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Reframing the Reality of African American Women at Risk for HIV/AIDS Using an Ecological Model Sara Adkins

University of Puget Sound

## Reframing the Reality of African American Women at Risk for HIV/AIDS Using an Ecological Model

Jacquelyn is a 32-year old HIV- positive African American female. She was diagnosed with HIV at 24 years of age, although it took her a few years to come to terms with the diagnosis and seek treatment. She and her brother were raised in the city by their mother and father, both of whom were employed. Jacquelyn was pushed hard by her parents growing up, as they wanted her to go to college and have a successful career and life. For the most part, Jacquelyn resented this pushing, and often just wished her parents would acknowledge her successes and tell her that they loved her. By high school, Jacquelyn had had several romantic and sexual relationships, although nothing that lasted more than a few months. Jacquelyn had received basic sex education in health class, and was simply told by her mother not to have sex. After high school, Jacquelyn attended a local university where she met Ryan, whom she dated throughout college and after they graduated. Jacquelyn quickly became financially dependent on Ryan, as she quit her job in order to keep up in school and spend more time with him. Jacquelyn was not Ryan's only sexual partner, although he led her to believe this by telling her how special she was and that he loved her. Jacquelyn often suspected that Ryan was being unfaithful to her. Ryan was also a drug user, although Jacquelyn was unaware of this fact. Jacquelyn and Ryan never used condoms during intercourse, as he told her that he was clean and she did not want to risk losing him as a partner by insisting they use protection. Ryan was diagnosed with HIV three years into their relationship, although he did not tell Jacquelyn until they ended up in the doctor's office and she insisted to be told what was going on. Shortly after this, Jacquelyn tested positively for HIV.

Despite a growing belief that AIDS is no longer a fatal disease, African American women are dying from AIDS-related illnesses at an alarming rate (U.S. Department of Health and Human Services [USDHHS], 2010a). Today, women account for more than one in four new HIV/AIDS cases in the United States, and two out of three of these newly infected women are African-American. In 2006, the rate of new HIV infection for black women was nearly 15 times as high as that of white women, and nearly four times that of Hispanic/Latina women (Centers for Disease Control and Prevention [CDC], 2010a). HIV disease is the third leading cause of death for black women age 35 to 44 and the fourth leading cause of death for black women age 25 to 34. African American women are clearly disproportionately affected by HIV disease, but few HIV prevention strategies exist that are specifically adapted to the realities of their lives and that address the multifaceted risk determinants for African American women. Although much of

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the research informing the understanding of HIV risk and transmission has focused on individual behavior of "high-risk" populations, African American women continue to be disproportionately affected by the HIV/AIDS epidemic not because of their individual risky behavior, but rather because of a volatile mixture of gender, race, and class inequalities that, when combined, greatly increase the risk for becoming infected with HIV. The purpose of this paper is to explore this volatile mixture in an attempt to create an effective prevention program model specifically tailored for African American women.

An ecological framework model adapted from the work of El-Bassel, Caldeira, Ruglass & Gilbert (2009) will be used to provide a comprehensive overview of the risk determinants that drive the HIV/AIDS epidemic among African American women. Rather than cultural representations intended to be generalized to all African American women, this framework serves to examine how the various facets of African American women's lives within each system of the framework interact to additively impact African American women's risk to HIV disease. The ecological perspective, as adapted by El-Bassel and colleagues (2009), can be applied to understanding the risk determinants for HIV for African American women on four levels of risk: (1) the ontogenetic system, which refers to personal factors such as substance and drug abuse and sexually transmitted diseases; (2) the microsystem, which refers to relationship contexts, such as relationship power and intimate partner violence; (3) the exosystem, which refers to external stressors that influence immediate environments and increase the likelihood of engaging in risky sexual behavior, such as poverty and medical mistrust; and (4) the macrosystem, which includes broader cultural belief systems about gender roles, social norms, and attitudes toward safer sex practices. This framework model will be applied and expanded to address the comprehensive,

interactional risk determinants which influence the HIV/AIDS epidemic among African American women.

#### **Ontogenetic System**

The ontogenetic system refers to personal factors that increase a person's risk for acquiring HIV disease. One such personal factor is the use of drugs or substances. Substance abuse has been recognized as a major risk factor for heterosexual transmission of HIV and other sexually transmitted infections among African American women (El-Bassel et al., 2009).

Because substance use results in impaired judgment and negotiation skills, it is highly related to increased risk of having unwanted sexual intercourse, having unprotected sexual intercourse, and having intercourse with multiple partners, all which increase risk for HIV disease. Injection drug use, both direct and indirect, has also been recognized as a major risk factor for HIV transmission among African American women. Injection drug use contributes to the HIV epidemic's spread far beyond the circle of those who actually inject, as people who have sex with an injection drug user are at risk for infection through the sexual transmission of HIV, and children born to mothers who contracted HIV through sharing needles or having sex with an intravenous drug user may also become infected (CDC, 2002).

Since the beginning of the AIDS epidemic, injection drug use has directly and indirectly accounted for more than one-third (36%) of AIDS cases in the United States. In 2000, intravenous drug- use associated AIDS accounted for 26% of all AIDS cases among African Americans. Since the epidemic began, 57% of all AIDS cases among women have been attributed to injection drug use or sex with partners who inject drugs, compared with 31% among men. Approximately 55% of black women infected with HIV/AIDS are classified as intravenous drug users, and approximately 59% of heterosexually transmitted cases among black women are

the result of being the sex partner of an intravenous drug user (Quinn, 1993). Additionally, drug dependency may lead women to exchange sex for money or drugs in risky, unprotected encounters (El-Bassel et al., 2009).

Crack cocaine has been particularly identified as contributing to the spread of the epidemic, as users often trade sex for drugs or money (Edlin et al., 1994). Studies have shown that crack smokers are at least three times more likely to be infected with HIV than non-smokers (CDC, 2002; Edlin et al., 1994). In research examining the use of crack cocaine and high-risk sexual practices, it has been found that 30.4% of HIV-positive women who use crack cocaine had exchanged sex for money, and that women who had recently had unprotected sex in exchange for money or drugs were as likely to be infected with HIV as men who had sex with men (Edlin et al., 1994). When high-risk sexual practices were accounted for, crack smoking was not significantly associated with HIV infection, indicating that the higher prevalence of HIV infection among crack smokers was due to the greater frequency of high-risk sexual practices. Sexually transmitted diseases were also widespread among the crack users in this study, with 80% of users reporting having had an STD, indicating that the spread of STDs among crack smokers may facilitate the spread of HIV. Because African Americans represent a disproportionate number of crack cocaine and injection drug users, their risk of contracting HIV is much higher due to direct and indirect intravenous drug use, sharing of unclean needles and increased risky sexual practices (CDC, 2002; Edlin et al., 1994).

African American women are further placed at personal risk for HIV/AIDS due to sexually transmitted diseases or infections. Sexually transmitted infections have been shown to facilitate the transmission of HIV due to compromised tissue membrane (Nusbaum, Wallace, Slatt & Kondrad, 2004). This is a major risk factor for HIV because most STIs do not present

major symptoms, causing under-diagnosis rates estimated at 50% or more. Significant STD disparities exist between racial groups, with the great disparities seen for gonorrhea and congenital syphilis (CDC, 2007). Of all cases of gonorrhea reported to the CDC in 2005, 68% occurred in African Americans. African American females aged 15-19 have gonorrhea rates higher than any other race, age or gender, with approximately 3% of African American adolescent females in 2005 being diagnosed with gonorrhea. In 2005, an estimated 41.6% of all chlamydial infection cases occurred among African Americans, affecting African Americans eight times more often than whites.

According to the CDC's report, the reasons for these disparities are multifaceted, but race and ethnicity do not account for differentials in health outcomes in general or STDs specifically. Poverty, income, and socioeconomic status are cited by the report to be the important codeterminants in STD infection, but these factors are so intertwined with issues of race that the relationships are often hard to discern. Because African Americans continue to experience higher rates of STDs than any other race/ethnicity in the United States, the African American community is more at-risk for HIV infection as the presence of certain STDs can significantly increase the chance of contracting HIV infection, and a person who has both HIV infection and certain STDs has a greater chance of infecting others with HIV (CDC, 2010a). Exploration of the microsystem may help to illuminate the relationship contexts which might put African American women at increased risk for contracting STDs and HIV.

#### Microsystem

The microsystem refers to relationship contexts and environments that place African American women at higher risk for HIV disease, including relationship power and intimate partner violence (El-Bassel et al., 2009). African American women are more likely to become

infected by a steady sexual partner and less likely to use condoms with this partner than with a casual sexual partner (El-Bassel et al., 2009). The burden of convincing a partner to practice safer sex is often placed on women, which has been extremely challenging for many African American women, who often lack power in sexual relationships (El-Bassel et al, 2009.; Quinn, 1993). This lack of sexual power is a major obstacle to the practice of sexual risk reduction behaviors, as reliance on use of condoms requires equal power distribution between sex partners (Quinn, 1993). In an effort to explore the degree to which power in sexual relationships influences women's safer sex negotiations, Pulerwitz and colleagues (2002) applied a measure of sexual relationship power and examined women's ability to negotiate safer sex practices. Women with high levels of relationship power were five times as likely as women with low levels to report consistent condom use, indicating that relationship power plays a critical role in safer sex decision making and HIV risk, as condoms are the major tool available for the prevention of HIV. Risk estimates in this study indicated that 52% of the lack of consistent condom use among women in the population could be attributed to low relationship power. While it was observed that women with high relationship power reported the most condom use, only 8% of the sample reported consistent condom use with their partner, with consistent use of about 13%.

Women's nonuse of condoms, then, must be placed within a framework of gender relations and power imbalance. The prevalence of non-condom use among African American women has been found to be approximately 45.3% (Wingood & DiClemente, 1998). Women who engage in unsafe sex practices have been found to maintain the belief that their ability to judge men is well-developed, their standards for partners are high, and that using a condom necessarily invokes the notion of reckless sexual behavior or lack of trust in a partner (Sobo,

1993; Quinn, 1993; Wingood & DiClemente, 1998). In open-ended interviews with African American females conducted by E.J. Sobo (1993) about the advantages of not using condoms, many female respondents claimed that condom-less sex is a "sign of trust" and "honesty" and "commitment" (p. 473). One woman said, with unsafe sex there is "nothing in between you both physically and emotionally. You are the closest to him that you can be" (p. 473). Using condoms has been shown in African American female populations to be perceived as a sign of infidelity. Further, women who do not use condoms have been shown to be three times more likely than women who do to be insulted if their partner suggests that condoms be used (Wingood & DiClemente, 1998). Negotiating safer sex when a partner does not have favorable attitude towards using condoms and when the suggestion of condom use introduces questions of infidelity becomes increasingly difficult with gender power imbalances in safer sex negotiations.

Because of gender power imbalances that impact women's ability to negotiate safer sex practices and male condom use, an alternative female condom has been recommended to protect against STDs and HIV (Choi, Roberts, Gomez & Grinstead, 1999). By conducting in-depth interviews with women from various racial/ethnic groups, Choi et al. defined four major types of facilitators and barriers to female condom use: mechanical, psychosexual, interpersonal, and situational. Women reported mechanical barriers that included difficulty with insertion of the female condom and discomfort. Women also reported that they did not have access to female condoms as easily and conveniently as male condoms, which severely decreased their use.

Among African American women, the most common objections to using the female condom were its large size, possible messiness and inconvenience, and the belief that insertion would be difficult and uncomfortable (Schilling, El-Bassel, Leeper & Freeman, 1991).

However, a recent study examining the acceptance of the female condom by African-American

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women found that nearly two- thirds of women indicated that their sexual partners would be very favorable or somewhat favorable to the female condom, and 73% were willing to discuss the use of the female condom with their sexual partners. Sixty-five percent of women also strongly agreed that it is easier for a woman to use a female condom than to convince her sexual partner to use a male condom. Results indicate that the female condom may hold promise as a tool in preventing the spread of HIV disease, but that in order for women to actually use this device, they must be educated in how to properly insert it, and it must be made more readily available. The very nature of safer sex practices disempowers women's ability to negotiate safer sex practices and puts them at higher risk for contracting HIV.

Safer sex practices and negotiation are also highly influenced by intimate partner violence. Intimate partner violence (IPV), defined as physical or sexual assault, or both, of a spouse or sexual intimate, has become a significant public health concern in the United States and around the world (Sareen, Pagura & Grant, 2009). Nearly 25% of women in the United States have been physically and/or sexually assaulted by a current or former sexual partner, and according to estimates, nearly 1.5 million women are assaulted by intimate partners annually (Bauer, Gibson, Hernandez, Kent, Klausner & Bolan, 2002). Recent research has found an association between IPV and sexually transmitted diseases, including HIV. Three possible explanations may clarify the association between IPV and HIV: HIV transmission may occur through forced sex with an infected partner; women exposed to IPV may have limited or compromised negotiation of safer sex practices; and/or women at risk of IPV may engage in sexual risk behaviors such as early age of intercourse, multiple partners, non-monogamous partners, and substance abuse (Sareen et al., 2009). The evidence shows exactly these patterns, as IPV among female STD patients is common and is associated with risk behaviors and partner

factors that increase females' risk of contracting STD and HIV. Specifically, IPV has been shown to be related to increased sexual coercion and decreased sexual and condom negotiation practices, putting women at increase risk for STD/HIV infection (Bauer et al., 2002). Further, IPV has been shown to be significantly associated with the use of alcohol and/or drugs and a non-monogamous sex partner, both of which are associated with high-risk sexual behaviors. Physical IPV and sexual coercion create environments of fear, male dominance, and control that deprive women of power and agency to negotiate risk reduction techniques, often forcing them to choose between protecting themselves from HIV or IPV (El-Bassel et al., 2009).

African American women are further placed at risk for HIV within relationship contexts by African American men who have sex with men and women, but do not identify as gay or disclose their bisexual activities to female partners, known as being on the "down low" (Millet, Malbranche, Mason & Spikes, 2005). In 2002, the leading cause of HIV transmission for both black men and women was sex with a man, which indicates that black men may be putting black women at risk of HIV. In an effort to examine the risk that bisexual men pose to women in minority communities, Millet et al. conducted a meta-analysis regarding black men who selfidentified as straight but engaged in sexual activities with other men without the knowledge of their female sexual partners. The results show that sexual identity and sexual behavior among black men are sometimes incongruent, and that black men who have sex with men (MSM) are less likely than other non-black MSM to disclose their bisexual behavior or identity. The results also indicated that black MSM who do not disclose their behavior or identity may engage in fewer sexual risks with male sex partners than black MSM who do disclose. Further, being on the "down-low" was not found to be specific to African American males, yet two crucial factors make bisexual behavior among men in African American communities more of a concern than in other communities. HIV is more prevalent in African American communities, which in and of itself places African Americans at increased risk. Taken with the research that shows that black MSM are more likely than MSM of other races to identify as bisexual and be bisexually active, black women with bisexual male partners are thus at increased risk for HIV compared to women from other racial groups with bisexual male partners. This is true even if women know that their sexual partners are being unfaithful, due to what is known as the "monogamy narrative".

In interviews with African American women regarding monogamy and cheating in relationships, Sobo (1993) identified what is now known as the "monogamy narrative". This narrative describes an idealized, monogamous, heterosexual union, which participants identified as bringing the most status and self-esteem. Research indicates that nearly 40% of unmarried African American men between the ages of eighteen and forty-five have multiple partners at once (Sobo, 1993). However, because admitting that one's partner has sex with others damages self-esteem and social status, women often deny infidelity by telling these monogamy narratives, claiming that their men and their relationships are ideal. This is problematic as women must engage in unsafe sex to maintain monogamy narratives, as safe sex would signal infidelity. In one of Sobo's interviews a woman said, "If my husband came to me and handed me some condoms, I think I'd shoot him because I'd know then that he's out there doing something that he ain't got no business doing" (p. 470). Because women have faith in the monogamous ideal and closely associate it with status, they engage in denial tactics to maintain the monogamy narrative, including lack of condom use, which contributes to HIV infection among African American women. This is true in the case illustration of Jacquelyn and her partner Ryan, who did not use safer sex practices during sexual intercourse. Even if Jacquelyn had suspected that Ryan was unfaithful to her, her fear that he would leave her if she suggested using protection outweighed

the fear that she would contract and STI or HIV. Because of this fear of losing him, Jacquelyn was able to convince herself that she knew how to choose a man, and that he would never be unfaithful to her.

#### **Exosystem**

The exosystem seeks to understand the external stressors that influence immediate environments and increase the likelihood of engaging in risky sexual behavior, such as poverty, lack of health insurance and resources, and medical mistrust (El-Bassel, 2009). Across racial and ethnic lines, women face a much greater risk of poverty than do men. This may be due to the fact that women are paid less than men working the same hours with the same qualifications, are segregated into low paying occupations, and spend more time providing unpaid care giving (Cawthorne, 2008). Women are also more likely to bear the costs of raising children, face the economic costs of pregnancy, and are more likely to experience domestic or sexual violence, which can lead to job loss, poor health and homelessness (Cawthorne, 2008; Gilbert & Wright, 2003). The poverty gap between women and men across racial lines widens significantly between the ages of 18 and 24, with 20.6 percent of women at or below the poverty line, compared to 14 percent of men (Cawthorne, 2008). Because of the intersections of race and gender, African American women are more likely to be living in poverty than men or women in any other racial or ethnic group.

Black women face particularly high rates of poverty, with one in four African American women living in poverty (USDHHS, 2010a). A recent analysis using the Panel Study of Income Dynamics, the longest running panel data set in the United States, estimated the likelihood of poverty across the lifespan for American adults, and found that by age 35, nearly one-third of the United States population will have faced a year in poverty (Rank & Hirschl, 1999). More

specifically, by age 75, 91% of black Americans will have experienced at least a year in poverty, and 68% will have encountered extreme poverty. Unemployment is a large contributor to African American poverty, with the unemployment rate for African Americans remaining twice as high as that of white Americans (Bureau of Labor Statistics, 2010). Further, African American women in the United States are more concentrated in impoverished, urban environments, characterized by deteriorating housing, extreme isolation and a decaying sense of community as a result of residential, institutional and individual discrimination rooted in racism and the legacies of slavery and segregation (Gilbert & Wright, 2003). Because African American women are at more risk for living in poverty due to racial and gender inequalities, they too are at increased risk for HIV disease.

A powerful link exists between poverty and HIV risk, and there is a widespread HIV epidemic in America's low income urban areas. A new analysis conducted by the Centers for Disease Control and Prevention (2010b) suggests that many low-income cities across the United States have generalized HIV epidemics, characterized by an overall HIV prevalence in the general population of more than 1 percent. According to the analysis, poverty is the single most important factor in predicting HIV infection among inner-city heterosexuals. Areas defined by the U.S. Census Bureau as high-poverty, in which at least 20 percent of the residents have household incomes below the poverty line, are particularly affected by HIV in a devastating way, with much higher prevalence of HIV in these areas. Additionally, individuals living below the poverty line within low income urban areas were found to be at greater risk for HIV than those individuals living above it (2.4 percent prevalence vs. 1.2 percent), though both groups had higher HIV prevalence rates than the nation average (0.45 percent). Although racial disparities characterize the overall U.S. epidemic, the analysis found no difference in HIV rates by

race/ethnicity in this low-income population. The Centers for Disease Control and Prevention suggest that the absence of race-based differences is likely due to existing high prevalence of HIV in poor urban areas, which places individuals living in these areas at greater risk for exposure to HIV, regardless of race or ethnicity. Because African American women are more concentrated in these impoverished, urban environments, they are more at risk for HIV disease due to the many factors associated with poverty and social inequality, including limited and inadequate health care access and information and substance abuse. Additionally, the stress of living impoverished and underprivileged areas may contribute to HIV risk for African American women.

African American women with lower socioeconomic status face more frequent and more severe stressors, including unemployment, homelessness, victimization and exposure to community violence (El-Bassel et al., 2009). It has been suggested that these chronic stressors have negative physical and psychological consequences that may lead to maladaptive coping strategies that place African American women at high risk for HIV/AIDS. Across racial and ethnic lines, women with lower socioeconomic status are more likely to experience high levels of stress and engage in riskier sexual practices with higher-risk partners (Ickovics, Beren, Grigorenko, Morrill, Druley & Rodin, 2002). Because women in low socioeconomic environments face the need to cope with chronic stressors, the risk of HIV/AIDS may be given less importance than more immediate and relevant concerns related to basic survival such as food and housing (El-Bassel et al., 2009). Moreover, poor African American women may use alcohol or illicit drugs as a coping mechanism, or engage in prostitution as a way to obtain food, shelter, or drugs, both of which increase their risk for HIV/AIDS.

African American women in poverty also have lower quality and limited access to education and healthcare, which limits preventive HIV resources available to them and increases the chance that they will engage in HIV-related risk behaviors (El-Bassel et al., 2009). Using data from the 1995 Survey of Family Growth, Cornelius and colleagues (2000) examined patterns of HIV-related risk behaviors including consistent condom use, number of sexual partners and sex education in birth control methods among African-American females. Approximately one- third of African American females in the study reported not receiving any formal sex education, while the other two- thirds reported receiving sex education about birth control methods, STDs, and abstinence. Only one-third of respondents reported consistent condom use with their partners, which varied by age, marital status, region, place of residence, education, lifetime number of sexual partners, and perceptions of anxiety. Along with consistent condom use, the number of sexual partners is also highly correlated with risk of HIV infection. Nearly one in four African American females between 14 and 44 had at least seven lifetime sexual partners. Further, African American females who had partners who had not used condoms in the last 12 months were less likely than those who reported occasional condom use to believe that they were infected with HIV. According to the data, a significant number of African American women are engaging in activities that put them at risk for HIV infection but these women do not perceive themselves to be at risk.

This lack of perceived susceptibility to HIV disease may be due to unmet sexual education needs of African American women. According to a knowledge, attitude, and behavior survey among a sample of African American women in a low income area, there is a great knowledge deficit of HIV transmission, protective behaviors, prevalence and nature of HIV (Quinn, 1993). On average, the level of AIDS knowledge was only about fifty percent correct.

In particular, an extremely low level of knowledge about protective behaviors was observed, although these women reported high-risk behaviors during the 12 months prior to the survey. Attitudes related to perceived susceptibility for HIV indicated that 51.6% of respondents were worried about getting AIDS. While it is clear many of these women were concerned about contracting HIV disease, they reported not having the knowledge to protect themselves. Less than 72% of respondents reported that they would use a condom while they are high, and only 65% agreed that they would use a condom after alcohol use. The use of drugs or alcohol clearly presents a threat to condom use, which could place African American women at risk for HIV infection. Because the women in this study are representative of women diagnosed with AIDS in terms of socioeconomic status, urban location, and education level, this data highlights an important knowledge deficit about prevalence, protective behaviors, and practice in skill building that could be addressed to reduce African American women's risk to HIV infection.

Alternatively, the lack of perceived risk may be related to the fact that African American women are aware of the relation between behavior and level of risk, but devalue the risk to their group. Studies have shown that African Americans have a tendency to underestimate personal risks or personal susceptibility to AIDS as compared with other groups (Gilbert & Wright, 2003). There is a puzzling paradox between self-reported high risk behavior and personal perception of risk for contracting AIDS. Gilbert and Wright elucidate that although some researchers explain this in terms of "AIDS denial", it might be related to a psychological need for socially stigmatized individuals to minimize further stigma, particularly because AIDS can be considered the most stigmatizing disease in United States. For example, Jacquelyn had received sexual education in high school and knew that HIV existed, but did not consider herself to be at risk, even though she and her partner did not use protection. Jacquelyn may not have been in denial

of the fact AIDS is a serious disease that could affect her, but perhaps instead was attempting to minimize the stigma that exists around her as an African American female. This is similar to the stigma related to condom use. The inner narrative seems to be "if I attempt to protect myself, I acknowledge that I am at risk". This is a terrifying thought for some people, particularly for those who are already socially stigmatized for their appearance or behavior, and do not wish to do anything that might further stigmatize them or their group.

It may also be true that medical mistrust mediates the relationship between sexual education, perceived risk, and use of effective prevention strategies. Many African American women may not seek prevention services because of their mistrust of service and medical providers. A recent study examining the role of trust in use of preventive services among lowincome African American women found that trust is highly associated with use of recommended preventative services in African American women (O'Malley, Sheppard, Schwartz & Mandelblatt, 2004). Additionally, research has shown that African Americans are more likely to report mistrust of doctors and other medical personnel, less overall satisfaction with healthcare, and are more likely to perceive racism in the medical care system than white patients (LaVeist, Nickerson & Bowie, 2000). Perception of racism and mistrust of the medical system was found to lead to less overall satisfaction with care. This pervasive sense of distrust of public health authorities among African Americans is a long-held attitude stemming from centuries of discrimination and mistreatment. One of the most widely known examples of mistreatment of African Americans within the healthcare setting is the Tuskegee Syphilis Study (Thomas & Quinn, 1991). The Tuskegee experiment was a clinical study conducted between 1932 and 1972 in which impoverished African American sharecroppers were purposefully infected with syphilis in order for the United States Public Health Service to study the natural progression of untreated

syphilis. The men were never informed that they had the disease, and were never treated for it, even after the discovery of an effective cure. In fact, extraordinary measures were taken to ensure that participants in the experimental group did not receive effective treatment. After the 1972 disclosure of the study in the national press, relatively little discussion of the experiment within public health literature has occurred.

The failure of public and health professionals to address the Tuskegee experiment and its implications contributes to the barriers between the black community and health care service providers. There is no question that the Tuskegee experiment greatly contributes to fears of genocide and mistrust of the medical system within the African American community. Thomas and Quinn (1991) explain that given the conduct of the study that showed no regard for the lives of the participating men, it is really no surprise that African Americans today do not readily dismiss assertions that HIV is an intentional, manmade virus allowed to run uncontrolled in their communities. In order to elucidate some assumptions or assertions regarding HIV in African American communities, the Southern Christian Leadership Conference conducted a survey to determine HIV education needs among black church members in cities (Thomas & Quinn, 1991). Approximately 35% of the respondents indicated that they believed that AIDS is a form of genocide, and another 30% stated that they were unsure. Forty-four percent believed that the government is not telling the truth about AIDS, while an additional 35% were not sure. Additionally, 34% believed that AIDS is a manmade virus, while 44% were unsure. The results of this survey indicate that medical mistrust in the African American community and belief that AIDS is a form is genocide is a legitimate cause for concern, and a serious barrier to accurate HIV information and protection methods. It is also probable that medical mistrust is rooted in the real-life experiences of African American patients, who have more avoidable hospitalizations compared with white patients, yet undergo fewer medical procedures when needed (LaVeist et al., 2000). This has important implications for African American women, as stronger patient-provider relationships with high levels of trust may indirectly lead to decreased risk of HIV through adherence to recommended preventative services.

#### Macrosystem

The macrosystem includes broader cultural belief systems about gender roles, social norms, and attitudes toward safer sex practices, which increase African American women's susceptibility to HIV disease (El-Bassel, 2009). Understanding the contemporary status of African American women based on social constructions of race, gender and class is essential to understanding the realities and contexts in which HIV is transmitted in this population. The social construction of gender enforces fundamental power imbalances by relegating women to inferior status and roles relative to men, limiting their sexual efficacy and control (El-Bassel et al., 2009; Wingood & DiClemente, 2000). El-Bassel and colleagues explain that three main overlapping processes may be occurring to reduce women's self-protective behaviors against HIV risks: silencing women to behave in passive ways, instilling fear through intimidation and the threat of violence, and internalization of a sense of self that is weak, unworthy, and without rights. Additionally, the sex ratio imbalance in the African American community may serve to exacerbate pre-existing gender inequalities and power imbalances that render African American women less powerful and less able to negotiate safer relationships. Each of this may contribute to a women's ability to protect herself from HIV.

African American women often lack self-efficacy in negotiating safer sex and making decisions regarding sexual activities (Gilbert & Wright, 2003). This may be due to the fact that they are socialized to be sexually passive, taught to defer to men in sexual decision making.

Research regarding African American mother-daughter discourse about sex shows that mothers often express reluctance to educate their children in an open manner, fearing discomfort or that they will unintentionally encourage their daughter's sexual activities (O'Sullivan, Meyer-Bahlburg & Watkins, 2001). Many reported being torn between the desire to maintain their daughter's childhood innocence and the need to counteract social influences which encourage girls' sexual activity at very young ages. Girls were also reluctant to enter into these conversations, thinking that their mothers were just trying to learn more about their sex-related experiences and control their sexual outcomes. Often, girls reported dismissing their mother's communication as weak attempts to scare them into abstinence. Unfortunately, results of this study indicated that mothers rarely acknowledged positive aspects of sexuality outside the context of harm. This seemed to ultimately deter their daughters from confiding in them or seeking sexual education from them. Additionally, mothers did not address psychosexual issues such as commitment, love, jealousy and desire, which girls in the study reported being most interested in discussing. Because young African American girls are not given an understanding of or allowed to explore their own sexuality, it is often understood only in terms of reactivity, victimization, and restraint. Thus, girls may implicitly be learning from a young age they should not acknowledge their own sexual desire or interest, and that male feelings or actions are more legitimate, reducing a female's sense of confidence and agency. This, in turn, leads to increased rates of intimate partner violence and sexual coercion, which increase an African American woman's risk for HIV/AIDS.

Jacquelyn puts up with a lot from her partner, Ryan, including believing that he's cheating on her but not insisting that they use protection. Ryan is also absent a lot, but never tells Jacquelyn where he is or what he's doing. The less than desirable relationship dynamics

and the activities that Ryan is engaging in, including having unprotected sex with multiple partners and using intravenous drugs puts Jacquelyn at increased risk for HIV disease. Research has attempted to identify why many African American women tolerate less than desirable relationship dynamics. A complex part of this tolerance and increased HIV-infection rates among African American women is the sex ratio imbalance, the fact there exists more African American women than men. Gilbert and Wright (2003) explain that with high rates of incarceration, unemployment and drug abuse among African American men, combined with the male homosexual population, and the fact that there are simply more African American women than men, the pool of long-term African American male partners is continually shrinking. This diminished pool creates heightened risk for African American women in three ways: men's multiple relationships, women's tolerance of less than desirable relationship dynamics, and women's perceived need for multiple male relationships for financial stability.

According to Gilbert and Wright (2003), social exchange theory predicts that when one gender is in short supply, this results in relatively less power for the larger gender group, in this case, African American women. This imbalance of power leads to men demonstrating less commitment to relationships and having relatively greater numbers of female partners, leading to a greater number of African American females at risk. Thus, even if African American females have few lifetime sexual partners, they may be especially at risk for HIV due to the high prevalence of infection among sex partners, largely African American men. Women may also be more tolerant of their male partner's multiple sexual partners and relationships if men are in short supply.

The sex ratio imbalance has been used to explain the risk of HIV/AIDS among African

American women at historically black colleges and universities, where the ratio of more women

to men has been defined as the key element of the campus dating environment (Ferguson, Quinn & Sandelowski, 2006). Students interviewed at historically black colleges and universities associate the gender ratio imbalance on campus directly with men having multiple sex partners and indirectly with females complying with men's condom use preferences. Having a gender ratio on campus where women outnumbered men caused women to have to decide whether to participate in the campus dating scene where "man-sharing" was a common-place, normative behavior. In addition to facilitating a limited dating environment, the sex ratio imbalance also limited women's ability to communicate with their partners about condom use. Interviews with students revealed that inconsistent or no condom use was normative among students on their campus, and that this was related to women's views that men had negative attitudes toward condom use, and would reject women who suggested it. This perception, along with the desire to secure an available man on campus, further contributed to women not communicating safer sex practices to their partner.

The patterns of "man-sharing" and decreased condom use negotiation that were demonstrated in historically black colleges where the sex ratio imbalance characterizes dating and partner selection, may bring to light the ways that this imbalance functions to place African American women at increased risk for HIV in the general population. If women perceive little chance of finding a new partner if they displease their current partner, they may choose to accept current social situations in order to not disrupt them. This may be related to over-looking male partner's infidelity, or not using condoms so as not to imply infidelity. African American women are more likely to tolerate undesirable relationships particularly if they perceive a need to have a man in their life based on societal standards and financial necessity. This is also particularly true for women who view themselves as weak and unworthy (Amaro & Raj, 2000).

This internalized oppression may fuel a woman's drive to stay with a man who has professed love or affection for her, even if his actions do not demonstrate this. Consider, for example, the case of Jacquelyn, who was not told as a child that she beautiful or valued, and because of this she grew up seeking the love and attention of a male figure. When she finally found this attention and what she believed to be love, she did everything in her power to stay with him, as she didn't have an internal understanding of herself as worthy and deserving of true love and commitment.

The stigma surrounding HIV disease is also highly related to the spread of the AIDS epidemic. The CDC estimates that one million people are living with HIV in the United States and that one in five (21%) are unaware of their infection status (CDC, 2010a). Research has shown that individuals are more likely to seek out and follow through with HIV testing that they perceive to be nonthreatening, nonjudgmental, and responsive their individual needs and circumstances (Valdiserri, 2001). Because we know that African American women often expect discounting, discrediting or judgmental attitudes from health care providers and professionals due to personal previous experiences or experiences of others, they are then less likely to seek testing in a timely manner. This puts more people at risk, for those who do not know they are infected with HIV are less likely to take steps to prevent spreading the virus.

#### **Conclusions**

By using an ecological framework to examine the risk determinants that drive the HIV/AIDS epidemic among African American women, we can see how the systems within the ecological model complexly interact and affect one another. For example, substance use and abuse may be part of the ontogenetic system of personal factors that increase risk for HIV disease, but substance abuse is highly related to and influenced by chronic stress due to poverty,

which is part of the exosystem of external stressors. Similarly, condom use negotiation and relationship power are part of the microsystem of relationship contexts, but these relationship contexts are heavily influenced by macrosystem cultural beliefs about gender roles and social norms. What this framework truly highlights is that prevention models and programs must be developed which recognize all levels of the ecological framework, as prevention models based on individual risk behaviors alone overlook or obscure the interactions between systems, which this paper has demonstrated to be fundamental to the spread of the epidemic in African American women's communities. Additionally, these prevention programs place blame on the victims of HIV, labeling them as drug users, prostitutes or at fault for living in "AIDS denial", which ignores the pervasive forms of oppression and discrimination that fuel the spread of the disease.

#### **Application Section**

Although contemporary HIV/AIDS prevention programs are taking innovative and important steps in reducing HIV infection rates among African American women, more effective prevention plans can be developed by recognizing an ecological model of HIV risk for African American women. This model highlights the ways in which prevention programs can be explicitly tailored to the unique realities of African American women and girls' HIV risk by examining an interactional systemic model of HIV risk across ontogenetic, microsystem, exosystem and macrosystem levels, specifically recognizing the ways in which the macrosystem level of cultural beliefs about gender roles and social norms is highly influential of the other systems. Because the pervasive forms of racial and gender discrimination and socialization within the macrosytem often result in African American women and girls feeling negatively about themselves, unable to advocate for their own safety and protection, and more likely to engage in high-risk behaviors, age-appropriate HIV prevention programs should be developed

which specifically target improving young African American girls' feelings of self-worth and self-efficacy. This, in turn, will provide them with the tools they need to be advocates for their own safety, improving their ability to negotiate condom use and safer sex practices and decreasing their willingness to stay in undesirable relationships.

#### **Brief Overview of Contemporary Prevention Programs**

On July 13, 2010, the White House released the National HIV/AIDS Strategy (NHAS), the nation's first-ever comprehensive coordinated HIV/AIDS plan with clear and measurable goals to be achieved by 2015 (USDHHS, 2010b). The vision for the NHAS claims, "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 socioeconomic circumstance, will have unfettered access to high quality life-extending care, free from stigma and discrimination." To achieve this goal, the Federal government intends to reduce new HIV infections by intensifying prevention efforts in the communities where HIV is most heavily concentrated, expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches and educate all Americans about the threat of HIV and how to prevent it. For African Americans, the strategy specifies that, by the end of 2010, the CDC will release an evaluation of prevention successes and challenges, so that by the end of 2011 a list of resources and effective programs for reducing HIV infections among black Americans can be identified and implemented. The NHAS identifies several evidence-based prevention strategies that they suggest need to be expanded and better implemented such as condom availability, access to sterile needles or syringes and access to HIV testing. While these prevention strategies are necessary and important, they must be understood within the broader framework of the ecological model and the interactions between the systems, as simply employing these

techniques on the ontogenetic level will fail to produce a dramatic decrease in HIV infection rates among African American women. Let's take, for example, increasing condom availability among African American women. While it would seem that increasing condom availability would decrease the number of HIV infections, as consistent male condom use is estimated to reduce the risk of HIV transmission by 80 percent, this paper and the ecological model have demonstrated that simply having access to condoms does not ensure their use, due to lack of ability to negotiate condom use because of power imbalances, sexual coercion, or fear of alienating a sexual partner. In order for the NHAS to be most effective for reducing HIV rates among African American women, the ecological framework must be applied to better understand how to most effectively tailor these prevention programs.

Another HIV prevention program that is widely utilized is SISTA (Sisters Informing Sisters about Topics on AIDS), which is a peer-led skill- building intervention project to prevent HIV infection in African American women (CDC, 2010c). The goal of SISTA is to reduce sexual risk behavior by heterosexually-active African American women, by giving women social and behavioral skills to adopt HIV risk-reduction strategies. Small-group sessions are delivered by peer facilitators in a community setting where many discussions and lessons occur, including the challenges and joys of being an African American woman, sexual assertion skills, safer-sex decision making skills, and proper condom-use skills. The SISTA program includes poetry by African American women, discussions, and role-playing scenarios, which are used to enhance participant's experience, as well as facilitate dialogue. This program has been shown to be highly effective for improving safer sex and prevention strategies used by African American women, and should be adapted to reach younger audiences of African American females.

#### **Rationale for Prevention Program**

M. Corpening (personal communication, November 4, 2010), the African American Women's Engagement Case Manager at the Pierce County AIDS Foundation (PCAF) works with women who she says have had a "hard life", and are often difficult to connect with because they have been moved around in the social services system so frequently, often without the care they deserve. Corpening facilitates an African American women's support group at PCAF, where women are invited to share their own stories if they feel comfortable, and make connections with other African American women who are HIV positive. When asked why she believes that African American women are so disproportionately represented among HIV/AIDS cases, Corpening responded that she believes that it is fundamentally about a lack of identity and self-worth. "[African American girls] don't see themselves as beautiful, and have been told they're not beautiful," she explains, "When a man comes into their life and says "I love you" they fall for it and don't ask questions. They want to be loved. And they think they're supposed to settle". Corpening further explains that often African American females don't look within themselves for love because they don't know how to find it there, so they look for love in "all the wrong places". Because, as Corpening explains, you can't negotiate essential life skills or practices without a basic foundation of self-esteem or self-worth, facilitating self-esteem in young African American girls is fundamental in addressing the problem of HIV/AIDS among African American women. With this basic foundation and comprehensive sex education, girls can then better understand how to negotiate safer sex practices, learn how to advocate for better relationship dynamics, and understand the true impact that HIV/AIDS could have on their life.

To more effectively address the unique needs of African American women in HIV/AIDS prevention, I propose that a series of workshops be implemented at elementary, middle and high schools across the country, specifically concentrated in communities where HIV is more

prevalent. These workshops will be modeled after the Challenge Day Program, a well-developed course currently used in schools across the country to provide youth and their communities with experiential workshops and programs to facilitate connection through celebration of diversity and expression (Challenge Day Program, 2009). In the proposed prevention program, called Positive Changes, this model will be adapted for the explicit purpose of promoting HIV awareness and prevention skills for young African American females, and to reduce the fear and stigma that exists around HIV disease. The curriculum and goals for each of these workshops will vary upon age-group, and the skills that young girls will learn in these workshops will build upon each other as the girls progress through school and through the series. Facilitators of the program will be HIV educators, teachers, and African American women who are HIV positive. The curriculum for elementary school girls will focus on promoting self-esteem and selfefficacy, as this is the basis for effective HIV prevention skills. The curriculum for middle school girls will build upon this, continuing to foster self-esteem and self-efficacy while also focusing on the body, safer sex, and STDs/STIs. The high school curriculum will focus on selfesteem, but discuss in more depth safer sex practices, sexual assertiveness and HIV/AIDS comprehensive education. All curriculums will be facilitated in a manner similar to the SISTA program, using various forms of communication and dialogue including poetry, art, journaling, and role-playing. A handbook for the proposed prevention program designed specifically for high schools is attached in the appendix of this paper.

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