

Women: The Hidden Victims of the HIV/AIDS Epidemic in the US

By

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This essay examines women's marginalized status in the HIV/AIDS epidemic through their erasure over time and investigates the hyper-*invisibility* of women of color because of their intersectional experiences.¹ Furthermore, this essay discusses how gendered social norms and systemic oppression has disadvantaged women in their fight for equal treatment. From both a historical and a contemporary perspective, the author undertook a literary analysis of scholarly articles and books to examine the HIV/AIDS epidemic, treatment availability, and the events that fueled the movement for the inclusion of women as one of the disease's at-risk groups. This essay also discusses society's contradictory assertions about women's vulnerability to HIV exposure as either "deviant" or "victim," the formation of ACT-UP and major participants of this movement, and the critical importance to women of the re-classification of HIV/AIDS definition in 1993.

The discriminatory nature of the HIV/AIDS epidemic has affected many populations, stigmatizing those living with the disease as unworthy and deviant. In the 1980s, headlines referred to HIV as a "gay-related immunodeficiency disease" and "gay cancer" with images of emaciated bodies of gay white men that cast shadows of shame and promiscuity over their lifestyles. Women were rarely mentioned in these initial conversations about HIV/AIDS and, when they were, they were typically portrayed as prostitutes or IV drug users (Stuntzner-Gibson 1991). Similar to the association of gay men's lifestyles with sexual deviancy in the 1980s, women living with HIV/AIDS were also assumed to be participants in immoral behavior.

Subsequently, the culture of silence and shame that

¹Intersectionality refers to the interrelated nature of social classifications such as race, class, and gender, which usually create overlapping patterns of disadvantage. Intersectional experiences are the disadvantages or unique encounters endured by individuals on the sole premise of their race, class, gender, or sexual orientation.

circled people living with HIV/AIDS echoed loudly among women who were thought to be safe from this disease IF they lived virtuous, or moral, lives. This line of thought was evidenced in January 1988, when Dr. Robert Gould incorrectly suggested that women were *not* at risk for contracting HIV in a cover issue of *Cosmopolitan magazine* and Laura Randolph blamed bi-sexual Black men for increasing heterosexual transmission among Black women in *Ebony magazine*. This narrative of inherent heterosexual safety from HIV was perpetuated throughout the early years of the HIV/AIDS epidemic.

Although women were *not* silent in the HIV/AIDS epidemic, their efforts to raise awareness and be visible often were silenced. In 1982, the Centers for Disease Control and Prevention (CDC) issued their first version of the definition of AIDS, which excluded any mention of gynecological symptoms despite women accounting for 12% of AIDS cases (Corea 1992). In 1983, over two years into the epidemic, "Female partners of men with AIDS" was added as a risk group (Fisher et al. 2009). It would take more than a decade (1993) for the definition of AIDS to be expanded by adding symptoms that present in women. As society worked to silence women as potential victims, it made vociferous statements to control the autonomy of these women deemed ineligible for contraction of the disease. Additionally, significantly omitted from the discussion was how women got HIV. It was as though this disease had magically infected these women. According to the Office on Women's Health "Women were implored to use condoms, only have one partner, and refrain from promiscuous behavior" as if these behaviors alone would shield them from HIV/AIDS. Several assumptions were made in offering this advice, which misrepresented women's experiences. First, by assuming that women are always in a position to negotiate condom use, second, their fidelity to one sexual partner was reciprocated by their partner, and

third, assuming that monogamy ensures no risk of HIV/AIDS (Rosenthal & Levy 2010). This advice targets heterosexual women and reflects society's gender bias in sexual matters.

This bias is apparent in *Cosmopolitan's* article "Reassuring News About AIDS: A Doctor Tells Why You May Not Be at Risk," in which a psychiatrist gave erroneous medical advice on how women are *not* part of the population at risk for AIDS IF they are pure and ethical wives. According to Gould, "There is hardly any danger of contracting AIDS through ordinary sexual intercourse" (Gould 1988). These remarks minimized women's vulnerability to HIV and blamed those women living with HIV for engaging in illicit behavior. Gould's words negligently discredited women's vulnerability. As a widely read woman's magazine, *Cosmopolitan* was a source women trusted, and the distribution of incorrect information by a medical doctor gave women a false sense of safety. This article was so inflammatory that it triggered the mobilization of the women's contingent of ACT UP.

ACT-UP-- the AIDS Coalition to Unleash Power, was founded in 1987 by queer activists and their allies (some of whom suffered losses to the disease) to combat stigma and raise awareness. ACT-UP advocated against oppressive policies and practices that discriminated against diverse communities. The early attribution of a specific gender and race to the HIV/AIDS epidemic resulted in women being left ignorant of their vulnerability to transmission until people around them began to get sick with the disease. To counter misinformation, the women's delegation boycotted *Cosmopolitan magazine* in 1988 and disrupted Dr. Gould's appearances. ACT-UP ridiculed the classification of AIDS as a gay male disease. Their stance resulted in numerous protests to push the CDC to broaden its definition of AIDS to include recurrent AIDS-defining opportunistic infections in women. In this campaign for re-classification, Katrina Haslip, a formerly imprisoned black woman living with AIDS, failed to be noted by the media for her revolutionary efforts. Haslip was a leading voice in ACT-UP and achieved success for re-classification after a four-year campaign. However, by then she was too ill to attend the conference, so another woman spoke on her behalf saying "I'm going to smile. This is only happening because of us, and you let us die" (Adler 2022).

In the same month that Dr. Gould's *Cosmopolitan magazine* article appeared, incorrectly stating that women were *not* at risk for HIV infection as long as they engaged in traditional sexual activities, *Ebony*

magazine ran a cover story entitled "The Hidden Fear: Black Women, Bisexuals, and the AIDS Risk" about the alarming rates of Black women contracting HIV through heterosexual contact. Gould excluded Black women from his target population, as shown by his stereotyping of Black hypersexuality through the discussion of African women who contracted HIV through heterosexual contact where he stated that African men "take their women in a brutal way" tantamount to rape (Gould 1988:147). Gould's views insinuated a probable explanation for HIV transmission among heterosexual Black women in the United States (Scott 2022).

The HIV/AIDS epidemic disproportionately affected the Black community, and hence Black women. Instead of addressing the economic and healthcare inequities that exacerbated the AIDS epidemic in Black communities, media outlets usually emphasized how men placed black women at risk, frequently scapegoating bi-sexual black men (Newman et al. 2008). A lack of resources and acknowledgment were main factors influencing higher infection rates. Statistics showed that many women who contracted HIV through heterosexual sex, more often than not, had partners who were former or current intravenous drug users. Despite the fact that AIDS had been around for 10 years by that time, women still knew very little about their vulnerability. The intersectional experience of black women created further impediments. In order to alleviate their marginalization, black women advocated for equal treatment with white women. If all women were already ostracized, they wanted to be a part of it, not omitted from it.

After 12 years of uncountable fatalities, the CDC included bacterial pneumonia, tuberculosis, and stage III cervical carcinoma as symptoms in the AIDS criteria. The tripling increase in AIDS diagnoses in women from 1986 to 1999, from 7% to 23%, reflects the epidemic's delay in comprehensive surveillance (Ruiz et al. 2001). While some continue to stigmatize HIV/AIDS as a gay man's disease, tremendous progress has been made over the course of this 40-year epidemic. The 1993 re-classification of AIDS diagnosis opened the floodgates for better surveillance of the disease among women. In 2006, the CDC recommended opt-out HIV testing as part of routine physicals. NY and Nebraska were the final states to abandon written consent testing in 2014 (Bayer et al., 2017).

Women have come a long way in their fight for recognition within the HIV/AIDS epidemic. Between 2010 to 2018, there was a 24% *decline* in female HIV/

AIDS diagnoses among women (KFF 2020). This decline in women's diagnoses is evidence of the success of women like Katrina Haslip's efforts. As rates continue to decline, however, it is imperative that we not forget about the power differences between men and women in society. Examples of these power differences may include women's inability to negotiate condom use, domestic abuse resulting from a woman's questioning their male partner's sexual health, and public blame for seeking medical advice on HIV testing. While women work towards equality across many fronts, their efforts throughout the HIV/AIDS epidemic *should not* go unrecognized. They fought the odds when the FDA authorized the use of Truvada for PrEP in 2012, and the CDC promoted the use of PrEP in a clinical environment in 2014 (Auerbach 2015). From the reclassification of AIDS in 1993 to the most recent win of women's inclusion in the clinical trials of Apretude, a drug approved by the FDA in December 2021, women have *not* stopped fighting for equality in treatment for HIV/AIDS (ViiV Healthcare 2022).set

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