vs. 18%) and are more likely to live with their children (76% vs. 34%) (Schuster et al., 2000).

In addition to hesitations about disclosure, there are other factors that inhibit HIV-positive women from accessing support from family. Many of their families face multiple stressors, including

interpersonal violence and drug use, which limit their ability to provide support (Latham et al., 2001). In addition, a national study found that “multiple HIV infections are remarkably common in families of HIV-positive women:” 35% of the HIV-positive participants had family members with HIV, most often a sibling or a husband (Fiore et al., 2001, p. 213). Creative programming is needed to assist women before, during and after disclosure and bolster the families of HIV-positive women, given the multiple stressors that they face, so that they might be a source of support to these women (Fiore et al., 2001; Latham et al., 2001; Serovich et al., 2007).

Sexuality/Prevention for Positives

Relationships with sexual partners are another key psychosocial issue for HIV-positive women: “The sexual and relational aspirations of HIV-positive women appear to mirror those of women generally and many women living with HIV continue to pursue these despite additional challenges” (Keegan, Lambert, & Petrak, 2005, p. 654). An eight year study of 389 HIV-positive women in New York City documented how the participants’ sexuality changed over time, alternating between periods of safe and unsafe sex, different types of sexual partnering, and shifting sexual orientations (Aidala, 2006). While the majority of HIV-positive women report being sexually active, they also report a range of sexual and relationship issues including lowered libido, reduced intimacy, fears of infecting partners and being re-infected by partners, relationship avoidance (which translates into more casual partners) and difficulties in sustaining condom use in long-term relationships (Keegan, Lambert, & Petrak, 2005).

As with family, disclosure is a major issue in sexual relationships. A study of 180 Black HIV-positive women in New York City found that “only half of the women and half of their network members discussed and disclosed an HIV status” (Miller, Korves, & Fernandez, 2007, p. 862). In other words, most of the women in this study did not disclose their HIV status to their partners, nor were they aware of their partners’ status. Similarly, research has found that women are often unaware of their male partners’ sexual histories: a national study found that while 13-34% of men who have sex with men reported also having sex with women, but only 6-14% of women reported having a bisexual partner (Montgomery, Mokotoff, Gentry, & Blair, 2003). These findings may explain why 36% HIV-positive women in New York City do not know the source of their HIV infection (New York City Department of Health and Mental Hygiene, 2007).

Especially in an environment where HIV-positive women may not be aware of their sexual partners’ HIV status or sexual history, it is important for them to practice safer sex in order to avoid transmitting the virus to others and reduce their own risk of re-infection. However, several studies, many of them conducted in New York City, have found low rates of condom use among HIV-positive women, with between 23% - 50% of participants reporting unprotected sex (Demmer, 2002; Kanouse, Collins, Miu, & Berry, 2005; Massad, Evans, Wilson et al., 2007; McGowan et al., 2004; Wilson et al., 2004; Wilson et al., 2006). Women who have been sterilized (Massad, Evans, Wilson et al., 2007), use oral contraceptives (Kanouse et al., 2005) or exchange sex for money or drugs (McGowan et al., 2004) are less



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likely to use condoms. Unstably housed women and women who use drugs are more likely to report exchanging sex for money (Aidala, Gunjeong, Garbers, & Chiasson, 2006). Condom use has declined as access to HAART has increased because women believe the medication reduces their risk of transmitting the virus (Demmer, 2002; Wilson et al., 2004). This research identifies the need to create culturally appropriate, on-going risk reduction counseling programs for HIV-positive women and their partners that take into account the impact of HAART, sterilization, housing instability, drug use and poverty on condom use.

Wingood et al. (2004) created a randomized controlled trial to test the impact of risk reduction group counseling on the sexual behavior of a predominately Black sample of HIV-positive women living in mid-size cities in Alabama and Georgia. The women's sexual behavior was measured six and twelve months after they participated in the four session intervention. The researchers found that the participants were less likely to report unprotected sex and experienced fewer bacterial STDs than a comparable group of women that had not received the intervention. The success of the program was attributed to the information transferred, the social support created among the group, and efforts to address gender-specific barriers to participation, including child care and transportation (Wingood et al., 2004). This example illustrates that interventions can help HIV-positive women reduce their sexual risk, especially when they are specifically tailored to meet women's circumstances and needs.

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MEDICAL CARE

Access to Care & Adherence

In addition to the psychosocial challenges of living with HIV, positive women obviously face a range of medical issues. The advent of antiretroviral (HAART) medication has reduced HIV symptoms and delayed the onset of AIDS, but access to medical care and these medications varies, with gender being a significant variable. "US women are less likely than men to have access to appropriate health care and to utilize services, including the latest antiretroviral drug therapies" (Burke, 2003, p. 452). A study of unstably housed people with HIV in New York City found that women were more likely to be hospitalized and identify an emergency department clinic as their usual location of care than men (Cunningham, Sohler, McCoy, Heller, &

Selwyn, 2005). A Chicago study found that HIV-positive men were more likely to use HIV medication than HIV-positive women (Kenagy et al., 2003). Many factors contribute to this inferior access including dissatisfaction with care (Burke, 2003), untreated drug use (Sharpe et al., 2004) and difficulties securing housing support and transportation (Kenagy et al., 2003). This research echoes the findings from the psychosocial research: providers must design systems of care that meet women's unique needs in order to fully engage them in services.

Co-morbidities

Women with HIV also experience a unique set of co-morbidities, or other non-HIV illnesses, when compared to HIV-positive men and HIV-negative women. The Women's Interagency HIV Study (WIHS) enrolled 2,628 women, 2,059 of whom were HIV-positive, between 1994 and 1995 and interviews them on a semiannual basis (Women's Interagency HIV Study, n/d). The WIHS study sites include New York City (two sites), Washington DC, Chicago, Los Angeles and San Francisco. The inclusion of high-risk non-infected women allows researchers to compare the health outcomes of HIV-positive and HIV-negative women. Analysis of this data has found that HIV-positive women were more likely to get a hysterectomy (Massad, Evans, Weber et al., 2007), and be diagnosed with anemia (Levine & Berhane, 2001) and cancer (Hessol et al., 2004) than HIV-negative participants. HIV-positive and HIV-negative women were equally likely to be overweight or obese (Mulligan et al., 2005). HIV-positive women had better dental health than their uninfected counterparts because of their access to dental services through HIV-specific funding (Shiboski et al., 2005). Other studies that have compared HIV-positive and HIV-negative women have found that positive women experience higher rates of pneumonia (Kohli et al., 2006) and syphilis (Chesson, Heffelfinger, Voigt, & Collins, 2005).

Pregnancy & Perinatal Transmission

Since the beginning of the epidemic, nearly 8,500 children in the United States have been infected perinatally: the virus was transmitted to them from their mother during pregnancy, childbirth or breastfeeding (Centers for Disease Control and Prevention, 2007). The number of babies infected perinatally each year has been reduced dramatically by prenatal protocols, including antiretroviral medications during pregnancy and cesarean delivery, which can reduce the vertical transmission rates to 2% or less (Centers for Disease Control and Prevention, 2007; "Cesarean delivery for HIV-positive women," 2000; Dominguez et al., 2003). Still, 67 cases of perinatal transmission were reported in 2005 (Centers for Disease Control and Prevention, 2007). Many states, including New York, developed mandatory prenatal HIV testing policies to identify HIV-positive women in need of prenatal care and reduce the number of HIV-positive infants ("Prenatal HIV testing and antiretroviral prophylaxis at an urban hospital in Atlanta, Georgia, 1997-2000," 2004; Sarnquist, Cunningham, Sullivan, & Maldonado, 2007; Webber et al., 2003). Concerns have been raised, however, about the lack of drug adherence among pregnant and post-natal HIV-positive women that can lead to drug resistance. In a



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study of 53 HIV-positive pregnant women residing in urban areas, including Brooklyn, NY, Ickovics et al. (2002) found that adherence was extremely low, especially postpartum. Adherence problems, during pregnancy and throughout the lifespan, may erode the ability of women to benefit from antiretroviral medications. For example, researchers in New York City recorded much higher rates of drug resistance (34% vs. 15%) among HIV-positive pregnant women between 1999-2001, compared to pregnant women with HIV between 1991-1994 (Welles, Bauer, Larussa, Colgrove, & Pitt, 2007).

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women today

In spite of these resistance issues, healthy pregnancies are a very real option for HIV-positive women today. Pregnancy rates among women with HIV have steadily increased since 1997, especially among younger, healthier women who have access to HAART (Blair, Hanson, Jones, & Dworkin, 2004; Bryant et al., 2007; Craft, Delaney, Bautista, & Serovich, 2007). A multi-site study of over 2,000 HIV-positive pregnant women that began in 1989 found that 22% had at least one repeat pregnancy, and 23% of that subgroup had more than one repeat pregnancy (Bryant et al., 2007). Several studies have examined pregnancy decisions among HIV-positive women (Craft et al., 2007; Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2001; Wilson et al., 2003). Craft et al. (2007) found that 26% of the 74 HIV-positive, urban, primarily African American, women who participated in their study had chosen to become pregnant since being diagnosed with HIV. These women weighed concerns about vertical transmission and their own personal health against their desire to have a child (Craft et al., 2007). Interestingly, “medical personnel were more influential upon the decision to terminate a pregnancy than the choice to become pregnant” (Craft et al., 2007, p. 933). Another similar study of HIV-positive, urban, primarily African American women found that perceived risk of vertical transmission and desire for motherhood factored heavily into the women’s pregnancy decisions (Kirshenbaum et al., 2004). Stigma, religious beliefs and attitudes of partners and health care providers also played a major role in pregnancy decision-making (Kirshenbaum et al., 2004).

Women’s concerns about vertical transmission in these studies suggest that they may not be adequately educated about the actual risks of pregnancy. Many factors could contribute to women’s misinformation on this issue including the possibility that reproductive “counseling may be complicated by health care provider opinions, expressed directly or indirectly, that may jeopardize a women’s ability to make independent and informed decisions” (Kirshenbaum et al., 2004, p. 112). More research is needed to understand opinions of medical professionals about pregnancy among HIV-positive women and how these are shaped by racism, classism and bias against drug users. Indeed, reproductive techniques that “safeguard the uninfected while providing effective, affordable care to the HIV-seropositive patient” are largely unavailable in the United States (one of the few programs that exists is at Columbia University Medical Center in New York City) suggesting some reluctance on the part of the medical profession, and/or society at large, to facilitate pregnancy among HIV-positive individuals (Sauer, 2003).

STRUCTURAL FACTORS

In addition to these psychosocial and medical issues, there are a range of structural factors that shape the lives of HIV-positive women including the criminal justice system, housing and social stigma. These external factors mediate women's quality of life and access to care and support systems. Research about these structural determinants of health suggests how social systems might be altered to improve health outcomes for HIV-positive women.

Criminal Justice Systems

National statistics. Since the 1980s, the number of women who are incarcerated has grown exponentially. There were 19,761 women incarcerated in State prisons in 1986 (Snell, 1994). By 1996, there were 74,730 women in State or Federal prison and by 2007 that number had grown to 115,308, or about 7% of the imprisoned population (Mumola & Beck, 1997; Sabol & Couture, 2008). Sixty percent (60%) of the women in State prison meet the criteria for drug dependence or abuse and 58% are serving time for non-violent drug, property or public order offenses (Bonczar, 2007; Mumola & Karberg, 2006). In 2006, 2.4% of the women (n=2,138) in state and federal prison were HIV-positive (Maruschak, 2008). There are nearly 100,000 women in jails on any given day (Sabol & Minton, 2008), over one million women on probation and nearly 96,000 women on parole. (Glaze & Bonczar, 2007). African American women are disproportionately impacted by the criminal justice system. Although African Americans comprise 13% of the U.S. population, 28% of female prisoners are Black (Sabol, Couture, & Harrison, 2007); Black women are incarcerated at a rate that is 3.7 times that of White women (Sabol & Couture, 2008).

New York statistics. In the state of New York, there are 2,821 women in prison, 23,700 women on probation and 3,100 women on parole (Correctional Association of New York, 2008). Eighty-four (84%) of the incarcerated women were convicted of non-violent offenses (Correctional Association of New York, 2008). The number of women who are incarcerated in New York State grew by more than 600% between 1973 and 2008, but these numbers have been on a decline and are down by about 25% since 1997 (Correctional Association of New York, 2008). Two-thirds of New York State inmates come from New York City (Correctional Association of New York, 2008).

New York State has the second largest population of female prisoners with HIV in the United States (Maruschak, 2008). In 2006, 350 female inmates in New York were known to be HIV positive, about 12% of the female inmate population (Maruschak, 2008). This rate of HIV infection among female prisoners is higher than among male prisoners of whom 6% are HIV-positive (Maruschak, 2008). HIV rates are higher in the New York City jail system: a 1999 study by the New York Department of Health found that 18% of the women entering the city's jails were HIV-positive; a lower rate, 7.3%, was found among men. (Correctional Association of New York, 2006)



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Research on HIV-positive women and incarceration explores programs and policies that will reduce the number of women who go to prison and tests interventions that promote continuity of care between the community and prisons. Freudenberg et al. (2007) studied a group of nearly 2,000 individuals that left New York City jails between 1997 and 2004. About one-third of the sample (n=704) were women and 10% of these women were HIV-positive. In general, these researchers found that female participants were more likely to be homeless, use drugs and have health problems than male participants. Women were also more likely to have been arrested for a drug related charge.

Their study of the re-entry outcomes highlights the gender, age and race differences among ex-prisoners and suggests that programs to meet these diverse needs must be tailored for each group. They concluded, “[M]any health and reentry programs for women in jail are still developed by men for a male model of needs, the problems women in this study experienced suggest the need for a more women-specific programs” (Freudenberg et al., 2007, p. 741). A study of HIV-positive inmates in Jacksonville, FL, reached the same conclusion (Lanier & Paoline, 2005). While the study found few differences in the male and females needs (housing, medical care, income support) there were significant behavioral differences. For example, men were more likely to abuse alcohol while women were more likely to have used crack (Lanier & Paoline, 2005). The authors concluded that “gender specific alcohol and drug interventions may be warranted” (Lanier & Paoline, 2005, p. 571).

Richie (2001) conducted interviews with 42 incarcerated and formerly incarcerated women. The article includes the following quote from an HIV-positive participant detained in an urban jail:

Each time [I go to jail], I just keep getting worse and worse because I can’t keep up with all of the medicine I am supposed to be taking. Last time, I almost died...If I could just get some of this [medical problems] under control, then I could work on finding a place to live and finding a job. But I am just so sick all of the time now. (p. 373)

This quote speaks to the need to create community-based alternatives to incarceration programs and programs that allow criminally involved women to access seamless health care as they transition in and out of incarceration. In addition to improving health care outcomes, a multi-site study of HIV-positive and at-risk women in four urban areas, including New York City, found that “having a regular healthcare provider for more than 2 years...was significantly correlated with decreased risk of incarceration” (Sheu et al., 2002, p. 748).

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Rhode Island has developed a model program for identifying HIV positive inmates and linking them with health care both during incarceration and re-entry (Farley et al., 2000; Rich et al., 2001). Rhode Island requires that all jail and prison inmates be tested for HIV as part of a comprehensive program that includes posttest counseling, health education, substance abuse treatment, preventative medical care and referrals to community service providers (Farley et al., 2000). Between 1989 and 1994, 28% of all the women in Rhode Island who were diagnosed with HIV were identified through the prison testing program (Farley et al., 2000). Antiretroviral medication was well accepted by these women during their incarceration and 83% of them received follow up HIV care upon reentry, often with the same physician that had provided them care in prison (Farley et al., 2000). Case management services are also provided to facilitate access to housing and community based services (Rich et al., 2001). This program demonstrates that corrections can play a key role in reaching medically underserved populations, identifying HIV-positive individuals and linking them to care.

Housing

These studies about criminally involved HIV-positive women underscore the need for housing among people with HIV (Freudenberg et al., 2007; Lanier & Paoline, 2005; Rich et al., 2001; Richie, Freudenberg, & Page, 2001). Stable housing is key to promoting the health care and well-being of people with HIV (Aidala & Sumartojo, 2007; Cisneros, 2007). Only when basic needs, like housing, are met, can HIV-positive individuals focus on accessing medical care and meeting their treatment needs (Lanier & Paoline, 2005). Lack of housing promotes considerable instability in people's lives that may increase their risk behavior and reduce their medical adherence (Aidala, Cross, Stall, Harre, & Sumartojo, 2005; Elifson, Sterk, & Theall, 2007). A study of HIV-positive people living in New York between 1994 and 2002 found that among women, homelessness was associated with unsafe sex and exchanging sex for money or drugs (Aidala et al., 2006). Affordable housing programs operate locally and vary considerably across jurisdictions. Scott et al. (2007) compared HIV housing assistance in four major U.S. cities and found that New York City's comprehensive program, supported by city, state and federal dollars, was most successful in meeting the housing need of young HIV-positive women, when compared to New Orleans, Miami and Chicago.

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Stigma

The negative stigma faced by HIV-positive women represents another considerable barrier to their well-being. An online survey of 5,000 individuals conducted by amfAR (2008) found that:

- “59% said they would be somewhat or not at all comfortable with an HIV-positive woman serving as their childcare provider.” (¶ 4)
- 20% “would be somewhat or not at all comfortable having a close friend who is HIV positive.” (¶ 4)
- “Only 14% of respondents felt that HIV-positive women should have children.” (¶ 5)

The social stigma documented in this study represents one of three levels of stigma identified by Buseh and Stevens (2006) in their study of African American women with HIV. For one, women experience internal stigma that takes the shape of self-blame, shame and hopelessness. The second level of stigma is the social shunning and callousness identified in the amfAR survey. Rejection, fear, avoidance and verbal abuse by family or friends reflect this level of stigma. Institutional stigma is the third level of stigma identified by Buseh and Stevens. This stigma is experienced by HIV-positive women when they are treated poorly by social service agencies, medical providers, and correctional systems. Examples of this negative treatment include violations of confidentiality or marginalization that conveys a message of disregard and implies that these women are not deserving of respect. Buseh and Stevens (2006) found that the women in their study were able to overcome these multiple levels of stigma by being cautious about disclosure, identifying allies, “redefining stigma as ignorance and becoming advocates” (p. 2). This study offers specific coping mechanisms and illustrates that HIV-positive women can learn to manage the multiple levels of stigma in their lives. In addition to helping HIV-positive women cope with this structural barrier to care, attention must also be paid to how organizations and institutions treat HIV-positive women, with particular focus on how sexism, racism, classism and the stigmatization of sex work and drug use marginalize them.

MINORITY POPULATIONS

Given the demographics of this disease in the United States, the majority of the women in the research that is described in this paper are heterosexual African Americans in their 30s and 40s. There are, however, many sub-groups within this population of HIV-positive women, each with their own distinct needs and circumstances. This section will discuss research about four sub-groups including American Indian/Alaska Native (AIAN) women, Hispanic women, older women (defined in the literature as over 55 years old) and women who have sex with women (WSW).

American Indian/Alaska Native Women

Widespread racial misclassification of American Indians/Alaska Natives (AIAN) makes it difficult to estimate the number of AIAN people living with HIV. Bertolli, Lee and Sullivan (2007) examined the racial classifications in the federal HIV/AIDS Reporting System (HARS) of over 1,500 AIAN individuals receiving HIV care through the Indian Health Service and found that 30% had been racially misclassified, most often as Whites. The rate of misclassification in each of the six jurisdictions that were analyzed varied. In Los Angeles County, 54% of the AIAN people with HIV had been misclassified (Bertolli, Lee, & Sullivan, 2007). Almost 100,000 AIAN people live in New York City, making it the city with the largest AIAN population in the country (Evans-Campbell, Lindhorst, Huang, & Walters, 2006). New York City's Department of Health reports that 0.1% of HIV-positive women in New York are AIAN (New York City Department of Health and Mental Hygiene, 2007). This rate may underestimate the actual prevalence. A study of AIAN women in New York City conducted between 2000 and 2003 found that 6% of the sample was HIV positive (Evans-Campbell et al., 2006). Additionally, the participants also reported high rates of inter-personal violence (childhood abuse, rape, domestic violence).

Hispanic women/Latinas

Hispanic women in the United States are a very diverse group including monolingual and bilingual individuals, immigrants and U.S. born women, and people from multiple countries of origin, each with its own unique culture. In 2006, Hispanics comprised only 13% of the city's population, but 31% of the HIV-positive women in New York were Hispanic (Latino Commission on AIDS, n/d ; New York City Department of Health and Mental Hygiene, 2007). Most Hispanics in the U.S. (59%) are of Mexican origin, followed by Puerto Ricans who represent 9.6% of U.S. Hispanics (Guzman, 2001). Puerto Ricans, however, "account for the majority of HIV/AIDS cases among Hispanics in the United States" (Loue, 2006, p. 314). In New York, Puerto Ricans represent about half of the Hispanic population and are, by far, the largest Hispanic population in the state (Guzman, 2001). However, this search of the literature did not identify any articles specifically about Puerto Rican women living with AIDS in New York City.

A study of Central American HIV-positive immigrants in New York City reported that women were most often infected by their spouses and took a leading role in securing information and medical care for both themselves and their husbands because it was more culturally appropriate for women to seek this kind of assistance (Shedlin & Shulman, 2004). "The key elements for the provision of services to this population appear to be those that build on cultural norms and network human and institutional resources" (Shedlin & Shulman, 2004, p. 434). Schrimshaw's (2002) study of women with HIV in New York City found that Puerto Rican women reported higher levels of social conflict and depression and lower levels of social integration, compared to their Black and White counterparts. A comparison of monolingual (Spanish only) and bilingual (Spanish and English) people with HIV in Los Angeles



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found that although bilingual people were more acculturated than monolingual participants, there were no differences in health status between the two groups (van Servellen, Chang, & Lombardi, 2002). A similar comparison between U.S.-born and Central American-born women with HIV in Los Angeles found that U.S.-born Latinas were more likely to develop opportunistic infections (OI) (Wohl et al., 2003). The authors conclude that acculturation was associated with “more high-risk lifestyles and diminished social support,” placing US born Latinos at higher risk than Latinos born in Central America (p. 272).

Older women

Approximately 15% of the people with HIV in the US are over the age of 50 (Centers for Disease Control and Prevention, 2008). This estimate includes people who were over 50 at the time of their diagnosis, and people with HIV who have aged into this “older” age category. In New York City, 34% of the HIV-positive population is over 50 (New York City Department of Health and Mental Hygiene, 2007). Because most people with HIV under 50 years old and male, “Older women with HIV/AIDS constitute an invisible population that is often ignored by organizers of HIV prevention efforts as well as by HIV and aging organizations” (Emllet, Tangenberg & Siverson, 2002, p. 229). Research with this population reports that older women are more psychosocially stable than their younger counterparts: they are less likely to be homeless, actively use drugs or engage in unsafe sex (Aidala et al., 2006; Emllet, Tangenberg & Siverson, 2002; Gosselink & Myllykangas, 2007). Older women with HIV are also more likely to be connected to medical care and social services and report a greater number of co-morbid conditions and non-HIV-related medications than younger women (Emllet, Tangenberg & Siverson, 2002; Shah et al., 2002).

...issues relating to childbearing and parenting ... were not central to these older women's lives.

In a focus group with older HIV-positive women in San Francisco, Emllet et al. (2002) noted that participants conveyed “palpable excitement and relief” at the opportunity to meet and talk with other older women (p. 239). Many of the women’s groups in which they had previously participated focused on issues relating to childbearing and parenting that were not central to these older women’s lives. This group focused on learning about the “medical aspects of HIV and aging,” working through unresolved grief and AIDS-relating loss and building a network of peer social support (p. 239). The women in the group had spent much of their lives caring for others and this support group was an opportunity to learn more about caring for themselves and each other (Emllet, Tangenberg & Siverson, 2002).

Women who have sex with women (WSW)

The US Centers for Disease Control and Prevention (CDC) and the New York City Department of Health collect information about the sex, transmission category, race/ethnicity, age, health status and residence of people diagnosed with HIV and AIDS. Information about sexual orientation or identity is not collected. Only information about specific sexual behavior, namely male-to-male sexual contact and high-risk heterosexual contact, is collected within the transmission category. From this,

Women who have sex with women (WSW) have been virtually ignored as a group at risk for contracting HIV. The CDC does not include female-to-female HIV transmission as an exposure category, and the prevalence of HIV infection among WSW is not specifically tracked (Cooperman, Simoni, & Lockhart, 2003, p. 51).

Indeed, the risk of HIV transmission during female-to-female sex is very low (Cooperman et al., 2003; Young, Friedman, & Case, 2005). The CDC reports “no confirmed cases of female-to-female transmission of HIV” (Centers for Disease Control and Prevention, 2006, p. 1). Nevertheless, WSW are encouraged to take precautions to reduce any possible sexual risk (e.g. use of dental dams during oral sex, condoms for sex toys).

Although there is little to no risk associated with female-to-female sex, WSW are still at risk for contracting HIV through sex with men and intravenous drug use (IDU). Thirty-four percent (34%) of the young female IDU participants in a multi-city study conducted between 1997 and 1999 self-identified as WSW (Friedman et al., 2003). The WSW participants reported more risk factors than their non-WSW counterparts. The WSW were more likely to have been homeless, institutionalized in a mental health facility, and incarcerated. They were also more likely to report having unprotected sex with MSM, exchanging sex for money or drugs, and high-risk drug use behaviors. In the study’s high prevalence sites, WSW were more likely to be HIV positive (Friedman et al., 2003). Other studies have also shown that WSW have higher HIV risk and higher rates of infection than other male and female injectors (Young et al., 2005). Friedman et al. (2003) suggest including “issues of sexual identity and same-sex sexual behaviors among women” into research and interventions for IDUs as these issues may help to explain variation in risk behaviors and rates of infection (p. 904).

Young, Friedman and Case (2005) used qualitative data collected from sexual minority women injectors in New York City and Boston to try to understand why WSW IDUs engage in more high-risk activity than non-WSW. They concluded that the “multiple marginalizations” experienced by WSW elevate their risk (Young et al., 2005, p. 111). While WSW experience strong support from other WSW (Cooperman et al., 2003), WSW are stigmatized within the larger IDU community, limiting their access to syringes and elevating their injection costs (Young et al., 2005). Similarly, the authors found that WSW IDUs were disconnected from the cities’ lesbian/gay/bisexual/transgender (LGBT) communities and marginalized by medical providers, shelters, drug treatment programs and criminal justice systems (Young et al., 2005). They conclude by stating, “We must insist on making sexual minority women injectors the central concern of efforts to address HIV risk among both “lesbians” and women drug users” (p. 115).



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