Black Women, Racism, and HIV in the US

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Introduction

In the US and around the world, Black women living with HIV have been innovators and changemakers in the HIV community and intersecting movements since the earliest days of the pandemic. Yet Black women's contributions are regularly ignored or made invisible in the HIV field and in US society in general, where leadership roles have historically been held by white men. This disregard is a symptom of the same cause driving HIV among Black women: According to the US Centers for Disease Control and Prevention (CDC), US Black women are ten times more likely to be diagnosed with HIV than their white counterparts; and between 44 and 62 percent of Black women of transgender experience (trans women) are estimated to be living with HIV.

For more information: Factors Affecting HIV Among US Women of Different Races/Ethnicities

Most health experts report this **health disparity** (difference in health that is linked to unequal or unjust social conditions) is caused by **structural determinants of health** (systems and policies that shape the social conditions affecting a person's health), including poverty, racism, and gender inequality. These structural determinants result from generations of *white supremacist ideology* within individuals and throughout society.

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When people hear the term "white supremacist," they may often think of violent extremist groups like the Proud Boys or the Ku Klux Klan, or foreign states like apartheid-era South Africa. But the ideology (system of ideas) of *white supremacy* – the idea that white men embody superior characteristics of humanity and therefore must dominate society – is embedded in the thought patterns, beliefs, and mental processes that shape US culture. These ideas help maintain systems that, for many generations and in many ways, have put a higher value on the lives of white men than those of women and people of color – particularly Black women.

White supremacist ideology can manifest (show) in various ways, ranging from subtle, everyday prejudices to obvious expressions of hate and violence towards others or self. It can exist within the psyches of members of an oppressed (unjustly treated) group believing themselves inferior (less than), and in those of a dominant group believing they are superior (better than).

Many generations of individuals of varying ethnicities, cultures, and gender expressions have embraced social norms (standards) that uphold this often-unconscious hierarchy of humanness. The "ideal" of white male experience has been used as a gauge for how intelligent, desirable, and moral a person or group of people is believed to be. In that brutal calculation, Black women are left out.

Black Women, Intersectionality, and HIV

Intersectionality is the idea that many systems of oppression (unjust treatment based on aspects of identity) impact a person's life at the same time. For example: All women experience sexism. But Black women experience sexism that is also affected by racism, making their experiences distinct from those of Black men or white women.

Recognition of Black women's contributions and value is often limited to the way in which they serve others or perform tasks.

The term "intersectionality" was coined by Black feminist legal scholar Kimberlé Crenshaw, though the idea that the parts of a person's identity cannot be separated has been a foundation of Black feminist teachings for generations. These concepts help us understand how Black women experience discrimination through multiple intersecting systems of oppression tied to race, gender, class, health status, and more.

For more information: Why Race Matters: Women and HIV

Historically, Black women's labor, both in domestic and professional settings, has often been undervalued and exploited. During slavery in the US, Black women were forced into unpaid labor, which laid the groundwork for systemic undervaluation. After the abolition of slavery, Black women continued to work in low-wage jobs, particularly in domestic and service roles, and this legacy persists in various forms today. Recognition of Black women's contributions and value is often limited to the way in which they serve others or perform tasks. Black women's intellectual, moral, and civil contributions to society are rarely acknowledged.

As a result of the devaluation of Black women, unmerited stereotypes persist in society at large. Common misrepresentations include:

- "angry Black woman" (often applied when challenging unfair social conditions);
- "jezebel" (labeled "seductive" and "hypersexual" – sometimes for showing agency in her sexuality – which relates to how Black women's HIV prevention and care needs are perceived);
- "mammy" (dedicated to serving white people/society); and
- "welfare queen" (considered "cheating" and "lazy")

Black women frequently encounter these painful stereotypes, which can lead to social exclusion, impacting community engagement and self-perception.

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Another intersection of potential exclusion is *ableism*. A notion embedded in white supremacist ideology is that the ideal human is not only white and male but also in perfect mental and physical health. This notion dehumanizes people experiencing health conditions and other forms of disability, undermining their dignity.

As a result of these complex, intersecting biases resulting from racism, gender inequality, and ableism, Black women living with HIV experience stigma in profound and multifaceted ways. Some may face exclusion from support networks and communities, or experience layers of rejection, abandonment, and neglect. For many Black women living with HIV, these struggles may lead to internalized stigma, isolation, or shame. Some may withdraw from social interactions. These combined effects often increase stress, anxiety, and depression, affecting access to care, mental health, and overall well-being. Stigmas, biases, and stereotypes may ripple into every facet of their lives, following them into the healthcare, educational, justice, economic, and political systems.

For more information: Stigma and Discrimination Against Women Living with HIV

Black Women and Structural Determinants of HIV

The effects of unjust systems, and not individual behaviors or shortcomings, are what render Black women more vulnerable to acquiring HIV and to having worse health outcomes once they are diagnosed. Structural determinants are woven into society's systems. Education (including schools, school districts, superintendents, and the jurisdictions that fund them) and housing (including mortgage lending, public housing "projects," and realty practices) are just two examples. These systems and structures were designed to support dominant groups in keeping political and economic power for themselves, leaving large portions of society unable to thrive beyond the boundaries placed on them. Over time these limitations have blocked achievement and autonomy, and contributed to generations of unresolved trauma and distorted sense of self, for members of social groups made to live under them.

Economics and Stress

White supremacist ideology in the US has roots in enslavement, segregation, and discriminatory practices that have persisted over centuries. Discrimination in housing, education, and employment have contributed to an expanding racial wealth gap in which communities of color, particularly Black people, have been excluded (kept out) from economic opportunities. These economic injustices create barriers to social mobility, which can uphold cycles of poverty over generations. They also contribute to

sources of immense stress for Black women, including:

- Being a provider and caretaker/making and saving money (Black women in the US are far more likely to live in poverty than white women, according to several sources)
- Financial responsibility (84 percent of Black mothers are the sole or primary earner or earn more than 40 percent of their household income, via a Center for American Progress report)
- Single parenthood (64 percent of Black children live with a single mother compared to 24 percent of white children, according to Annie E. Casey Foundation data)

Research has shown that high levels of stress can affect physical as well as mental health, including speeding up the progression of HIV.

For more information: Mental and Behavioral Health, Women, and HIV

Historical Context of Current Inequities

The participation of marginalized communities in economic and political life has been discouraged and even threatened within systems and processes driven by white supremacist ideology.

- Longstanding, biased strategies in the housing sector have prevented Black people from growing their families' wealth through homeownership
- Public education systems based in funding from property taxes, set in a housing market that has historically blocked Black people from owning property, has produced schools in many areas that struggle with inadequate funding resulting in too-large class sizes, outdated educational materials, and fewer extracurricular opportunities
- Students attending these schools often face limited employment and earning potential, as well as disproportionate drop-out rates and excessive and severe discipline – all of which contribute to higher incarceration rates
- Black people are incarcerated at a higher rate than any other racial group in the US (37 percent of the population in prisons and jails, despite accounting for just 13 percent of the US population overall, according to Prison Policy Initiative) due to racial profiling, over-policing, and the economic injustices described above
- Incarceration separates an unjust proportion of Black individuals, particularly Black men, from communities and families they could be participating in and helping to build
- Black people are also unduly affected by laws and policies disenfranchising (removing voting rights from) individuals with felony convictions
- Disenfranchising Black people is another way white men have historically held political power and kept Black communities from electing leaders who might represent their interests. Tactics like literacy tests, poll taxes, and voter intimidation, used in the US South to maintain white dominance, echo in modern techniques such as identification (ID) laws, purging of voter rolls (removing people from voter registration for false reasons), and gerrymandering (changing boundaries of a voting areas to benefit one party).

The intersection of white supremacy and US political life involves a historical and ongoing effort to undermine the power and participation of marginalized communities.

Women's Health

White supremacist ideology shapes the healthcare system in ways that significantly affect access to care, quality of treatment, and health outcomes for women, particularly Black women.

- Many advances in science and medicine result from medical exploitation and experimentation on Black women. One key example is Dr. J. Marion Sims, called the "father of gynecology," who developed surgical techniques by operating on enslaved women without their consent and

without using anesthesia.
- During segregation, Black women were often denied access to quality healthcare facilities or received inferior care compared to white women. Today, Black women are more likely to be uninsured or underinsured compared to white women, which limits access to necessary medical services and preventive care. Black women from low-income backgrounds often face barriers to accessing quality healthcare, including lack of transportation, inability to afford out-of-pocket costs, and living in "healthcare deserts" far from available medical facilities.
- Biased attitudes and beliefs of healthcare providers affect their treatment decisions. Studies have shown that, compared to white women, Black women are often not taken as seriously when reporting pain, which can lead to inadequate pain management and treatment. These biases can also lead to misdiagnoses or delays in diagnosis.
- Lack of cultural humility among providers limits communication with patients and leads to misunderstandings that compromise care. Conversely, having a provider of the same race and/or gender (concordance) is linked to better health outcomes, but Robert Wood Johnson Foundation found that only 22 percent of Black adults report being the same race as their provider. This tracks with the fact that data show roughly 5 percent of US doctors are Black, and just 2.8 percent are Black women.
- Black women are more likely to suffer from chronic conditions such as diabetes, hypertension, heart disease, and HIV. Further, Black mothers are three to four times more likely to die, and their infants are more than twice as likely to die, than their white counterparts due to inadequate prenatal care, underlying health disparities, and systemic racism within the healthcare system.

To change these outcomes on a large scale, the unjust systems under which people live, access care, and even train as medical professionals must change.

For more information: Sexual and Reproductive Health, Rights, Justice, Pleasure, and HIV

What Is Power?

To be Black, a woman, and living with HIV in a society that has historically hailed whiteness, maleness, and wellness as the pinnacle of humanity is to be in a consistent quest to maintain personal power. *Personal power* involves having autonomy (control of what does and does not happen to you), confidence, and the capacity to make decisions that shape one's destiny. Possessing personal power as a Black woman living with HIV means acting with purpose and direction despite the many facets of opposition threatening one's personhood. Miraculously, many Black women living with HIV continue to overcome generations of oppression while working to end HIV-related stigma, decrease HIV transmissions, and bring awareness to vulnerable communities.

Black women living with and impacted by HIV must be at the forefront of efforts to end the HIV epidemic.

In the US, grassroots community organizing has been instrumental in changing the course of history, including key milestones in civil and women's rights. By mobilizing communities, raising awareness, and advocating for change, grassroots efforts have significantly advanced social justice and equality. Community organizing harnesses collective power to address local and national issues and advocate for change. This power arises from individuals and groups coming together to influence decisions, create solutions, and build a more equitable society.

To reach their goals, many movements rely on the concept of a *power shift*: the process of redistributing power from dominant, often hierarchical structures to community-based groups and individuals most impacted by the movement's concerns. This shift involves empowering marginalized communities to take control of their own destinies and influence decisions that affect their lives. Both outside and within the HIV community, people most impacted by racism, gender inequality, poverty, ableism, and other intersecting systems of oppression have the most information about what it is like to

live under these systems and what is needed to start to take them apart. Many movements express this notion in the phrase: *Nothing about us, without us.*

Making Power Moves

Power can be defined as "the ability to do something." In the realm of community organizing, there are two types of power: people power and money power.

People power refers to the collective strength and influence of individuals coming together to act in unity for a common cause. People power is rooted in the idea that individuals working together can amplify their voices and influence to put pressure on decision-makers and institutions, to act in the interest of the oppressed.

Money power is the strategic use of financial resources to support, sustain, and amplify organizing efforts, which plays a critical role in empowering communities, enhancing organizational capacity, and influencing decision-making processes.

The greatest manifestation of personal power among Black women living with HIV is their ability to motivate and guide others as they take on leadership roles. They use their internal wherewithal to inspire support and create solutions that improve outcomes for themselves and others.

Many Black women living with HIV are not waiting to be recognized before getting involved. So many have used their power to create organizations, businesses, and efforts that confront stigma and strive to prevent high prevalence rates in their communities.

Centering Black Women in the HIV Movement

The redistribution of power necessary to improve the overall wellbeing of Black women living with and impacted by HIV will require strategic, consistent, and long-term effort from people of all walks of life. Like most struggles for power, those deemed as the oppressed group who are on the frontlines take the charge to improve their own condition. HIV is no different.

Ultimately, to be successful, Black women living with and impacted by HIV must be at the forefront of efforts to end the HIV epidemic. Their voices and lived experiences hold the wisdom and genius necessary to identify and confront the plethora of issues faced by millions in the US.

As a result of these complex, intersecting biases resulting from racism, gender inequality, and ableism, Black women living with HIV experience stigma in profound and multifaceted ways.

This is what it means to *center* Black women living with HIV: to put people most likely to be pushed to society's margins at the center of our work; to approach each endeavor from the perspective of what changes would need to be made, or barriers removed, for Black women living with HIV to thrive; and to listen to and follow leadership of Black women living with HIV.

As the HIV community moves forward to end this epidemic, we must be cognizant of the work being done by the people, for the people, and support these efforts. When Black women living with HIV are at the center of coalition building and policy change efforts, the needle towards justice will move exponentially.

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