TRANSFORMING PARADIGMS: FROM BIFURCATION TO INTERRELATIONALITY IN HIV PREVENTION DISCOURSE

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To the Dean of the Graduate School:

I am submitting herewith a thesis written by La Cisha A. Crear entitled "Transforming Paradigms: From Bifurcation to Interrelationality in HIV Prevention Discourse." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Arts with a major in Women's Studies.

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DEDICATION

To my parents, my father Don E. Crear, my mother Mary L. Pilot, and step-father Willie L. Pilot,

thank you for your unwavering love and support.

To my siblings Donna Frazier and Donald Crear, thank you for always believing in me.

And

To the courageous women who are living with HIV, thank you for teaching me courage and strength.

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ABSTRACT

LA CISHA A.CREAR

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Women of color, particularly Black women are disproportionately represented in the AIDS epidemic. While women of African descent constitute only 13 percent of the population of women in the United States, they account for 64 percent or nearly two-thirds of all newly acquired HIV among women. This thesis explores the reasons why women of color communities, particularly women of African descent, are disproportionately impacted by the HIV epidemic. I argue that while prevention methods have been considerably effective, they are still are limited because they do not address the multilayered impact of race, class, and gender oppression as well as larger structural inequities. My goal is to expand HIV discourse on women and explore ways in which the reproductive justice framework can be applied to HIV prevention and advocacy. HIV is a reproductive justice issue. I believe that the reproductive movement and framework, which entail grassroots women of color organizations and their allies fighting for reproductive rights and social justice guided by a human rights principles, advance a radical means of addressing the needs of women of color impacted by HIV and AIDS.

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CHAPTER I

BLACK WOMEN AND THE HIV/AIDS EPIDEMIC

The construction of black women within the HIV/AIDS epidemic has been far from simple and not without problems as they moved from invisibility to being labeled as conduits for HIV transmission.

--Ayana K. Weekley

The degree to which women have been affected by the disease is inseparable from the historical scars of inequality in American society.

--Michele Tracy Berger

Introduction

This year marks 34 years of the AIDS epidemic in United States. According to the Centers for Disease Control and Prevention, there are nearly 1.2 million people living with HIV, and women comprise nearly a quarter (240,000) of them (CDC 2015). The majority of women (84%) acquired HIV through heterosexual contact, which is the predominant mode of transmission among women. In 2013 women accounted for 20 percent of new HIV diagnoses and 24 percent of new AIDS diagnoses. In addition, in 2012, there were an estimated 3,561 new AIDS related deaths and 117,797 cumulative AIDS related deaths among women by then end of 2012 (CDC 2015). Women of color are disproportionately affected by the AIDS epidemic. While they constitute only 25% of the female population in the United States, they make up an estimated 80% of new HIV acquisitions.

Furthermore, Black women are disproportionately represented in the AIDS epidemic. Black women constitute only 13 percent of the female population in the United States, yet they accounted for nearly two-thirds (64%) of all new HIV diagnoses among women in 2010 (CDC 2015). According to the Henry J. Kaiser Family Foundation, the rate of new HIV diagnoses for Black women was 20 times higher than white women and 4 times higher than Latina women. Further, the probability of a Black women being diagnosed in her lifetime is significantly higher (1 in 32) than for white women (1 in 526) and Latinas (1 in 106) (Kaiser 2014). Moreover, the CDC reports that the total estimated number of women receiving an HIV diagnosis declined from 10,686 in 2009 to 9,278 in 2012 (CDC 2015). However, the number of new HIV diagnoses among women sub-populations of Black women in the Northeast and South remain disproportionately high (Hodder et al. S69).

The proliferation of HIV and AIDS among Black women illuminates a deeper problem than high risk behaviors. It reflects their multiple intersecting oppressions of race, class, and gender. However, in order to contextualize and better understand the current problem of the disproportionality of HIV among women of Black women, it is important to examine their background and history relative to the HIV epidemic in the United States. Although women of color communities, particularly Black women, have carried an unequal burden of acquiring HIV from the very outset of the HIV epidemic, they were not identified as being at higher risk until several years into the epidemic.

In this thesis, I will explore the reasons why women of color communities, particularly women of Black women, are disproportionately impacted by the HIV epidemic, and I will discuss current HIV behavioral and biological prevention models advanced by the CDC. I will argue that while these prevention models have been considerably effective, they still are limited, especially among particular sub-populations because they do not address the multilayered impact of race, class, and gender oppression as well as larger structural inequities in society. This is evident by the fact that the number of overall new infections in the United States has remained relatively constant at an estimated 50,000 new HIV acquisitions per year. I will suggest that there are areas of opportunity for heightened consciousness and dialogical competence around HIV prevention for women and contend that an effective prevention strategy for women of color should be integrated, comprehensive, and women-centered in order to promote women's agency, voice, and power.

Furthermore, I assert that HIV prevention is a sexual health and reproductive justice issue. My goal is to expand HIV discourse about women and explore ways in which the reproductive justice framework can be utilized for HIV prevention and advocacy. I believe that the reproductive movement and framework, which entail grassroots women of color organizations and their allies fighting for reproductive rights and social justice guided by human rights principles, advance a radical means of addressing the needs of women of color impacted by HIV and AIDS.

In other words, the reproductive justice framework represents more than simply a paradigm shift in HIV/AIDS prevention models; it signifies a paradigm transformation — a comprehensive and generative model that extends beyond prevention tactics and speaks to the lived experiences of women of color. Further, it empowers and emboldens women to engage HIV in a more interrelational and holistic manner by challenging social, political, and economic inequalities as well as public policies pertaining to women's reproductive healthcare. In my thesis I will examine the reproductive justice framework models, which incorporate a reproductive health model (service delivery), reproductive rights (legal rights and advocacy), and reproductive justice (structural power inequities) (Asian Communities for Reproductive Justice 2), and explain why they are effective in addressing the needs of women of color. I will further discuss why I believe that in addition to existing HIV prevention models, the reproductive justice framework can be employed to address these issues more comprehensively.

This thesis is a confluence of my work experience with Black women in the HIV prevention field as outreach specialist and co-founder of The Afiya Center, an HIV prevention and reproductive justice organization in Dallas, Texas combined with my studies in feminist theories. My thesis has three chapters. In this opening chapter I will examine the background and historical trajectory of the HIV epidemic among Black women in the United States and analyze recent trends in this population. I will explore the initial communal and governmental responses to this epidemic as well as the subsequent erasure of women in HIV discourse. I will argue that this erasure contributed

women falling through the cracks of the epidemic, which further proliferated HIV and AIDS among women.

In the second chapter, I will examine current HIV prevention models used by the CDC such as the AIDS Risk Reduction Model and High Impact Prevention Strategy. The AIDS Risk Reduction model focuses on high risk behaviors and defines risk categories as men who have sex with men (MSM), high risk heterosexuals, and injecting drug users. I will point out that these categories rein scribe and reify stigma since behavior is often conflated with identity. As a consequence of these risk categories, many women who do not identify with these categories are lured into a false sense of security based upon their lack of perceived risk.

On the other hand, the current High Impact Prevention Strategy is directed towards larger geographical areas hardest hit by the HIV epidemic and focuses on cost and program effectiveness, and making an overall impact on the course of the HIV epidemic. It includes a combination of interventions and emphasizes the biomedical aspects of prevention such as treatment and prevention, which does not adequately address the intersections of race, class, and gender in relation to larger structural issues such as poverty, healthcare inequity, gender inequality, and violence. Many of the HIV prevention models such as the AIDS Risk Reduction and High Impact Prevention strategy presuppose that women have the agency and power to exercise and negotiate behavioral changes. In sum, I will argue that while the current HIV prevention discourse

acknowledges social and economic drivers, there are few prevention models that directly address them in a comprehensive and way.

In the third chapter, I will elucidate the reproductive justice movement and framework advanced by reproductive justice organizations such as SisterSong Women of Color Reproductive Justice Collective and Asian Communities for Reproductive Justice, which have historically been the vanguard of the movement. I will reveal the interconnections between reproductive justice and HIV and emphasize that HIV prevention is a reproductive justice issue. This chapter will outline SisterSong's three core values of reproductive justice as well as elucidate the definition and vision of reproductive justice put forth by Asian Communities for Reproductive Justice, an Oakland-based advocacy group and founding member of SisterSong.

Moreover, I will suggest that this model can be utilized to bring diverse individuals and organizations into conversation and collaboration with one another to build a network of allied social justice organizations and coalitions around intersecting issues women face including HIV/AIDS. I believe that models such as those put forth by progressive groups like SisterSong are more holistic and address the structural issues women of color face in an integrated and comprehensive manner. The reproductive justice models promotes complete mental, physical, political, economic, and social health, and their approach also provides a comprehensive, dynamic, and generative framework that addresses the interrelatedness of the issues embedded in the experiences of women of color. The human rights approach underscores the reproductive justice

framework and is inclusive of everyone. I believe this model provides a radical framework and new horizons for HIV prevention discourse on both a national and global scale.

Background and History

At the beginning of the epidemic, HIV was viewed as a disease of men who have sex with men, although soon afterwards it was also identified in women. On June 5, 1981 CDC reported the first cases of a rare pneumonia in young gay men, marking the beginning of the HIV epidemic. And in 1982, the following year, the CDC established the term "Acquired Immune Deficiency Syndrome" and identified four "risk factors" – male homosexuality, intravenous drug abuse, persons of Haitian origin, and hemophilia A ("The Global HIV/AIDS Timeline"). The first woman presented with symptoms as early as 1981, and the first African American woman with AIDS was reported in 1982 (Hammonds, "Seeing AIDS" 114). Women were not identified to be at risk for HIV until 1983, when the CDC added "female sexual partners of men with AIDS" as a fifth risk group ("The Global HIV/AIDS Timeline").

Moreover, between the years 1985 and 1988, the rate of HIV infection quadrupled among women of color, particularly for those living in impoverished inner cities (Berger 19). In 1988, the CDC announced that Blacks accounted for half of all AIDS cases ever reported among women (Lazarus). In 1991, a total of 20,000 women were living with an AIDS diagnosis, and the number of newly acquired cases of HIV in women doubled every one to two years. By 1992, women of color, African American, and Latina women

comprised the majority (72%) of women living with AIDS (Hammonds, "AIDS" 268). By 2007, the U.S. observed an increase in the number of new HIV infections by as much as 50 percent for the first time in over 10 years, largely among people of color. In addition, of the almost 1.2 million people living with HIV, more than 300,000 were women and girls. To put this statistic into perspective, the number of women with AIDS in the U.S. rose from 7 percent of all AIDS cases to 1985 to 27 percent of all AIDS cases in 2005 (Dixon Diallo, "HIV Prevention" 1). The proportion of women in the U.S living with HIV and AIDS had more than tripled since the beginning of the epidemic (amfAR 2008). Furthermore, since the beginning of the epidemic, an estimated 117,797 women diagnosed with AIDS have died by the end of 2012 (CDC 2015).

The Erasure of Women in HIV Discourse

Historically, women have been neglected in HIV/AIDS prevention, research, treatment, and care in the U.S. and globally. This lack of attention has contributed to women falling through the cracks of the epidemic. However, even women who were diagnosed and received treatment and care frequently experienced discrimination and were excluded from the attention of public health community. The CDC's initial failure to incorporate illnesses related specifically to women such as gynecological conditions such "cervical cancer," "pelvic inflammatory diseases," "human papillomavirus," "herpes simplex virus," and "recurrent genital candidiasis" in its diagnostic criteria for an AIDS diagnosis has led to women's disempowerment by exclusion from eligibility for federal government programs such as social security and disability insurance as well as Medicaid

and Medicare programs, which ultimately shorter life spans (Quinn 312). In the article "AIDS, Case Definition of," Theresa McGovern and Raymond A. Smith remind us that in 1990, a group of advocates, including women living with HIV, filed a class action lawsuit and launched a movement to force the CDC to expand to expand the surveillance definition of AIDS (32-36). By 1994, the CDC announced it would incorporate three additional conditions to the definition of AIDS, including cervical cancer, recurrent bacterial pneumonia, and pulmonary tuberculosis, based on a community proposal. Although the CDC conceded, it did not do so until it was targeted by legislative and community activism (32-36).

In her chapter, "Vessels, Vectors and Vulnerability: Women in the U.S.

HIV/AIDS Epidemic," Kimberly Christensen stresses that in low-income communities of color, HIV/AIDS may have gone undetected for years due to their lack of access to medical care. Christensen refers to Chris Norwood, an award-winning, feminist health care activist, who suggests that low income women of color may have experienced an increase in unexplained deaths due to undiagnosed AIDS cases (56). Like Norwood, Christensen draws attention to the unexplained deaths of low income women in the late 1970's and 1980's in urban centers such as New York City; Newark, New Jersey; Hartford, Connecticut; Washington, D.C; and other geographical areas that subsequently became the epicenters of the HIV epidemic (56). Furthermore, Christensen argues that we may never know when the incidence of HIV and AIDS began for low-income women due to the lack of attention they received. She attributes women's vulnerability to

HIV/AIDS to a myriad of factors, including homophobia and the stereotyping of AIDS as a white gay man's disease, "first world" cultural chauvinism, health inequalities among the poor, and the sexist devaluation of women (56-58).

In the article "The (Missing) Faces of African American Girls with AIDS," Nels P. Highberg offers a similar analysis as Christensen concerning the dominance of the "AIDS-as-gay-disease" among white men master narrative. Highberg points out that this narrative overshadowed other communities that were equally impacted and falsely gave the impression that only Blacks affected by HIV are those living in areas outside of the Unites States in areas such as Haiti and Africa (4). His observation mirrors Christensen's analysis of the myth of "first world" uniqueness, which relegates HIV infection patterns among Blacks to the developing world (57). Although these myths were debunked early on as it became increasingly clear that heterosexual women were at risk for HIV, women were and remain an afterthought in HIV prevention.

Even today, thirty-four years after the first woman reported, women still must agitate and to be included at the table in HIV prevention programming and research. Furthermore, Christensen argues that when women are valued, it is usually for their children's and their men's health interests rather than their own well-being (58). In other words, women were treated as means to an end, or "vessels" who might pass the virus along to their children through mother-to-child transmission and "vectors" of transmission to men (58). Christensen stresses that "until women's lives are valued as highly as those of their fetuses and/or male sexual partners, it will be impossible to

adequately address women's position in this epidemic" (58). Christensen's "vessels or vectors" metaphor calls attention to the persistent and pervasive devaluation of women in the public health field, particularly in relation to women and HIV.

Moreover, Christensen argues that inequalities in race, class, and gender create a "matrix of vulnerability" among poor women of color, which places them at higher risk of contracting HIV (55). In other words, poor women of color may have exhibited the same sexual behaviors as other women, yet due their multiple and interrelated oppressions, they were more vulnerable to acquiring HIV than other women.

Christensen's concept of the "matrix of vulnerability," which goes beyond individual behavior and points to larger structural factors such as social, political, and economic oppression influencing high incidence rates among women, harkens back to Patricia Hill Collin's concept of the "matrix of domination." In *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment,* Hill Collins analyzes interconnections among systems of oppression and how they are organized and experienced by Black women (18). Her analysis, which can be extended to HIV prevention methods, resembles that of some HIV/AIDS researchers.

For example, in their article "Structural Approaches to HIV Prevention," Geeta Rao Gupta and her colleagues urge that for prevention efforts to succeed, we must incorporate structural approaches that address the fundamental elements impacting and precipitating both risk and vulnerability. Second, they stress that structural factors at various levels and distances impact and determine risk and vulnerability on an individual

level. Third, they maintain that structural approaches should approached in a "contextually sensitive way," depending on the situation and relevance of influence. Finally, the authors suggest, that while structural approaches may be difficult to assess due to their multiplicity, there are alternative ways of assessing their effectiveness, and they call for more to be developed (764). Furthermore, Gupta and colleagues suggest that the interrelationship of structural factors with regard to HIV vulnerability is complex, varied, and ever-changing in both form and effect, and they urge that prevention efforts must be responsive to these realities (766).

In the same way, Stefan Baral, Carmen H. Logie, Ashley Grosso, Andrea L. Wirtz, and Chris Beyrer, in their article "Modified Social Ecological Model: A Tool to Guide the Assessment of Risks and Risk Context of HIV Epidemics," make similar points. They assert that, "successful HIV prevention strategies for key populations require effective integration of evidence-based biomedical, behavioral, and structural interventions. The future necessitates comprehensive epidemiologic data characterizing multiple levels of HIV risk" (1). The arguments put forth by Stefan et al. are extremely useful because they shed light into the problem of both distinguishing and contextualizing risks.

Similarly, Dázon Dixon Diallo, in the article "Reflections of a Human Rights Educator," reveals the necessity of approaching HIV prevention from a contextual perspective. She reflects on her early HIV activism and the painful experiences of women of color living with HIV. Her reflections, which foreground women's

experiences, emphasize that HIV must be discussed and dealt with in the context of women's lives (125). Dixon Diallo admits that in the beginning of the AIDS epidemic, the manner in which early activists initially handled HIV issues was inadequate because the activists were managing a myriad of individual issues without a language or framework to connect them. She concedes that AIDS activists were responding to both HIV as well as to various socio-economic issues. Dixon Diallo writes, "we were indirectly responding to a myriad of issues -- substance abuse, violence, poverty, misogyny, internalized oppression, family neglect/abandonment" (125). To explain her perspectives, Dixon Diallo utilizes her apex/axis metaphor and explains that, "HIV is the apex of the experience, and the axis upon which issues turn in people's lives." (126). She further delineates that "the issues are the hanging baubles that keep spinning in motion, while those who experience the pain from these issues are lying and sitting in the center looking up" (126).

According to Dixon Diallo, her organization, SisterLove, was created out of the necessity to respond to the needs of the community during the height of the AIDS epidemic. Through her work at SisterLove, Dixon Diallo supported women's empowerment by educating women on human rights and social justice. Through this educational process, they learned how to contextualize the AIDS epidemic more holistically within a broader context of women's reproductive and sexual health and rights and utilize a human rights framework for their activism (126). In addition, Dixon Diallo argues that the human rights framework illuminates the interconnections between

the various issues women living with HIV face and enables them to better articulate and qualify their responses to HIV (126). She further maintains that a major aspect of addressing HIV among women of color requires us to examine our attitudes and beliefs about poverty, classism, racism, sexism, homophobia, and human rights (127). Dixon Diallo's article is instructive to those working in the HIV/AIDS field, since her activism works at the intersections of HIV/AIDS, gender, and human rights by building holistic and comprehensive strategies and programs to address the multiple needs of Black women and other women of color living with HIV, and by supporting their agency, voice, and power.

Furthermore, in their pivotal work, *African American Women and HIV/AIDS:*Critical Responses, Dorothy J. Gilbert and Ednita M. Wright provide a comprehensive analysis of the impact of the HIV epidemic on African American women. In particular, Gilbert and Wright examine the sociocultural construction of HIV within prevention discourse and argue that many traditional approaches to HIV prevention cast Blacks as having individual behavior deficits (1). They also maintain that traditional methods of HIV prevention, which focus on individual behavior, "high-risk" populations, and racial and ethnic groups without consideration of the social context, obscures the fact that disempowerment also contributes the proliferation of HIV (1). Gilbert argues that traditional methods fail to acknowledge larger interrelated structural issues like poverty, institutionalized racism, economic insecurity, racist policies, and social isolation (6). In addition, Gilbert also provides insight into African American women's vulnerability to

HIV and stress that sexism and gender inequality contribute to escalating the rates of HIV transmission among African American women. She also points out that African American women's responsiveness to HIV risks is challenged by their experience of the triple burden of racism, classism, and sexism (6). In other words, African American women may not sufficiently appreciate their risk of acquiring HIV because they consider HIV to be just another adversity among many and may not perceive it to be the worst possible challenge they could face.

Moreover, Gilbert argues that initial prevention efforts among Black women failed for two reasons. First, they observe that messages about how to prevent transmission of the virus primarily targeted gay, white males and did not to resonate with other ethnic and minority communities due their lack of cultural specificity. Secondly, she notes that prevention methods generally did not consider the larger socio-economic realities and the full range of gender, health, mental health, and racial disparities as well as structural disadvantages such as poverty, institutional racism, economic insecurity, regressive legislation, and isolation to be relevant (6-13).

In the same way, in "AIDS the Secret, Silent, Suffering Shame," historian and early HIV/AIDS activist Evelynn M. Hammonds calls attention to the devaluation of women in public health, and acknowledges that when it became more evident to public health professionals and scholars that women were greatly impacted by the epidemic, they were still excluded from most research on AIDS (268). Hammonds characterizes responses to the AIDS epidemic as the "4S epidemic – Silence, Secrets, Suffering, and

Shame," and posits that the HIV/AIDS epidemic can be used as a tool to examine

American attitudes towards a plethora of social issues. Hammonds asserts that

"epidemics provide a lens for examining social, cultural, and moral values that determine
how societies respond to disease...and think about issues of sexuality, deviance, drug
use/abuse" (269). In addition, Hammonds suggests that the AIDS epidemic disrupts the

African American community's culture of silence around the social issues that
particularly affect them (269). According to Hammonds, although we are increasingly
understanding the extent of the AIDS epidemic in the African American community,

African American women were never prioritized in early prevention programs.

Moreover, Hammonds reminds us that many African American women, who lacked media representation in mainstream prevention efforts, did not perceive themselves to be at risk for HIV as late as 1990 (273). Similar to the conclusions of Gilbert and Wright, Hammonds asserts that early prevention efforts promoted behavioral changes without considering the social context of Black women (273). Hammonds further observes that Black women living with HIV that are disproportionately impacted by impoverished living conditions, inadequate housing, poor health, violence, isolation, discrimination, substance abuse, and other issues that affected their lives prior to acquiring HIV (273).

Communal and Governmental Response

In her work *The Boundaries of Blackness*, Cathy J. Cohen, feminist and social activist, makes a similar point as Hammonds pertaining to media representation, She

argues popular Black media did very little to disrupt traditional AIDs representation (248-249). Also, Cohen explores the impact and response of the AIDS epidemic in the Black community in the U.S., and critically examines the political response to HIV and AIDS in African American communities, arguing that the political and public agendas of African Americans have historically been monolithic and dominated by consensus issues such as race, a topic around which all members of the community could unite and rally. She contends that the AIDS epidemic challenges notions of unity. The HIV and AIDS epidemic reveals various cross-cutting issues, or issues disproportionately affecting specific members of marginal groups, based on social, political, and economic divisions that threaten perceptions of shared identity and unity in the African American community (8). Cohen believes that in order to effectively deal with HIV and AIDS, the African American community must address the larger context in which issues such as stigma, fear, rejection, invisibility, classism, sexism, homophobia, and drug phobia occur (8). Moreover, Cohen suggests that the indifference of the community and government and their initial lack of action were due to the misconception of AIDS belonging exclusively to gay white men, drug users, and marginalized groups exhibiting "immoral behavior." Consequently, there was little political activism in the Black community in response to the AIDS epidemic (20-21).

Cohen explicates her complex "theory of marginalization," which frames her discussion of the multiple factors influencing responses to AIDS in the African American community and its historical distrust of the government around public health issues (27).

Cohen puts forth that her theory highlights the different ways in which marginality is experienced "across" and "between" groups (36). She examines how identities, norms, ideologies, institutions, and social relationships rein scribe and reify marginality, and recounts historical examples to illuminate marginality among groups in the U.S. Furthermore, Cohen constructs her marginalization theory by delineating four areas of marginalization, which include "categorical marginalization," "integrative marginalization," "advanced marginalization," and "secondary marginalization." She differentiates these various forms of marginalization to reveal the dynamics of how those who are considered deviant are excluded from resources by the external dominant group, as well as internally within their community.

Recent Trends among Black Women

There have been important advances in HIV prevention in the U.S. and globally. Prominent and influential public health organizations worldwide such as the World Health Organization (WHO), UNAIDS, the Centers for Disease Control and Prevention (CDC), and the National Institute of Health (NIH) currently endorse and promote campaigns that call for an "AIDS Free Generation," in which there are no children born with HIV; children, teens, and adults have little risk of acquiring HIV; and those with HIV who have access to treatment can prevent AIDS diagnoses (Fauci). Another similar campaign "Getting to Zero," promoted by the World Health Organization, puts forth a vision of a world with no new infections, no AIDs-related deaths, and no discrimination against people living with HIV/AIDS (World Health Organization). Although I concede

that because of the many biomedical advancements, many groups are experiencing a decline in HIV acquisitions, Black women continue to acquire HIV at disproportional rates, as well as bear the burden of the epidemic.

Sally L. Hodder and her colleagues' article, "Challenges of a Hidden Epidemic: HIV Prevention Among Women in the United States," documents that although there was a decrease in the incidence of HIV in white men between ages 20 and 25, there was an increase among women of the same age group (S69). In addition, Hodder et al. point out that although there is a myriad of advances in prevention, there is also a lack of progress in reducing new infections. They report that the incidence of HIV has not changed from over 50,000 cases annually since 1991 (S69). Likewise, in the article "The HIV Epidemic Among Women in the United States: A Persistent Puzzle," Danielle F. Haley and Jessica E. Justman argue that the HIV epidemic among Black women has remained stagnant and elusive for twenty years (715). They point out that since 1999, Black women have accounted for almost a quarter of new HIV acquisitions (715). Haley and Justman call for fresh ways to enact HIV prevention research and surveillance among women in the United States (715). As Haley and Justin emphasize, "HIV risk among U.S. women is not only complex, but also dynamic." In other words, there are multiple underlying factors influencing HIV risk that depend on the social environment (715).

As in the past, research on women today is still not a priority in the field of HIV prevention, although there are several clinical trials that focus on women as well as biomedical advances in prevention such as Pre-Exposure Prophylaxis (PrEP), which

gives women more agency and control over their own health. Overall, however, prevention efforts for women are still insufficient, and HIV acquisitions remain high among women of color. As Haley and Justman point out, many initial prevention protocols that focused on the risk-behavioral model were unsuccessful because they failed to appreciate the complexity of HIV risk (715). These authors agree that underlying environmental and social factors such as poverty, crime, incarceration, and male to female sex ratios, whereby women outnumber men, make Black women more vulnerable to risk (715).

Further, Haley and Justman call for a combination of strategies including individual, network, and environmental ones for impacting women at greatest risk (715). In my view, the socio-ecological model, which addresses individual behavior, sexual networks, and larger organizational, communal, and structural factors provides one of the best opportunities for success. Both articles by Hodder and her colleagues and Haley and Justman expound on the limitations of approaching HIV prevention in a narrow way and call for new methods for approaching HIV prevention research and programs, not based upon risk alone, but rather by adopting a more multidimensional approach to prevention that incorporates traditional and innovative strategies.

CHAPTER II

AN EXPLORATION OF HIV PREVENTION MODELS

In the previous chapter, I first discussed how Black women are being disproportionately impacted by the HIV epidemic in the U.S. Next, I gave a brief overview of how HIV acquisition rates continued to increase over the last 30 years, from the onset of the epidemic until today. I also discussed the erasure of women from HIV prevention, research, and treatment and care. Further, I discussed the apathetic communal and governmental response to the epidemic in the Black community which contributed to Black women falling through the cracks and further proliferated the incidence of HIV. Finally, I looked at recent trends among Black women, and pointed out that although recent CDC data indicate a decline in the acquisition of HIV among Black women in recent years, new studies indicate that their HIV incidence rates are five times higher than the CDC estimated.

In Chapter Two, I will describe the AIDS Risk Reduction Model (ARRM) and the High Impact Prevention Strategy. I will argue that although these interventions may be may be efficacious in a controlled environment such as a study or intervention group, they are less effective in the real world because they do not take into consideration how the social environment and economics may impact one's ability to practice safer sex behaviors. In other words, I will argue that although women may often have the

knowledge and tools to protect themselves, they frequently do not have the power and control to do so.

The HIV/AIDS prevention models are underscored by their own social and behavioral theories and strategies for identifying risk as well as tools for promoting behavioral change. Some of these models, which incorporate one or more psychological theories, include the AIDS Risk Reduction Model (ARRM), the Health Belief Model (HBM), Social Cognitive Theory, Stages of Change, Diffusion of Innovation Model, Theory of Reasoned Action, and Empowerment Theory (Washington State Department of Health). The AIDS Risk Reduction Model (ARRM), which I have used in my outreach work, is effective in identifying high risk behaviors and methods for reducing transmission risks, but constructs risk categories that can reinscribe and reify stigma, since behavior is often conflated with identity. These categories include men who have sex with men (MSM), individuals with multiple and/or concurrent sex partners, and injecting drug users. As a consequence, many women do not identify themselves with these categories and downplay and fail to appreciate their risks; thus, they are lured into a false sense of security. For example, the HIV prevalence rate is higher for married women in Zimbabwe than single women ages 15-24. HIV prevalence is as high as 14 percent for married women and 26 percent for divorced or widowed women compared to 6.2 percent for single women in the same age group who have never been married (United Nations Children's Fund).

On the other hand, the current High Impact Prevention strategy, which was endorsed by the CDC in 2011 to achieve the goals of the 2010 National HIV/AIDS

Strategy (NHAS), is applied on a larger national scale that filters down to state and local programs. High Impact Prevention is more spatially targeted towards larger geographical areas hardest hit by the HIV epidemic. It strongly considers cost and program effectiveness and overall impact on the course of the HIV epidemic. In addition, it emphasizes the biomedical aspects of prevention such as "treatment-as-prevention," or in other words, the use of antiretroviral drugs by people living with HIV to reduce transmission to others (CDC 2011). Although High Impact Prevention acknowledges and considers social, economic, and cultural factors, it does not specifically address the interrelationality of race, class, and gender with regard to larger structural issues such as poverty, healthcare inequity, gender inequality, and violence in any substantive way.

The AIDS Risk Reduction Model

As mentioned above, one example, of an HIV prevention model is the AIDS Risk Reduction Model (ARRM), which was first introduced in 1990. It has been widely used HIV prevention programs throughout the U.S. In the article "Towards an Understanding of Risk Behavior: An AIDS Risk Reduction Model," Joseph A. Catania, Susan M. Kegeles, and Thomas J. Coates explain that "ARRM rests on the premise that to avoid HIV infection, people exhibiting high risk activities must typically perceive that their sexual behaviors place them at risk for HIV infection" (54). According to Catania, Kegeles, and Coates, the ARRM paradigm integrates concepts from previous psycho-

social models of problem solving (54). They observe that ARRM incorporates behavioral change theories such as the "Health Belief Model, 'efficacy' theory, emotional influences, and interpersonal processes" (54). Further, the AARM model puts forth a three stage process. Stage one involves recognizing and labeling one's behavior as high risk and viewing it as a problem. Stage two involves making a commitment to reduce high-risk sexual contacts and increasing low risk activities. Stage three involves information seeking and obtaining remedies and enacting solutions to reduce risk (68). Moreover, Catania, Kegeles, and Coates identify other important factors related to AARM's effectiveness including knowledge of the risks associated with various sexual practices and ways of incorporating low risk activities in sexual relationships, perceptions of susceptibility to contracting HIV, the perceived costs and benefits associated with reducing high risk and increasing low risk sexual activities, self-efficacy beliefs, emotional states, and social factors including verbal communication skills, reference group norms, help seeking processes, and social support (68).

In an article by Family Health International (FHI360), a non-profit human development organization, entitled "Behavior Change: A Summary of Four Major Theories," the authors examine the primary components of ARRM and point out that addition to the three stages and influences, there are other internal and external factors that may motivate individual movement across stages such as high levels of distress, HIV/AIDS, or adverse emotional states that may encourage or hinder the labeling of one's behaviors (5-7). They also admit that ARRM is limited by its focus on the

individual as if not connected to their larger social environment. In addition, they also report the suggestions of the ARRM researchers to give more consideration to social and cultural issues impacting an individual's choices and behaviors (5-7).

High Impact Prevention Model

The High Impact Prevention Strategy is a multi-pronged effort, comprised of various interventions that have the most impactful effect on prevention on the prevention of new infections. High Impact Prevention is promoted by the CDC as the best combination of prevention that is able to meet the challenges of preventing HIV due to utilizing cost-effective and scalable science-based interventions that are more targeted towards larger geographical areas hardest hit by the HIV epidemic (CDC 2011). The High Impact Prevention strategy was endorsed by the CDC in 2011 and guided by goals the 2010 U.S. National HIV/AIDS strategy (CDC 2011). The National HIV/AIDS Strategy is the result of a broad-based collaboration between community and federal partners. The Office of National AIDS Policy held fourteen community discussions with thousands of people throughout the U.S. to inform the strategy (National HIV/AIDS Strategy 2010). The vision for the 2010 National HIV/AIDS Strategy states,

The United States will become a place where new HIV infections are rare and when they do occur, every person regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance will have unfettered access to high quality, life-extending care, free from stigma and discrimination. (2010 National HIV/AIDS Strategy)

The main goals of the National HIV/AIDS Strategy include reducing new infections, increasing access to care and improving outcomes for people living with HIV, and reducing HIV-related disparities (2010 NHAS).

According to the CDC, High Impact Prevention is feasible because it utilizes costeffective and measurable interventions informed by science (CDC 2011). While
interventions are targeted at all people at risk for HIV infection, they focus on
populations disproportionately impacted such as men who have sex with men (MSM)
who represent 2 percent of the U.S. population, yet account for 61 percent of all new HIV
acquisitions. High Impact Prevention targets communities of color who are
disproportionately impacted as well. For example, in 2009 African Americans comprised
14 percent of the U.S. population, but accounted for 44 percent of new HIV diagnoses.
Also, Latinos represented 16 percent of the population but accounted for 20 percent of all
new HIV acquisitions. Among women, the rate of infection among African American
women was 15 times higher than among white women. Further, transwomen are hard hit
as well. A 2008 review revealed that 28 percent of transwomen tested positive for HIV
(CDC 2011).

The Centers for Disease Control and Prevention (CDC) is the national public health organization with the primary responsibility for HIV Prevention in the United States. The CDC works with state and local health department as well as community based organizations to support and provide technical assistance in order to achieve the vision and goals of the National HIV/AIDS Strategy (CDC 2011). The High Impact

Prevention interventions promoted by the CDC emphasize the biomedical and behavioral aspects of HIV prevention but do not address structural issues. While the CDC acknowledges the importance social, economic, and demographic factors such as stigma, discrimination, income, education as factors that drive vulnerability, the High Impact Prevention Strategy does not adequately address them.

In the article, "The Future of HIV Prevention in the United States," Johnathan Mermin and Kevin A. Fenton write that the CDC's strategy of High Impact Prevention utilizes "combination prevention" (347). They use terms such as "cost per infection averted," "feasibility," "effectiveness," "prioritizing," and "evaluation" to describe their approach to High Impact Prevention and maintain that these are economically sound ways to decrease the acquisition and transmission of HIV. Both Mermin and Fenton have expertise in public health. Mermin is the current Director of National Center for HIV/AIDS and Viral Hepatitis, STD, and TB Prevention, and Fenton is the former Director. They explain that "policy makers and programs should decide about costeffectiveness thresholds and how feasibility of implementation should be defined. To be successful, interventions need to be at a scale sufficient to have an effect on the epidemic" (347-348). In essence, the High Impact Prevention approaches are more discerning in regards to where, when, and how interventions should be engaged, and take into greater consideration economics. Mermin and Fenton assert that this is the way forward to an "AIDS free America" (348).

Problems with HIV Prevention Models

Most HIV Prevention models are based on interventions that presuppose that women have the agency and power to exercise and negotiate behavioral changes. While the current HIV prevention discourse acknowledges social and economic drivers, there are few prevention models that directly address them in a comprehensive and way. In fact, even hugely successful prevention efforts such as the national award-winning "Rap-It-Up" media campaign launched in 1998 by Black Entertainment Television (BET) and the Kaiser Family Foundation are based on traditional prevention methods. The "Rap-It-Up" campaign mobilized various celebrities to urge youth to get tested and know their HIV status (Kaiser 2006). In addition, it had many positive outcomes such as establishing a toll free hotline, web site, and text message service. Further, the campaign tested over 11,000 people. Despite this success, by focusing simply on mass testing and condom distribution, the "Rap-It-Up" campaign overlooks the deeper problem of how social environment and economics impacts one's relative ability to practice safer sex behaviors. Consequently, if one does test HIV positive, the same social socio-economic issues may prove to be barriers in accessing and remaining treatment and care.

Furthermore, traditional HIV Prevention models utilizing campaigns like "Rap-It-Up" are based on interventions that presuppose that women have the agency and power to exercise and negotiate behavioral changes. In the article "Who is Epidemiologically Fathomable in the HIV/AIDS Epidemic? Gender, Sexuality, and Intersectionality in Public Health," S.L. Dworkin stresses this point. She observes that "surveillance

categories do not currently rely on the intersection of several identities or behaviors and therefore do not facilitate easy analysis of the contextual factors that shape risk" (618). While the current HIV prevention models and strategies do acknowledge social and economic drivers, there are few prevention models that directly address them in a comprehensive way.

CHAPTER III

THE REPRODUCTIVE JUSTICE FRAMEWORK AND MOVEMENT

HIV Prevention is a Reproductive Justice Issue

In Chapter Two, I discussed different HIV/AIDS prevention theories and models, including CDC's High Impact Prevention Strategy. I argued that while they may impart important ideas and tools for behavioral changes and that they have some efficacy, they may not be effective depending on the social environment. This last chapter of my thesis builds upon the first two chapters and applies an alternative framework, the sexual and reproductive justice framework, to the issue of HIV/AIDS prevention. In this chapter, I will analyze the reproductive justice movement and framework advanced by the reproductive justice organizations SisterSong Women of Color Reproductive Justice Collective and Asian Communities for Reproductive Justice, which are in the vanguard of the movement. I will describe connections between reproductive justice and HIV and explain that reproductive justice encompasses the issue of HIV. Finally, I will suggest that because this framework is responsive to Black women's needs, it should be adopted as a model for HIV/AIDS prevention.

The reproductive justice movement and framework were advanced by reproductive justice organizations such as African American Women Evolving,

SisterSong Women of Color Reproductive Justice Collective, and Asian Communities for Reproductive Justice. Loretta Ross, who was a co-founder and the national coordinator

for SisterSong from 2005-2012, states that SisterSong's three core values of reproductive justice include "the right to have a child, to not have a child, and the right to parent a child" (Ross 17). In addition to SisterSong's core values, The Asian Communities for Reproductive Justice, an Oakland-based advocacy group and founding member of SisterSong, define reproductive justice as:

the complete physical, mental, spiritual, political, economic, and social well-being of women and girls, and will be achieved when women and girls have the economic, social and political power and resources to make healthy decisions about our bodies, sexuality and reproduction for ourselves, our families and our communities in all areas of our lives. (Asian Communities for Reproductive Justice 1)

Both SisterSong and Asian Communities for Reproductive Justice promote a reproductive justice platform that provides a comprehensive framework and strategy that fosters power within women. This framework can be broken down into three areas that include reproductive health (service delivery), reproductive rights (legal and policy advocacy), and reproductive justice (structural change and challenges to power inequalities) (ACRJ 2).

Additionally, the reproductive justice movement utilizes intersectionality as a lens and tool for analysis and advocacy. Intersectionality is a Black feminist theoretical term that was first coined in 1989 by Kimberlé Crenshaw in her ground-breaking article "Demarginalizing the Intersection of Race and Sex." The theory of intersectionality

disputes the universalizing of gender as a primary category of analysis in relation to other experiences of difference such as race, class, sexuality, and nation. In addition, the concept of intersectionality highlights and addresses the multiple identity formations in relation to interlocking systems of oppression. To put it another way, intersectionality interrogates established approaches to systems of privilege and inequality that employ a single-axis analysis that denies the multidimensionality of women's experiences and forms of discrimination (May 156).

The intersectional analysis framework addresses the total woman as well as the community in which she is linked. As applied to HIV, the theory of intersectionality illuminates the multiple, layered identities of women of Black women living with HIV. It empowers them to analyze their multiple identities and lived experiences in relationship to structural power inequities as well as to better understand the contextual factors impacting their risk and vulnerabilities to acquiring HIV.

In addition, to the three pronged strategies of service delivery, legal and policy advocacy, and challenges to structural power inequities, the reproductive justice framework incorporates a human rights advocacy platform to support a broad range of protections for women on an international scale. The reproductive justice model can be utilized to bring individuals and organizations into collaboration and strategic partnerships with one another to build a network of allied social justice organizations and coalitions. In addition, organizations can mobilize around intersecting issues facing women such as HIV, while maintaining their primary field of work and activism. Models

such as those put forth by progressive groups like SisterSong are holistic and address the structural issues women of color face in an integrated and comprehensive manner. They promote complete mental, physical, political, economic, and social health, and their approach also provides a comprehensive, dynamic, and generative framework that articulates the interrelationality of issues embedded in the experiences of women of color. The human rights approach underscores the reproductive justice framework that is inclusive of all women and provides new horizons for what HIV discourse can and should reflect on both a national and global scale.

Finally, another important aspect of reproductive justice is self-help. The self-help component is a collaborative process of telling women's stories as healing modalities and using these narratives to address and heal the physical and psychic violence and trauma inflicted upon them. Self-help is a dynamic and generative practice that gives women voice and agency. It is necessary because of the high prevalence of violence inflicted on women at risk for HIV as well as women living with HIV.

In the editorial article "A Call to Incorporate a Reproductive Justice Agenda into Reproductive Health Clinical Practice and Policy," Melissa L. Gilliam, Amy Neustadt, and Rivka Gordon present an overview of a 2008 conference entitled "Beyond Choice, Examining Reproductive Justice, from Scholarship to Activism." This conference was hosted by the Section of Family Planning and Contraceptive Research and others at the University of Chicago which brought together scholars, activists, and clinicians to examine reproductive justice issues. During the conference, they affirmed that

"reproductive justice gives voice to poor women, women of color, incarcerated women, immigrant women, female youth, and women with disabilities and other women and girls on the margins who have been subject to reproductive coercion and discrimination" (243). Also, they acknowledged the roots of reproductive justice among women of color and gave examples of pioneers such as Shirley Chisholm and Frances Beal, who both worked within the mainstream feminist health movement to change perceptions of women's health as a social justice issue (243).

Moreover, conference participants asserted that reproductive justice expands beyond simply rights, to address socio-economic and personal influences that have clear implications and drive high rates of HIV and STDs among certain populations of women (244). This conference was important because clinicians and health workers came together as a professional group to advocate for marginalized women in the health healthcare. They articulated specific ways in which they could invest more through practices such promoting comprehensive sex education over abstinence only and as well as other reproductive health issues such as better access to care, family planning, and sexual violence, among others. Finally, they addressed the need to better advocate around polices that give marginalized women more voice and power (245).

Connections between Reproductive Oppression and HIV

There are important connections between reproductive oppression and HIV.

Reproductive oppression is defined as "the controlling and exploiting of women and girls through our bodies, sexuality and reproduction (both biological and social) by families,

communities, institutions and society" (ACRJ 3). The reproductive justice framework employs this definition in order to correctly identify problems and in order for women of color to mobilize and mount an appropriate response. Women who are at risk for acquiring HIV and women living with HIV face reproductive oppression. Women who are at risk experience this through the enforcement of abstinence only education, where they receive partial information rather than being empowered with the complete tools to protect themselves. Also, sexual and intimate partner violence is a form of reproductive oppression that places women at greater risk for HIV.

Moreover, women who are living with HIV experience more partner violence. Governmental initiatives such as the Interagency Federal Working Group on the Intersection of HIV/AIDS, Violence against Women and Girls, and Gender-Related Health Disparities attempt to address women focused issues. In September 2013, the White House released a set of policy recommendations to discuss and address the intersections of intimate partner violence among women at risk for and living with HIV. This initiative is a great example of traditionally disparate federal organizations working together collaboratively to address whole women's intersectional issues and promote awareness and action around these issues.

Women living with HIV experience reproductive oppression on many levels as well. In the 2013 Positive Women's Network publication entitled "Unspoken: Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States," Vanessa Johnson, Naina Khanna, Shari Margoles, and Christina Jada Peńa examine

polices, review relevant literature, and survey 179 women living with HIV in relation to their lived experiences and access to sexual and reproductive healthcare (12). Johnson and colleagues report that HIV/AIDS continues to spread among women of color at an alarming rate and that Black and Latina women account for 80 percent of HIV/AIDS diagnoses among women, although they represent only 25 percent of the female population in the U.S. (16). They stress that the majority of women living with HIV face many barriers to care and information around sexual and reproductive health services. They also reiterate assertions by the International Planned Parenthood Foundation and the Center for Health and Gender Equity that the United States has been slow in incorporating HIV/AIDS, sexual and reproductive health services, and gender equality models utilized internationally, which can inform strategies and interventions (16).

Moreover, as Johnson and colleagues point out, stigma and discrimination against persons living with AIDS huge are still problems. They note that until 2010, women's rights to bear children in Mississippi were violated because women with HIV/AIDS were required by law to sign a document stating they would not get pregnant in order to receive financial benefits from the state (20). Johnson and colleagues also stress that although many women living with HIV wish to start a family, many fear disclosing this to providers due to discrimination, bias, and stigma in health care settings (21). In addition, women living with HIV make up 1.7 percent of the female prison population, but many face discrimination in prison and are often segregated from the general population (22). In addition, sex positivity is not encouraged among women living with

HIV, thus stigmatizing these women who are sexually active. Further, there are more than thirty states that criminalize HIV. They point out that most laws are not based on scientific information, but rather community ethos. Other sexual and reproductive health challenges for women living with HIV include limited family planning options, a lack of provider sensitivity and expertise pertaining to HIV, and inadequate research. Moreover, their right to parent their children is challenged due to discrimination in court custody cases, adoption, foster care and surrogacy in which a woman's HIV status may determine outcomes in these situations. A woman's HIV-positive status is on trial rather than her ability to parent (23).

New Horizons for HIV Discourse

The reproductive justice model provides for a broad range of protections for women on an international scale. This model can be utilized to bring individuals and organizations into conversation and collaboration with one another to build a network of allied social justice organizations and coalitions around intersecting issues facing women such as HIV. I believe that models such as those put forth by progressive groups like SisterSong are holistic and address the structural issues women of color face in an integrated and comprehensive manner. They promote complete mental, physical, political, economic, and social health, and their approach also provides a comprehensive, dynamic, and generative framework that articulates the interrelationality of issues embedded in the experiences of women of color. The human rights approach underscores the reproductive justice framework and is inclusive of everyone. I believe this model

provides new horizons for what HIV discourse can and should reflect on both a national and global scale.

Conclusion

In this thesis I have attempted to expand HIV discourse on women and explore ways in which the reproductive justice framework can be applied to HIV prevention and advocacy. I believe that the reproductive movement and framework, which entail grassroots women of color organizations and their allies fighting for reproductive rights and social justice guided by a human rights principles, advance a radical means of addressing the needs of women of color impacted by HIV and AIDS. In other words, the reproductive justice framework represents more than simply a paradigm shift; it signifies a paradigm transformation – a comprehensive and generative model that extends beyond prevention tactics and speaks to the lived experiences of women of color. Further, it empowers and emboldens women to engage with HIV in a more interrelational and holistic manner by challenging social, political, and economic inequalities as well as public policies pertaining to women's reproductive healthcare.

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