

*Sex*  
**Power &  
TABOO**

**Gender and HIV in the  
Caribbean and Beyond**

Dorothy Roberts • Rhoda Reddock  
Dianne Douglas • Sandra Reid



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THE SOCIAL AND  
ECONOMIC CONTEXT OF  
BLACK WOMEN LIVING  
WITH HIV/AIDS IN  
THE UNITED STATES:  
*Implications for Research*

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*Celeste Watkins-Hayes*

INTRODUCTION

Jackie, a petite African-American woman in her early 40s, asserts, 'HIV will not take me out. I just do not believe that.' The daughter of a barber turned minister and a civil servant, Jackie grew up in a lower-middle class neighbourhood in Louisiana and was heavily ensconced in the church. For years she grappled with her sexuality, suppressing her attraction to women and occasionally dating some of the neighbourhood men to demonstrate that she could fit into the hetero-normative demands of her environment. Diagnosed with HIV a month after the birth of her first child in 1991, Jackie describes then entering a dark period of drug and alcohol abuse sparked by being given 'a death sentence'. After numerous failed attempts at drug rehabilitation, her doctors gave her an ultimatum that Jackie finally heeded: stop the drinking or die sooner. She spent almost a year in substance abuse treatment, with an extended stay at a residential facility that primarily serves HIV-positive individuals. With seven years of sobriety, Jackie has established herself as an informal mentor to several women in her Chicago community who have recently been diagnosed with HIV or who struggle with addiction. She facilitates support groups at least twice a month, frequently offering both practical advice and spiritual guidance on how to live as an HIV-positive woman. Jackie currently is in a long-term relationship with a woman and had dated consistently prior to

that for the past several years. In many ways, she has reconstructed her life, focusing on her work in the city's HIV/AIDS community, raising her 13-year-old daughter and 11-year-old son, and working as a security guard as she prepares to take classes at the local seminary.

Stevie, 44, is also HIV-positive, but her everyday battle with the virus differs somewhat from Jackie's. Diagnosed in prison in 2001, Stevie is still embroiled in a struggle to come out of the tailspin that has consumed her life over the past several decades. She grew up in poverty, shuttled between her aunt's care and juvenile housing centres as she and her ten siblings exhibited behavioural problems after the death of both their parents when Stevie was four. Her drug use, that started in her early teens, escalated through her 30s and involved exchanging sex for drugs, homelessness, and gang activity to support her habit. Since her release from prison in 2003, Stevie has participated in a drug rehabilitation programme but openly worries whether she will be able to avoid the 'people, places, and things' that threaten her recovery. Despite her numerous attempts to find work, it has eluded her so far, no doubt due in part to her criminal background and lack of employment experience since her job in the early 1990s as a Certified Nurses' Assistant. Stevie, at one time, sporadically attended an HIV-support group at the social service agency that offers her case management, but she is very leery of revealing details about her life to people with whom she has not established trust. Her adult daughter and granddaughter call frequently from Indiana, encouraging Stevie to stay clean and sober, and to get support so as to learn more about what it means to have HIV. Intimate relationships are not a possibility to Stevie right now as she calls herself 'half a woman, because I got something they can't cure and I can't shake'. She recalls hearing men in her neighbourhood scornfully describe HIV-positive women as 'carrying the package'. Stevie doubts whether she will ever be in a relationship again, mired in anger toward her boyfriend of 14 years when she lived on the streets. Although she also had unprotected sex outside of the relationship, Stevie is convinced that her boyfriend secretly had sexual relationships with men and infected her. Stevie acknowledges that these internal battles with her feelings about being

HIV-positive may threaten her physical health, and she believes that perhaps therapy is the only way for her to constructively deal with the anger and depression that literally keep her awake at night.

Forty-two-year-old Ernestine shares Jackie and Stevie's health status, but in some ways, lives worlds apart from them. Diagnosed in 1995, Ernestine remarried a few years later to a man who would later test positive as well. They are the co-owners and operators of a thriving local day-care centre and invest in real estate to supplement their \$70,000-plus annual income. Self-employment allows Ernestine to establish her own daily pace, resting, taking her medications, and visiting her doctors whenever she needs to without economic consequences. Perhaps, partly because of her husband's expressed fear of the financial repercussions of disclosure and partly because her HIV status has become an increasingly less daunting part of her life, Ernestine has not disclosed, nor does she intend to disclose, their status to the parents at the centre or to any of their other business associates. 'It's personal and really none of their business,' Ernestine says with a shrug. 'It's not like I would share that I have a yeast infection or something with them. Why then would I tell them that I'm HIV-positive?' Ernestine doesn't participate in the local HIV/AIDS support groups, lamenting that they seem more like Narcotics Anonymous meetings because of the large number of participants who are both HIV-positive and recovering substance abusers. Nor, Ernestine reasons, does she require the information that group facilitators and members share about how to access subsidised housing, job training, and other survival resources. The biggest challenges that Ernestine describes are not directly HIV-related and instead centre on how to best balance the family businesses while raising her son and meeting various family obligations. Praised by her extended family as 'really having it together', Ernestine is often called upon to provide advice, loans, or a few hours of her time to help her siblings, cousins, nieces, and nephews with whatever needs they may have.

The stories of Jackie, Stevie, and Ernestine highlight some of the commonalities and differences in a population that is increasingly impacted by HIV – black women between the ages of 18 and 45.

Despite, or perhaps because of, their diagnoses, work, family, and romantic relationships must be carefully negotiated and managed. The women navigate a complicated maze of past circumstances and choices, present constraints and resources, and future goals and opportunities to ensure their survival, with HIV sometimes taking a central role and other times taking a back seat to more pressing concerns. While Stevie laments her health status daily and Jackie derives a sense of community and civic engagement from it, Ernestine limits her focus to medically managing the infection. Ernestine and Jackie are cognizant of the ways in which the infection alters their lives, yet, they share the opinion of many HIV-positive women who do not consider it to be their lives' most tragic event (Ciambrone 2001). All three of the women describe employment as very important, but their varied experiences finding and securing work, create dissimilar levels and kinds of economic stress. While Ernestine and Jackie have found ways to have romantic relationships despite their HIV diagnoses, Stevie feels paralysed. Many of the women's social support resources come from (and are given to) family, but relationships developed within social service agencies serve as critical ties for Stevie and Jackie. The women all consider their children to be their biggest accomplishments. Nevertheless, they harbour some guilt for those times when they weren't present, supportive, or 'in their right minds' as they wrestled with their HIV diagnoses and other demons at different points in their lives.

In short, the questions of how to create financial stability, strong and supportive family and friendship ties, and healthy romantic relationships are ones that these women work to answer daily. But unlike most other mothers, lovers, and family members, they do so while living with an illness that can be extremely stigmatising, physically and emotionally debilitating, and potentially deadly. HIV/AIDS, unlike many other diseases, has a particular cultural significance that obliges its carriers, and those most intimately involved in their lives, to grapple with some of the most weighty and contentious issues of our social fabric: sex, sexuality, drugs, money, and the differential access that particular groups possess to protect and treat themselves. This is an infection that many believed,

and continue to believe, is a kind of punishment, complete with sympathetic and unsympathetic victims. In short, HIV carries a social meaning that requires analysts to understand it not only as a medical epidemic, but also as a social and cultural spectacle.

The Centers for Disease Control and other national and international agencies have charted the increasing number of HIV and AIDS diagnoses among women around the world, sounding the alarm of a growing and persistent health threat that leaves young women, and women of colour, particularly vulnerable. In the Caribbean, AIDS was the leading cause of death among adults 15-44 years of age in 2005 (UNAIDS/WHO 2005). While African Americans represent about 12.5 per cent of the US population, they accounted for 50 per cent of new HIV cases that year and made up 66 per cent of women living with HIV/AIDS. Black women in the United States are estimated to be more than 12 times as likely to be infected with HIV than their White counterparts (UNAIDS/WHO 2005; US Centers for Disease Control and Prevention 2007). These statistics suggest that the HIV/AIDS epidemic is sociological in its dimensions, processes, and implications as the story of who is infected and affected is increasingly delineated by racial and gender inequalities (Kaplan 1995).

## **SOCIAL CONTEXT AND HIV/AIDS TRANSMISSION**

While many risk behaviours are performed by men and women of various sexual orientations and racial and socioeconomic backgrounds, the rising infection rates among women, people of colour, and impoverished individuals, along with the persistently high rates that remain among men who have sex with men (MSM), suggest that groups that have been socially or economically marginalised are particularly vulnerable to HIV infection (Essien et al. 2005). This realisation has led many researchers to focus increasingly on contextual factors and the disparate environments in which sexual, social, and economic networks are embedded, rather than placing a singular emphasis on individual risk factors

and behaviours (Adimora and Schoenbach 2005; Gilbert and Wright 2003; Huber and Schneider 1992). In the United States, for example, this suggests that we interpret the growing numbers of infected black women using a framework that takes seriously both the structural conditions and individual experiences that have historically and currently influenced health outcomes for this group.

The notion of intersectionality has particular relevance for current debates on HIV/AIDS because it views race, class, gender, and sexuality as elements of personal identities that are simultaneous, overlapping, and structurally embedded (Collins 1990; Glenn 2000). As Glenn (2000) highlights, these social constructions also operate as organising principles of collectivities, institutions, and historical and social processes. Memberships and statuses bestowed on the basis of race, sexual orientation, class, and gender help to determine how power is distributed, balanced, maintained, and challenged as individuals negotiate cultural meanings through symbols and images and material relations through resources and privileges. Introduced by black feminists who felt at once a part of, and excluded from both scholarly work on inequality and women's and black liberation movements, intersectionality is a conceptual framework that acknowledges the ways in which multiple social locations influence the life experiences, opportunities, investments, and constraints of individuals and groups, *vis-à-vis* social relations. Various forms of inequality and exclusion rendered through racism, sexism, class subordination, and homophobia intersect and interact with one another, creating what sociologist Patricia Hill Collins (1990) calls interlocking systems of oppression. As individuals navigate their social worlds and encounter privileges and/or disadvantages by virtue of their various social group memberships, they generate choices, actions, and behaviours that affirm, acquiesce to, resist, or create alternatives to dominant ways of thinking and behaving.

While most HIV/AIDS researchers do not conduct analyses that explicitly adopt the analytic stances of intersectionality or black feminist thought, many have deduced that using the discrete social categories of class, gender, race, or sexuality to examine the HIV/AIDS epidemic over-simplifies what is actually a complex blend of

interrelated group memberships. Studies of how multiple systems of inequality create conditions for particular risk behaviours to be adopted are now prominent in the field, and the growing feminisation of the HIV/AIDS epidemic in the poorest areas all over the globe only strengthens the argument for this approach (Amaro and Raj 2000). Marriage; transactional sex to receive money, food, accommodations, protection, and other basic needs; sex for drugs exchanges; the sharing of intravenous needles within a social network; relationships between younger women and older men; and other intimate partnerings that often glean financial resources and security can be understood as simultaneous social and economic relationships (Gupta 2004; Wohl et al. 1998; Parker, Easton, and Klein 2000). Even when not explicitly done for economic purposes, sex's social functions 'are entangled in people's need to seek and express trust, in their search for status and self-esteem, and in their efforts to escape loneliness and relieve boredom' (UNAIDS/WHO 2004, 11). Sexual networks, therefore, are likely to share many of the characteristics of other social networks in that they can confine or spread HIV infection within and across communities in ways that parallel the social and economic exchanges of people's lives (Laumann et al. 1994, 2004).

The youth of many female victims is particularly disturbing, suggesting that age operates as yet another social location that carries distinct meanings tied to the AIDS epidemic. Evelyn Hammonds writes, 'It suggests that they were infected at an age when they had the least control over their sexual lives. They were at an age when they were vulnerable to the demands not just of partners of their own age, but older men as well' (1995, 440). Relationships with such strong power imbalances can leave individuals little wherewithal to negotiate the terms of preventive behaviours such as condom use. Hammonds goes on to point out that, 'many of these young women also live in ... communities where few support systems exist to protect them and allow them to grow unmolested to adulthood' (1995, 440). Indeed there is a great deal of evidence to suggest that sexual violence places its victims, the majority of whom are believed to be women, at higher risk for HIV infection

(Bensley, VanEenwky, and Simmons 2000; Wyatt et al. 2002). 'Many HIV [prevention] strategies assume an idealised world in which everyone is equal and free to make empowered choices,' a UNAIDS/WHO report highlights, where individuals 'can opt to abstain from sex, stay faithful to one's partner or use condoms consistently' (2004, 9–10). Many analysts have concluded that the societal-wide and community-based social, economic, and political statuses of women put them in positions of disadvantage relative to men in protecting themselves from infection as they are likely to have fewer opportunities to avoid or control situations and areas where HIV transmission is more likely (Farmer, Connors, and Simmons 1996).

In US communities, residential segregation, past and current racial discrimination, the targeted marketing of legal and illegal drugs in poor neighbourhoods, inadequate health care, and limited economic resources conspire to perpetuate joblessness, drug sale and use, sex work, high incarceration rates, homelessness, and untreated health problems among the most vulnerable citizens (Chow, Jaffee, and Snowden 2003; Wilson 1987; Wright 2003). These conditions create a backdrop for a diminished capacity among individuals to prevent their exposure to HIV, hepatitis, and other sexually transmitted diseases (Gilbert 2003). Homelessness, for example, has been found to represent a serious physical danger, due in large part to how it reduces the ability to physically protect oneself in precarious situations and spaces (Lee et al. 2000; Fisher et al. 1995). Adimora and Schoenbach (2005) argue that the sex ratio in many black communities due to higher mortality rates among black males shapes the structure of sexual networks for many black women in important ways. Particularly because of the relatively low rate of interracial dating among black women, 'the shortage of men places women at a disadvantage in negotiating and maintaining mutually monogamous relationships' (S118; also see Adimora et al. 2001). As marital rates decline across populations in the United States, this trend is intensified in black and poor communities, threatening the stability of long-term intimate relationships and creating a climate for an increased frequency of partner changes (Wilson 1987; Edin and Kefales 2005).

In the United States, high incarceration rates and the disproportionate impact of drug policies on poor communities of colour have racial, class, and gender implications that researchers believe have led to a social context for HIV and other sexually transmitted diseases to proliferate (Johnson and Raphael 2006; Mahon 1996; Kim et al. 2002; Grinstead, Zack, and Faigeles 2001). As Adimora and Schoenbach (2005) summarise in their review of relevant literature:

The partner entering prison is now at risk of forming new (sometimes coercive) sexual connections with a pool of individuals among whom the prevalence of high-risk behaviours, HIV infection, and other STIs are high ... The partner who remains behind in the community forfeits the social and sexual companionship of the incarcerated partner and may pursue other partnerships to satisfy those needs. (S119).

Additionally, researchers have also identified a high prevalence of both HIV risk behaviours and HIV and other infections among imprisoned women populations (McClelland et al. 2002; Smith et al. 1991). Many of these dynamics are direct and indirect by-products of the infiltration of crack cocaine into disproportionately affected poor communities, bringing with it high risk sexual and drug behaviours, as well as, higher crime and police presence as part of the US's War on Drugs (Fullilove et al. 1993; Forbes 1993).

These lines of research have encouraged a more nuanced understanding of the social context of risk and highlight the danger of directly linking certain individuals or groups to health outcomes without appreciating the interrelationship between individual attitudes and behaviours and environmental opportunity structures and constraints. Studies of people currently infected that attempt to delineate the social consequences of HIV/AIDS for individuals, families, and communities can similarly benefit from such an approach. When our analyses of individual behaviours and experiences become inextricably linked to the structural, historical, and situational contexts of people's lives, this allows us to extrapolate

larger sociological and epidemiological lessons while appreciating the complexity and distinctiveness of individuals. Further, intersectional frameworks encourage us to understand how race, class, gender, and sexuality operate simultaneously as dynamic social categories that have particular relationships to dominant power structures and grant disparate levels of access to the political, economic, and social resources of a particular environment. These memberships, and the statuses that they confer, have the potential to shape how individuals, and the public at large, understand not only the social context of risk, but also what it means to have HIV.

Previous research has focused a great deal on the psychological impact of living with HIV, such as the disease's impact on depression, anxiety, coping ability, and stress-related growth (Ball et al. 2002; Prado et al. 2004; Updegraff et al. 2002; Siegel and Schrimshaw 2000; Miles, Gillespie, and Holditch-Davis 2001; Murphy et al. 2002; Hough et al. 2003; Lee, Kochman, and Sikkema 2002). Recent work has also explored how HIV/AIDS has influenced individual and collective political engagement (Berger 2004; Cohen 1999). However, less is known about the everyday experiences of people living with HIV/AIDS (PLWHA) and how they differ based on their social positions. This research gap has at least two consequences. First, scholars limit their opportunities to systematically tease out the diverse needs of those who struggle with the disease in ways that might offer empirically-grounded policy and social service prescriptions that also address inequalities within this population. Second, without more complex examinations of PLWHA circulating in the public discourse, the debate will likely not elevate above a preoccupation with who does or does not 'deserve' their brush with the deadly disease. Several scholars have demonstrated the ways in which public portrayals of people living with HIV/AIDS explicitly and implicitly draw hard and fast distinctions between innocent victims' of the epidemic and those who 'earned their fate' (Hammonds 2004). Without more sophisticated counter-analyses, these depictions will likely continue to play a central role in how the public distributes its sympathy, attention, and resources, potentially deepening the very inequalities that contribute to the

disparate infection rates among populations that we see today. A better understanding of the various ways in which people engage with communities, institutions, and individuals in the wake of discovering their health statuses is therefore likely to improve how we offer appropriate interventions and frame the public conversation about HIV/AIDS and its continuing significance in the United States.

We know a great deal about the effects of employment status, economic resources and relationship dynamics on the prevalence of certain risk behaviours and on health outcomes among those currently infected (O'Leary and Martins 2000; Dixon et al. 2001; Ickovics et al. 2002; Stoskopf, Richter, and Kim 2001). Effectively reversing the analysis to explore what health means for these social domains potentially allows us to offer other kinds of hypotheses to elucidate the implications of the AIDS epidemic. The remainder of this essay explores the possibilities for filling this research gap by looking at how we might trace the various ways in which black women living with HIV formulate, sustain, and even interweave their economic survival strategies and intimate relationships. First, I outline how previous research on the economic processes of black women can inform our knowledge of how HIV/AIDS complicates those survival strategies. Second, I caution against constructing the intimate lives of HIV-positive black women solely in a context of risk, or against the backdrop of the highly publicised 'down low' debate about black men who fail to disclose same-sex sexual behaviours to female partners. These foci have shaped the conversation about black women living with HIV/AIDS in distinct ways, hampering fuller portraits of how they create, maintain, or go without intimate relationships. Third, I explore new ways of thinking about the intersection of women's economic and intimate lives using the case studies presented at the beginning of this essay. I conclude by calling for more ethnographic, mixed method, comparative, and longitudinal work that captures the commonalities and differences among HIV-positive black women of various ethnicities, socioeconomic classes, and sexual orientations.

## THE CONTOURS OF ECONOMIC SURVIVAL: HIV-POSITIVE BLACK WOMEN AND THE LABOUR MARKET

In countries hardest hit by the AIDS pandemic, the initial lack or eventual collapse of financial stability among families of HIV-infected individuals has led to overall economic decline in the hardest hit areas. This monetary impact of the epidemic is most apparent in nations without publicly subsidised health care or widespread access to highly active antiretroviral therapy (HAART). A recent International Labour Office (ILO) (2004) report describes the gendered dimensions of the economic impact of AIDS in poor countries in the following way:

Women are often deprived of rights to housing, property or inheritance upon the loss of their spouses to AIDS, or if it becomes known that they are infected; bearing in mind that women perform the majority of agricultural tasks in rural areas, any decline in agricultural production caused by labour shortage due to HIV/AIDS leads to food insecurity, depriving women and men of the means to feed their families; and income and food insecurity, in turn, leads to family break-ups, migration, child labour, trafficking and prostitution, all of which increase the risk of HIV transmission and cause a deeper decline into poverty (p. 30).

The economic impact of HIV/AIDS in the United States has not been as visible, yet it arguably remains a critical issue. Socioeconomic status has long been viewed as a predictor of certain risk behaviours and HIV transmission (Gillies, Toley, and Wolstenholme 1996; Ward 1993), but the economic conditions of individuals already infected are just recently coming under analysis (Ezzy, DeVisser, and Bartos 1999). This is partly because researchers, particularly at the beginning of the epidemic, when the post-diagnosis life expectancy was limited, largely thought of infected individuals as medical subjects rather than labour market actors. Indeed, declines in labour force participation among the diagnosed

have been documented (Ezzy et al. 1999). Yelin et al.'s (1991) study of San Francisco-based individuals found that 50 per cent of those who worked before being diagnosed with HIV had stopped working within two years of the onset of the first symptom of HIV-related illness, and all had stopped working within ten years after the onset. A study of 305 AIDS patients as part of the Boston Health Study conducted in 1990 and 1991 found that while 76 per cent of respondents had a job at the time of diagnosis, that number dropped to 53 per cent just 16 months later (Massagli et al. 1994). Having a job involving physically demanding labour, or reporting high levels of stress, depression, and anxiety (Ezzy et al. 1999), significantly increased the likelihood that people living with HIV/AIDS would leave work.

In recent years, advances in and access to treatment – effective drug therapies, better monitoring of viral loads and T-cell counts, and adequate diets – have greatly improved the capacity of PLWHA to carry out the normal routines of life and to extend their life expectancies. Although many express a desire to return to work (Ezzy et al. 1999; Ghaziani 2004), such a move is not a foregone conclusion. In fact, it is not unusual for community-based social service agencies that serve those infected with HIV to describe work as a risky proposition, rife with pros and cons, in an effort to inform and protect their clients (Nixon and Renwick 2003). Concerns include:

- the unpredictability of positive drug effects, potentially debilitating medication side effects;
- the possible inability to return to disability insurance coverage should a relapse occur;
- the difficulties that might arise as one attempts to transition back into the labour force after a long absence;
- non-health related job (and therefore employee benefit) instability in the current economic climate;
- HIV-illness related symptoms, the effects of long work hours and work stress on health;
- potentially unhealthy work environments that compromise one's immune system;

- difficulty managing medical appointments and elaborate drug regimens (especially with food or refrigeration requirements) while working, and the fear that disclosure of HIV status might result in loss of the job (p. 1,273).

These worries conflict with the value that many people living with HIV/AIDS and society as a whole place on work. The powerful tension that individuals express between their own desires, financial needs, and fears of the embedded problems with working while living with HIV/AIDS lends itself to a calculus that involves economic and personal considerations as one decides whether to remain in the labour force following an HIV diagnosis or return after an extended absence (Brooks et al. 2004; Timmons and Fesko 2004; Nixon and Renwick 2003; Ferrier and Lavis 2003; Ezzy et al. 1999).

However, the employment research that has explored the effects and implications of HIV infection has focused almost exclusively on white, middle-class, gay men, a population likely to have greater levels of work experience and education than poor minority women with HIV/AIDS. The employment challenges faced by the HIV-positive – regardless of race, class, gender, and sexual orientation – may become overwhelming (Hergenrather, Rhodes, and Clark 2005). Yet the axes of racism, classism, heterosexism, and sexism dole out disparate labour market privileges and penalties to people based on their social group memberships. It would therefore be surprising if the disparities – varying access to jobs; lower on average employment rates, wages, educational levels, returns to schooling, and occupational statuses; as well as higher poverty rates – that are known to be the causes and consequences of inequalities in the labour market, did not also shape the work lives of those living with HIV (McCall 2001; Reskin, McBrier, and Kmec 1999; Cotter, Hermsen, and Vanneman 1999). Economic inequalities are therefore likely to contribute to, not only the disproportionately high HIV infection rates among poor and minority women, but also the opportunities and experiences available to them as they attempt to enter or re-enter the labour market.

Researchers seeking to explore the economic processes of those living with HIV/AIDS can draw upon existing hypotheses regarding the interactions of race, gender, and employment. As these individuals weigh their financial options, assemble an institutional network of medical providers and other supports, and assess their comfort levels with working after being diagnosed, the more economically advantaged among this population are more likely to have access to wealth reserves that will provide them with more choices. Whether, when, and how they work is therefore determined in part by that financial cushion. Yet for the most economically marginalised, an HIV/AIDS diagnosis may actually reduce some economic disadvantage by opening access to housing, health care, cash assistance, and other resources (Crane, Quirk, and van der Straten 2002). Working must therefore be weighed against the possibility of losing eligibility for some subsidised services. For working- or middle-class PLWHA who do not meet the eligibility requirements for government disability benefits and subsidised survival resources, the labour market may provide the sole economic option. The economic resources that people gain or lose following an HIV diagnosis, and the social meaning that individuals assign to these changes, are likely to be a function of where they were on the socioeconomic ladder prior to discovering their health status.

With such high numbers of impoverished women among those living with the disease, the distinct characteristics of the low-wage labour market highlight another important dimension of the issue of HIV/AIDS and work. It commonly offers jobs that are physically demanding, assign inflexible work schedules, and have few or no employee benefits (Newman 1999; Ehrenreich 2001). These conditions are likely to challenge the abilities and desires of infected individuals to effectively manage work and health simultaneously (O'Campo, Eaton, and Muntaner 2004). Among these would-be employees, human capital is another important factor that will likely shape economic survival strategies. As a sub-segment of women with HIV/AIDS seek employment, some of the very circumstances, histories, barriers, and behaviours that increased their risk of infection might also make them less employable. Like many of their male

counterparts, in the absence of consistent and viable alternatives, many of these women will employ informal and perhaps illegal economic survival strategies that will place their physical or mental health at risk and undermine their chances of entering the formal labour market at a later time.

Prior work on the economic support systems of impoverished women finds that they often create financial patchworks made up of help from friends, family, intimate partners, formal and off-the-books jobs, various forms of government assistance, and help from social service providers (Edin and Lein 1997; Dominguez and Watkins 2003). Poor, HIV-positive women are likely to engage in similar strategies, but resources may be harder (or easier) to assemble for this group, depending on whether and how these women choose to disclose their health statuses, the degree of acceptance by those in their social networks, and the resources that their contacts can provide. Consequently, discussions of women's financial wherewithal in the face of HIV/AIDS will likely benefit from broad conceptualisations of exactly how individuals make ends meet and the critical relationship between formal and informal channels.

If the goal is to help HIV-positive women create a set of economic survival strategies that build healthy families and communities, and help to maintain and even strengthen their health, several interventions are necessary. This population differs in employability, but many are likely to require educational and employment training services. For the hardest to employ, adding a combination of employer incentives, and drug and prisoner rehabilitation services is also a promising approach. There is evidence to suggest that an HIV diagnosis serves to 'save' some individuals from further drug use and other risky behaviours, potentially rendering them more attractive job candidates (Berger 2004). Successful policies and programmatic efforts that support these individuals in their quests to navigate the labour market and its pitfalls while dealing with a chronic illness represent the next necessary frontier in responding to the HIV/AIDS epidemic. By thinking creatively about how employment and social policy research can be brought to bear in our discussions about HIV/AIDS, the research community will be

better poised to provide the scholarship necessary to help fully understand these dynamics.

## **UNSPOKEN COMPLEXITIES & THE INTIMATE LIVES OF BLACK WOMEN LIVING WITH HIV/AIDS**

Intimate relationships among HIV-positive individuals have commanded some research attention, particularly in light of prevention initiatives designed to thwart the emergence of resistant strands of the virus or the disease's transmittal to uninfected persons (Aidala et al. 2006; Bedimo et al. 1998; Gielen et al. 2001). Sexuality among HIV-positive women is therefore often framed in terms of risk-reduction and sexual responsibility. While this is critically important for public and individual health, this emphasis has at least two consequences. First, HIV-positive women's romantic and sexual lives become medicalised, and the social functions of their intimate relationships are downplayed. This prevents both HIV/AIDS experts and the public at large from seeing these women in their complexity and contradictions in ways that both recognize their sexuality and help us to understand how intimate ties influence other domains within their lives.

Second, if not done carefully, the conversation on risk reduction can demonise the sexuality of women living with HIV/AIDS by constructing it as deviant and dangerous. Ideas about the women's 'guilt' or 'innocence' in becoming infected, their potential culpability should they infect others, and their subsequent 'undeservingness' or 'deservingness' therefore compete alongside more nuanced messages for the public's attention, sympathy, and resources. This need to rhetorically classify populations among those infected and affected by HIV/AIDS has long guided the political and cultural debate (Sacks 1996; Lawless, Kippax, and Crawford 1996). The mode through which an individual reports being infected with the virus and the measures that she takes to avoid infecting others serve as 'respectability proxies' of sorts for some. They allow the public's moral measuring sticks to tag some as 'innocent victims of the epidemic' and others as 'those who should have known better', or

even worse, 'earned their fate'. When combined with long-standing and embedded stereotypical notions about the supposed lasciviousness and irresponsible sexual behaviours of black women, those who are HIV-positive, witness their sexuality becoming highly scrutinised, feared, and viewed as problematic in the public realm. Evelyn Hammonds (2004) writes, 'Silence, erasure, and the use of images of immoral sexuality abound in narratives about the experiences of black women with AIDS. Their voices are not heard in discussions of AIDS, while intimate details of their lives are exposed to justify their victimization.' (311) In this essay's opening discussion, Stevie feels as though her only option therefore is to suppress that part of herself, horrified that 'carrying the package' makes her forever undesirable and vulnerable to stigmatisation and rejection.

HIV-positive black women in the United States were reintroduced to the public in a different way in recent years that has had implications for how we understand their sexuality. They gained attention as the sympathetic victims of a group that, in many respects, embodies the public's dual fear and obsession with sexuality and black masculinity – men on the 'down low'. These men, primarily but not exclusively identified as black, are thought to classify themselves as heterosexual and may even be involved in long-term heterosexual relationships. But, unbeknownst to their female partners, these men also secretly engage in sexual relationships with other men. A recent American media frenzy involved several high-profile television and print news stories, talk show discussions, and fictional and non-fictional accounts that shadowed the secret lives of men who identified themselves as 'living on the down low,' revealing their so-called parallel lives. A rigorous, albeit less well-publicised, response from scholars, activists, and other analysts of gender and sexuality, race and ethnicity, public health, and medicine emerged, attempting to respond to the public's seemingly insatiable appetite for this 'latest' dimension to the AIDS epidemic, while endeavouring to inject some corrective analysis into the debate.<sup>1</sup>

The 'down-low' discussions yielded several notable outcomes, but in many ways restricted rather than expanded how we think

about the intimate lives of black women living with HIV/AIDS. Productively, it reminded women and men, including those already infected with HIV, about the risks involved in unprotected sex. Further, the ideas that sexual preferences are easily discernable by physical appearance, and that same-sex desire has a particular 'look' or presentation were called into question, revealing the complexity of sexuality. In addition, thoughtful observers were encouraged to consider the intersecting familial, intimate, and professional realities of those living 'parallel lives', disrupting the notion that we can think of these spaces as discrete. The conversation highlighted the difficulty that individuals experience in their everyday attempts to impose such delineations for the sake of self-protection. It crystallised the notion that individuals often maintain silence and secrecy in order to protect normalcy and social resources such as status, legitimacy, and belonging as they interact in different environments.

Yet, the discourse was not unequivocally constructive. In fact, much of the debate seemed to reinforce the demonisation of non-normative sexuality, and some of its loudest contributors arguably did a disservice to AIDS education. Homophobia, and the 'down low' as a strategy that men and women of various racial backgrounds adopt to avoid prejudice and ostracism, went disturbingly under-addressed. One of the most strident prescriptions coming out of the discourse seemed not to be a strong and broad safe sex message, or the eradication of belief systems that confine individuals on the basis of sexual orientation, race, and/or gender. Rather, many commentators offered up techniques for the surveillance of Black male partners so as to discern 'the signs' that reveal sexual proclivities. Because this population has been largely understudied until recent years, researchers were not in the strongest position to offer empirical evidence to support or contradict the public's discursive leap from, undisclosed bi-sexuality among Black men to the rising HIV transmission rates among Black women.<sup>2</sup> Therefore, a public conversation about health, race, and sexuality largely sidelined scholarship in favour of more journalistic and autobiographical accounts. These offerings could offer little to no systematic scientific analysis.<sup>3</sup>

Portrayals in not only predominately white, but also black media outlets often implicitly constructed black women as the relevant constituency within black communities during this debate. Reminiscent of Cathy Cohen's (1999) arguments about the implications of what she terms 'secondary marginalisation', these women were juxtaposed against certain black men who saw their status calcified as a group 'undeserving' of sympathy and resources within both the AIDS epidemic and black communities. Black, heterosexual-identified men, frequently portrayed as absent figures or the root causes of the perpetual penury of black women in public discourse, were foregrounded and depicted as the very present and irresponsible predators of these same women. Gay-identified men, who continue to struggle against the AIDS epidemic, remained largely in the background, relegated to the status of 'lures' of otherwise 'straight' men and were therefore seen as indirect hazards to the health of black women. To the casual observer, AIDS seemed to be an epidemic suddenly ravaging the black community when in fact, large but traditionally marginalised segments within communities of colour – gay men, sex workers, prisoners, drug users, etc. – had been battling the disease for decades (Cohen 1999).

As this dialogue waged on and its spectators made pontificating about the 'down low' a cultural event, HIV-positive black women saw the public's interest in their romantic lives largely reduced to certain questions: (a) Do you even have an intimate life? (b) Are you a risk to others? (c) Were you infected by a man on the 'down low' and if so, how do you trust again? Such an account has become so widespread that Stevie incorporates a 'down low man' into her narrative of infection in order to make sense of her diagnosis, despite other reported potential means of infection. Jackie's same-sex desire goes wholly unaccounted for in the conversation, an omission replicated in HIV/AIDS discourse at large (Richardson 2000). Ernestine recognises that as a married woman with HIV, the issue of how HIV was 'brought into' the relationship may be raised by outsiders should they disclose their health status, effectively volleying 'guilt' and 'innocence' back and forth between Ernestine and her husband. Women's power over their own sexuality, including the

ways in which they talk about it, express their desires, and assert agency over their intimate lives, remains obfuscated (Hammonds 2004).<sup>4</sup> Their experiences are only of public interest in as much as they reflect the consequences of men's behaviour.

Refocusing the conversation and improving our understanding of the complex sexual lives of black women living with HIV/AIDS has both symbolic and practical implications. Hammonds (1995) points to the ways in which detailed, eloquent, and sympathetic media portrayals of white gay men struggling against AIDS 'reveal(ed) to the larger heterosexual world the emotional toll that AIDS has taken in gay communities while breaking down stereotypes about gay life' (p. 438). A population that had been hidden, maligned, and poorly understood was able to tell its stories, revealing some of the 'junctures and disjunctures in our beliefs about sexuality and sexual practices as well as the anxieties in American life about sex and morality' (p. 438). An empirically-informed and conceptually astute repair and revision of the collective construction of black women with HIV/AIDS has similar potential, if done in a way that also addresses and challenges the additional stigmas that these women experience by virtue of their intersecting racial, gender, and/or class statuses. That is to say, one cannot talk about black women's intimate lives in the face of HIV/AIDS without attending to the ways in which their racial and gender subordination attempts to delineate and limit how and who they love. As others have argued, the constant depiction of this population as sexually promiscuous and mired in drug-induced swirls of dependency and irresponsibility does a huge disservice, in large part, because of its investment in unchecked stereotypes (Hammonds 1995; Collins 1990). At the same time, scholars and other interlocutors would be wise to resist the temptation to tell the story of only 'respectable' black women with HIV/AIDS who demonstrate that it 'could happen to anyone,' even those who 'live right'. While counteracting negative images of black women, this too is a skewed representation of who is living with HIV/AIDS. It is by offering the range of experiences and decisions made by (or denied to) black women about their sexual lives that we are likely to produce a more complex,

nuanced, and accurate story about the ravages of the AIDS epidemic.

Further, revising how we think about the intimate lives of Black women with HIV/AIDS is important because these relationships have been found to influence health outcomes and other social domains such as family stability and overall life quality. Updegraff et al. (2002) found that the majority of HIV-positive women interviewed reported that their health status made them feel less interested in sex, more fearful in starting and maintaining romantic relationships, and less physically attractive (also see Baker, Sudit, and Litwak 1998; Gurevich et al. 2007). Yet intimate relationships can influence one's commitment to drug adherence, consistency with acquiring medical care, and general outlook in the face of an HIV diagnosis (Wagner et al. 2002; Barbee et al. 1998). Frequently the caretakers in relationships, HIV-positive women are often expected to manage the health of both themselves and their intimate partners, and gaining support around these responsibilities is critical for household stability (Wright 2003). Further, a focus on intimate ties can also tell us about how individuals prioritise and manage relationships (or struggle to do so); as they bear and raise children, develop economic survival strategies, gather social support, and compose their lives while their health is compromised (Squire 2003). As people are able to live longer lives in the wake of an HIV diagnosis, questions around how these individuals build strong, stable, and healthy families and navigate their health and sexuality take centre stage. Fuller portraits of how HIV-positive Black women across the spectrum of sexual attraction, create, maintain, or go without these ties are therefore critical frontiers for discovery.

### **THE INTERSECTION OF WOMEN'S ECONOMIC AND INTIMATE LIVES**

Research on the relationship between financial resources and intimate relationships often focuses on HIV transmission, and typically examines transactional sex and other partnerings that heavily depend on the economic power of men. However, returning

to the three cases outlined at the beginning of this essay might help us to delineate other ways in which economic survival strategies and intimate relationships among black women living with HIV/AIDS interrelate. Each of these aspects of women's lives hold certain utilitarian and symbolic functions, particularly as women reclaim their bodies following a diagnosis and assert themselves as social actors, rather than solely as medical subjects. For Jackie, sobriety and the eventual acceptance of her health status encouraged her to be self-possessed. This, in turn, armed her with the ability to take care of herself financially through her job as a security guard. Her work in her local AIDS community also encouraged her positive outlook as she began lending social support to other women in similar situations. As these personal resources coalesce around her growing comfort with her sexuality, Jackie is able to create a stable and loving relationship despite being HIV-positive. On the other hand, Stevie's struggle to come to terms with her health status has so far suspended her ability to do much else. Her focused frustration over what is happening to her body stymies any efforts to develop skills to improve her chances of finding work, and her sense of stigmatisation discourages her from pursuing an intimate relationship from which she could glean social support. Her social and economic isolation seem to feed off of each other, and she finds herself unable to restructure her life in the wake of her diagnosis.

Finally, Ernestine provides, among this group, perhaps one of the strongest examples of the intersection of work and intimate lives for women with HIV. For her, the choice of whether to disclose her HIV status in the work setting or to her business network is a joint decision because of her involvement in an intimate relationship. The possibility that Ernestine's husband will also be exposed to social scrutiny should Ernestine's (and possibly his) HIV status be revealed enters into both of their calculations as they weigh disclosure's potential costs to both their professional and intimate lives. The prospects of financial loss and instability that might result should the parents at the day-care centre or their business associates terminate their ties are important concerns for this couple. Their family's economic security, and Ernestine and her husband's abilities

to provide their son with a stable middle-class existence, is never far from her mind. As such, the careful management of privacy, the calculations about disclosure's potential financial and social consequences, and the fear of involuntary disclosure become jointly held concerns for these romantic and business partners. The economic and the intimate, the professional and the personal co-mingle, taking on added dimensions in the context of living with HIV.

## CONCLUSION

When HIV/AIDS gained prominence in the American collective imagination in the 1980s and 1990s, activists demanded that the public view those infected as political, economic, cultural, and social actors. These individuals claimed hard-won rights, made contributions to the larger society, and held relationships within families and communities that were finally acknowledged and respected. In fact, much of the political currency of HIV resulted from activists' painting the AIDS epidemic in collective terms, reminding the country that infection 'could happen to anyone' and that its imprint on our social fabric was vast and devastating. Certainly the highly public experiences of Ryan White, Arthur Ashe, and Magic Johnson drove this point home in the United States. Thus, HIV/AIDS slowly began moving, using sociologist Herbert Blumer's conception, from a 'personal trouble' to a 'social problem'.

However, there is a danger inherent in the 'it can happen to anyone' narrative. It under-emphasizes the ways in which inequality plays a critical role in risk exposure, prevention efforts, treatment access, and the everyday lives of those infected. The disease's calcifying racial, class, and gendered dimensions challenge us to increasingly interpret the disease as one of individual circumstances, attitudes, and behaviours that exist within environmental norms, forces, opportunities, and constraints. The lives of those touched by HIV/AIDS are both similar to and distinct from each other, and one's social location increasingly plays a part in how this medical experience is discovered, managed, and lived. As such, living with

HIV/AIDS is not independent of one's existence as a black woman of a particular class background and sexual orientation living in a society that either values or undermines those statuses. These social group memberships become intertwined with the medical condition and shape how individuals perform multiple roles – family member, economic contributor, intimate partner.

Examples abound that suggest that the ways in which a particular issue is framed in the imaginations of researchers, policymakers, and the public may either bolster or hinder certain collective responses. How we think about, research, and talk about HIV/AIDS shapes how we *define* the affected population, *delineate* the causes of this social problem, and *propose* subsequent solutions. The HIV/AIDS academic, service provider, activist, and policy communities have focused heavily, albeit rightly and necessarily, on prevention and medical treatment efforts. The challenge is to continue to have those conversations while also expanding the work on those already infected to better grasp the personal, familial, neighbourhood, and community implications of this pandemic.

Although the larger social, political, cultural, and economic contexts of these women's lives are complicated, capturing them in our research helps us to be more precise in our subsequent policy and programmatic interventions. We have numerous tools at our disposal to aid in the process. Research incorporating ethnographic, mixed method, comparative, or longitudinal methods is particularly suited to the task. Longitudinal analyses allow us to capture how social dynamics such as labour market activity and intimate relationships change over time. Ethnographic work permits us to incorporate both interviews and observation into our investigations, revealing not only what respondents say, but also what they do in the multiple environments where their HIV status is known (or unknown) and salient. Mixed method work encourages us to both quantify various social dynamics and provide texture to our investigations through the words of subjects and the observations of researchers. Comparative work opens the possibility for understanding how individuals fashion their lives after an HIV diagnosis across communities, countries, and cultures. This kind of

scholarship will help us to more fully understand what strategies need to be fashioned, what resources expended, and what attitudes promoted to improve the quality of the lives of those living with HIV, their families, and their communities.

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## NOTES

1. For key scholarly insights offered in recent years, see McCune 2006; Malebranche 2003; Miller, Sermer, and Wagner 2005; Millett et al. 2005; and Millett et al. 2006.
2. As the dimensions of sexual identity are often multifaceted and many potential study participants wish to remain hidden, subject recruitment for this kind of work is no easy task. However, researchers are increasingly finding ways to solicit participation among this population and to support or refute various assumptions

- that currently circulate about black men who have sex with men and women (MSMW).
3. The debate also squandered the opportunity to talk about the lack of safe sex measures in prisons where often-unspoken, same-sex behaviours also occur. Therefore, mass incarceration and its public health implications for men and women remained unaddressed. Critics also called for an analysis of the use of sexuality as power in a larger society that attempts to render black men economically, socially, and politically powerless, yet fixates (and often celebrates) their sexuality.
  4. Ironically, the paradigm of living 'parallel lives' applies to many who find themselves on the margins of the mainstream, including women who live with HIV/AIDS, who opt to carefully measure which aspects of their family, romantic, and work lives will intersect. Gradations of disclosure are carefully deployed as these women seek out safe spaces from the normative demands of their surroundings (Armistead et al. 1999). For the most careful analysts of the 'down low' debate, these realities were made plain and helped to frame a broader understanding of the ways in which individuals negotiate their intimate lives, even if putting others at physical and emotional risk while doing so.

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## BEYOND THE STRUCTURE VS. AGENCY DEBATE IN SEXUAL DECISION-MAKING:

3

Shanti A. Parikh

*Love Letters, Youth Romance and the  
Paradoxes of Condoms in Uganda*

### UGANDA'S HIV SUCCESS: AN OVERVIEW OF THE DEBATE

Uganda is regularly touted as Africa's leading HIV/AIDS success story. It is estimated that the country reduced its HIV prevalence rates among adults ages 15-49 from as high as 29 per cent in some prenatal sentinel sites during the mid-1990s, to around 5.5 per cent in 2003, increasing slightly to 6.7 per cent in 2006 (UNAIDS 2004, 2007). Policies, programmes and interventions to combat the epidemic have been in place for nearly 20 years and the country's ABC approach – abstinence, be faithful, use condoms – has been portrayed by some as the champion behind this success and has been replicated in various forms worldwide. The extent to which Uganda's declining HIV rates can be attributed to the ABCs, however, has stimulated great debate, as many feminists, reproductive health experts, medical anthropologists, and others argue that the behaviourist approach underlying the ABCs does not take into account the wider context – whether interpersonal, social, or economic – in which people in Uganda have altered (or not) their sexual decisions and behaviours. This latter analytic approach is often called political economy or a structural approach, and its proponents argue that people's sexual decisions or behaviours take place within the context of multiple social and economic obstacles, inequalities, and privileges that shape their everyday life.