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## **Theory-Based Policy Development for HIV Prevention in Racial/Ethnic Minority Midlife and Older Women**

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*In 2008, there were more than a million persons with HIV/AIDS in the United States. The CDC (2007) estimates that 15% of persons with HIV/AIDS are over age 50. At greater risk are women of color. Most intervention efforts have focused on intrapersonal aspects of an individual and his or her sexual-risk behaviors, with little or no attention directed toward interpersonal and socioenvironmental considerations of risk and prevention. This paper considers the limitations of current national policies relating to HIV prevention in minority populations, especially among midlife and older women of color. In particular, this paper examines risk and prevention policies in light of ecological perspectives, social capital, and dialogical theories.*

**KEYWORDS** *HIV/AIDS, prevention, midlife women, older women, minority women, African American, Hispanic*

The latest surveillance from the CDC indicated that persons aged 50 and over accounted for 15% of new HIV/AIDS diagnoses<sup>1</sup>, 24% of persons living with HIV/AIDS (increased from 17% in 2001), 19% of all AIDS diagnoses, and 29% of persons living with AIDS<sup>2</sup> (Centers for Disease Control and Prevention, 2007). However, it is difficult to determine rates of HIV infection among older adults, as very few persons over the age of 50 at risk for HIV

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routinely get tested. In 2005, the rates of HIV and AIDS among persons 50 and older were 12 times as high among Blacks (51.7/100,000) and five times as high among Hispanics (21.4/100,000) compared with Whites (4.2/100,000) (Linley, Hall, & An, 2007). Numbers of cases are expected to increase, as people of all ages survive longer due to highly active antiretroviral therapy (HAART) and other treatment advances. HIV-related illnesses present unique threats to older adults whose immune systems are already weakened by age. Women over the age of 50 from racial/ethnic communities are disproportionately affected by HIV/AIDS. In the United States, 70% of women age 50 or older living with HIV/AIDS are African American or Hispanic/Latina (CDC, 2007).

Racial/ethnic minority midlife and older women at highest risk already face a multitude of other problems, including racism, ageism, poverty, substance abuse, alcoholism, violence, and unemployment (Montoya & Whitsett, 2003; New York State AIDS Advisory Council, 2005). Among females diagnosed with HIV/AIDS in 2005, 80% of the HIV/AIDS cases were attributed to high-risk heterosexual contact (CDC, 2007). Older minority women who are financially dependent on male partners are at a disadvantage in negotiating condom use, and those who are sex partners of HIV-infected men, bisexual men, and injection drug users (IDUs) are difficult to identify and target (Satcher, Durant, Hu, & Dean, 2007).

Due to the lack of awareness of HIV in the older population, this age group has been omitted from educational prevention programs, intervention efforts, research, and clinical trials. Older adults in general are not routinely tested for HIV (Linsk, 2000; Savasta, 2004). While some women over 50 who are living with HIV were previously living with HIV and have aged into this population group, the majority of HIV and AIDS infections among older women are new infections (CDC, 2007). Despite the myth that older people do not have sex, many midlife and older women are sexually active (Lindau, Leitsch, Lundberg, & Jerome, 2006; Winningham et al., 2004) and some are injecting-drug users (Kwiatkowski & Booth, 2003).

An ecological perspective (Bronfenbrenner, 1977) is discussed as a framework for developing HIV prevention policy initiatives that directly influence midlife and older women from racial/ethnic minority communities. The ecological perspective highlights the interrelatedness of various contexts of the lives of older minority women and their risk for HIV/AIDS. The use of social capital (Putnam, 2000) and dialogical (Freire, 1971) theories may enhance the ecological perspective by creating a more integrated and comprehensive framework.

## BACKGROUND

There are several stigmas related to HIV that older women, especially minority women, encounter. These stigmas may influence women's reluctance to discuss HIV, disclose their status, and consequently inform others that they are living with HIV/AIDS (Fox-Hill, Gibson, & Engle, 2002).

Moreover, older women face ageism in general. They may be misdiagnosed by medical professionals and have limited access to HIV tests, information, and age-appropriate messages. Between limited HIV prevention programs for people over age 50, ageism, and the stigma surrounding the virus, older women are increasingly susceptible to HIV (Brown & Sankar, 1998; Levy, Ory, & Crystal, 2003; Sanders-Phillips, 2002; Winningham et al., 2004). It is important to note that women of all ages, minority or of the dominant culture, may be reluctant to discuss HIV and risky sexual behaviors due to societal stigma associated with the disease. However, this paper focuses solely on women aged 50 and older who are members of at-risk ethnic/racial minority groups.

The demographic profile of the AIDS epidemic has steadily changed over time, and HIV prevention messages must keep pace with these evolving trends. A variety of cultural, economic, biological, and political variables shape women's experiences. Therefore, a comprehensive understanding of these complicated factors is necessary to curtail HIV infections among older women, especially among African American and Hispanic/Latino women. Acknowledging complex social issues in comprehensive HIV prevention programs requires careful attention to stereotypes about HIV, aging, and these populations.

### Older Women's Risk for HIV-Infection

Some providers assume that older women are not sexually active or, if they are, they have the knowledge on how to avoid HIV infection. Two-thirds of women living with HIV were infected through heterosexual activity (CDC, 2007). Many postmenopausal women are less concerned with using barrier protections (condoms) because they are unlikely to get pregnant. Older women's thinning vaginal walls also increase their susceptibility to HIV and other sexually transmitted diseases (STDs). This is compounded by the surge in erectile dysfunction medications (e.g., Sildenafil) among older men, increasing the likelihood of sexual activity and possible HIV transmission.

HIV risk is not unidimensional but generates from multiple risk levels apart from biologic vulnerability. Risk factors contributing to unsafe sex practices among women can be found on three levels: (a) individual (e.g., self esteem), (b) interpersonal (e.g., partner communication, condom negotiation), and (c) socioenvironmental (e.g., stigma, ageism, poverty, sociocultural norms).

### Older Women's Perception of HIV-Risk

Many women 50 years of age or older do not have sufficient knowledge regarding HIV transmission and therefore are unaware of their risk for infection (Savasta, 2004). Research suggests that older women's limited knowledge of

HIV transmission comes from written literature, television, and friends (Henderson et al., 2004; Jacobs & Thomlison, 2009). In a recent study of 564 women aged 50 or older, few older women, even those with higher levels of risk (e.g., sex with a current or former IV drug user), were interested in HIV testing due to perceived lack of need or risk (Akers, Bernstein, Henderson, Doyle, & Corbie-Smith, 2007). Moreover, women in the study who lacked interest in testing tended to be African American, which may be due to sociocultural factors (Akers et al., 2007). Further research is needed to investigate whether interest in HIV testing varies among older women from different racial/ethnic backgrounds.

Studies investigating knowledge and perceptions about HIV transmission among older African Americans, especially older African American women, have highlighted the disparity of infection rates among the races (Stamperly, Mallory, & Gabrielson, 2005). Research suggests that older African Americans possess some knowledge about HIV as well as misinformation (Jackson, Early, Myers-Schim, & Penprase, 2005). Jackson et al. (2005) reported that older African Americans believed that HIV could be acquired through activities such as kissing and other forms of casual contact. While acknowledging the seriousness of HIV, respondents in this study (Jackson et al., 2005) believed that they were not personally susceptible to acquiring the virus. As noted previously, the literature suggests that risk factors for African American women are related to socioeconomic, knowledge, risk-taking behaviors, and perceived vulnerability (Stamperly et al., 2005).

In addition to impacting older African American women, HIV transmission is affecting Latinas (Russell, Alexander, & Corbo, 2000). Variables associated with transmission rates of HIV among Latinas have focused on cultural perceptions about gender, especially *machismo* (for males) and *marianismo* (for women). Russell et al. (2000) reported that traditional Latin culture vests authority to males. Women adhering to traditional Latin values are expected to be subservient to males. Russell et al. (2000) pointed out that sexual activity with multiple sexual partners for males is culturally acceptable. While Latinas may be aware that male partners are engaging in these activities, they may remain submissive and sexually available to male partners who engage in high-risk behaviors.

The older adult population in general has been overlooked in terms of HIV prevention education (Whipple & Scura, 1996), as efforts have been target to younger populations with youth-focused messages (Linsk, 2000). This lack of HIV risk-awareness/perception and risk-related behaviors is due, in part, to health care providers who may not address the issues of sex and HIV-risk with older women (Savasta, 2004). Providers are also less likely to discuss issues of HIV testing with these older patients compared to their younger patients (Savasta, 2004). Older minority women may be reluctant to discuss HIV/AIDS, risky sexual behaviors, or disclose their status if

they are living with HIV/AIDS because of the stigma attached to the disease (Montoya & Whitsett, 2003).

### HIV Prevention in Midlife and Older Women

Older women have yet to be considered in terms of gender-, age- and culture-specific HIV prevention (Mack & Ory, 2003). Many health professionals assume that older women are immune to HIV. The lack of HIV testing among older women often results in a later diagnosis, at a point when the illness may have significantly progressed and treatment may be less helpful. Policies regarding a narrow focus on “risk groups” have impeded HIV prevention efforts to the detriment of this population. Because unsafe sex behaviors and risk for HIV infection have been linked to a variety of factors, policies should strategically address the most salient factors that impact risk behavior and safer sex practices among older women. Prevention messages are lacking for older minority women, who might not respond to traditional prevention messages that do not consider social, cultural, generational, and economic factors (Winningham et al., 2004). Moreover, women of the same race or ethnicity may respond to prevention messages differently based on their country of origin, socioeconomic status, age, sexual orientation, and contextual factors (Fernández et al., 2004; Shedlin et al., 2006).

### Gaps in HIV Research and Policy Development

There has been increasing recognition that HIV sexual risk behavior involves complex and multidimensional processes (Neundorfer, Harris, Britton, & Lynch, 2005; Wenzel & Tucker, 2005). Individual, interpersonal, and socioenvironmental factors convene to increase an older woman’s vulnerability to HIV infection. However, current models that emphasize individual behavior change provide a somewhat limited insight into how HIV sexual risk is experienced, understood, and managed by those individuals who are most vulnerable to HIV infection. These models fail to consider some of the interpersonal/relational issues and contextual factors (e.g., ageism, racism, and stigma) that affect risk and risk reduction among older women.

Much of what we know about risk behaviors stems from individuals between the ages of 18 and 44. We cannot assume that policies regarding HIV prevention that affect younger women can be applied or translated to older women. It is imperative that policy makers understand how individual, interpersonal, and socioenvironmental concepts of sexuality, gender, culture, and aging shape and define the problems and their solutions.

## CONCEPTUAL FRAMEWORK

Current HIV prevention efforts have relied heavily on psychological foundations to explain risk behavior and identify the best methods to bring about permanent change. Interventions designed to reflect these theoretical frameworks tend to emphasize the individual and the influence of immediate peer groups and social networks when seeking to identify and change social norms (Catania, Kegeles, & Coates, 1990; Fisher & Fisher, 2000; Rosenstock, Strecher, & Becker, 1994). Although these theories of behavior change have effectively been incorporated into HIV prevention programs, older minority women have special needs and concerns regarding HIV and AIDS prevention and education. Policies and programs that effectively address these missing pieces are more likely to affect a greater number of women from racial/ethnic minority communities.

Highlighting the strengths and challenges that exist where gender, age, and race/ethnicity intersect may be instrumental in the design of HIV interventions. A new model of HIV prevention that enables older women to influence public health policy could be a major factor in reducing the number of new infections. HIV prevention strategies for older minority women must not minimize the diversity among women in terms of race, ethnicity, social class, and sexual orientation. Comprehensive policies and subsequent programs should focus on societal attitudes toward gender norms; historical and current experiences with racism and discrimination; physical, emotional, and social characteristics of the immediate neighborhood; access to and use of preexisting services; and societal and structural inequalities that perpetuate poor health outcomes.

### The Ecological Perspective

Historically, the HIV/AIDS epidemic has been viewed as an individual-level phenomenon whereby interventions have solely focused on understanding intrapsychic influences that affect sexual decision making. The ecological perspective (Bronfenbrenner, 1977) suggests the notion of reciprocity, or the interrelatedness of various contexts of an individual. An ecological approach to HIV prevention involves addressing intrapsychic and interpersonal issues along with socioenvironmental influences (DiClemente, Salazar, Crosby, & Rosenthal, 2005; Poundstone, Strathdee, & Celentano, 2004). Using an ecological perspective can help identify not only risks, but strengths, resilience, and assets of older minority women as individuals and as a community.

Utilizing an ecological perspective might expand the knowledge base and facilitate the development of a broader spectrum of HIV-prevention strategies for older women, such as community-level interventions, policy initiatives, institutionally based programs, and macrolevel societal changes.

This approach may produce reciprocal and reinforcing effects designed to facilitate the adoption and maintenance of safer sex behaviors among older women, resulting in a reduction of HIV infections. However, other factors may be overlooked, such as the importance of social networks (a form of social capital), an individual's or group's sense of empowerment (a component of Freire's dialogical theory), or cultural/ethnic influences. The use of social capital and dialogical theory may enhance the ecological framework by creating a synergistic effect by integrating several theories.

## Social Capital

Social capital has gained notoriety as a viable theoretical perspective for understanding and predicting individual experiences vis-à-vis social interactions embedded in the social environment (Narayan & Cassidy, 2001). Although not new, the term has been popularized in the 1990s through the work of Robert Putnam (2000). Social capital has been defined as aspects of social structures that facilitate collective action, emphasizing that social capital is productive and that without it, the achievement of certain goals would not be possible (Poundstone et al., 2004).

Very few studies have examined social capital in the context of HIV/AIDS. Holtgrave and Crosby (2003) examined poverty, income inequality, and social capital as predictors of U.S. state-level AIDS rates and found social capital to be the strongest predictor of AIDS rates. In South Africa, Campbell, Williams, and Gilgen (2002) examined civic participation (one aspect of social capital) as a proxy for understanding community influences on HIV infection. Findings revealed that participation in certain organizations (e.g., churches, youth groups) was protective, while membership in other social groups (e.g., groups with high levels of alcohol consumption) increased risk for HIV.

Social networks can involve dyads, groups, organizations, and communities. They can influence health outcomes in direct and indirect ways, including (a) social influence, (b) social engagement and participation, (c) prevalence of infectious disease and network member mixing, (d) access to material goods and informational sources, and (e) social support (Poundstone et al., 2004). Some researchers have demonstrated that patterns in the structure of relationships—rather than differences in individual risk behaviors alone—explain observed HIV patterns (Friedman et al., 2000; Smith, Grierson, Wain, Pitts, & Pattison, 2004).

## Dialogical Theory

Paolo Freire's ideas of democratic or empowering education have been a catalyst for worldwide programs in literacy, health education, youth services, and community development. According to Freire, the purpose of



education should be human liberation so that learners can be subjects and actors in their own lives and in their community.

To promote this objective, Freire noted the value of a dialogue approach in which everyone participates as equals and colearners to create social knowledge. The main points of Freire's principles are: start from the problems of the community; use active learning methods, that is, an open dialogue, *la plática*, among community members; engage all participants to define their own needs and priorities. The Freirean philosophy supports change for individuals and communities as they see the need for it and as they define the problem and the solution.

Of particular concern is the role of HIV prevention efforts and whether they are working or not and why. HIV communicators have been successful in broadening awareness of HIV; increasing knowledge of how HIV is contracted; placing HIV in the context of human rights; increasing demand for effective services; and mobilizing political support for national prevention plans. However, many prevention strategies have often treated people as objects of change rather than the agents of their own change, focusing on a few individual behaviors rather than also addressing social norms, policies, culture, and supportive environments. Moreover, information tends to come from "experts" rather than sensitively placing accurate information into open dialogue. This approach attempts to persuade people to act rather than negotiate the best way forward in a partnership process (United Nations Population Fund [UNFPA], 2002).

There has been a growing recognition of the need to bridge behavioral prevention approaches with social marketing strategies that focus on empowerment, participation, and social change. However, research suggests that much of health communication does not resonate with the needs, interests, competencies, and potential abilities that audiences (e.g., older minority women) may have. The Freirean strategy of *conscientização* (*conscientization*) (Freire, 1971, p. 19) may help to engage people in participatory processes of reflection, action, and reflection, thereby identifying the problems of their society and seeking solutions to them (Freire, 1971). HIV/AIDS prevention in older women could be improved by:

1. Increasing attention to older women by giving them a voice and placing stronger emphasis on considering them as active citizens. Considering the stigma and silence surrounding HIV in older populations and within ethnic minority communities, an important element is to create an environment where HIV can be openly recognized and discussed.
2. Recognizing popular culture (cultural themes applicable to older women) as a resource in developing prevention strategies to connect the content of the HIV prevention messages and real-life experiences of older minority women.

3. An improved analysis of the broader communication environment that HIV interventions operate within and detail to the broader contexts, the multiple mediators, and the complex synergies that social communication initiates. Recognizing contexts and environments promotes more comprehensive and complex designs of interventions (UNFPA, 2002).

### An Integrated Theoretical Framework for HIV Prevention in Older Minority Women

Policies and programs need to extend beyond individual risk-taking and incorporate interpersonal and socioenvironmental factors. Focusing on risk behavior overemphasizes an individual's poor decision making and neglects other conditions that motivate behavior; specifically, society's attitudes toward gender and historical and current experiences of racism, ageism, and discrimination. Health promotion strategies that integrate social justice themes and the importance of social networks may improve overall outcomes. In addition to addressing individual behavior changes, it may be important to encourage collective action to challenge the social causes of health inequities.

To address the gender and age dimensions of HIV/AIDS, a framework needs to be developed that lays the foundation for activities that address empowering women from racial/ethnic minority communities to prevent transmission and mitigate impact of infection. These activities must be embedded in all policies, plans, legislation, decision making, and representation required to slow down the rate of HIV infection. Specific actions to address the challenges faced in HIV prevention among older minority women include (a) policies and programs to mitigate the impact of HIV and AIDS should acknowledge the interface with poverty reduction, health, and prevention education; (b) research assessing the impact of HIV on policy and programming for older minority women, (c) building partnerships between research institutes, all levels of government, HIV/AIDS service providers, and organizations of older people to ensure the inclusion of older women in research, program, and policy work; (d) educating healthcare providers about the sexual practices of older women to allow for improved communication and more accurate risk assessment; (e) educating HIV service providers on the need to provide age-sensitive services and the specific issues related to HIV in the older female population; (f) strengthening legal and policy frameworks that promote gender and race equality, older women's empowerment, and stigma reduction for those infected by, affected by, or at risk for HIV; and (g) promoting the participation of older women living with and at risk of HIV in decision making regarding policies and programs.

## RECOMMENDATIONS

Integrating social capital with social justice themes that have an ecological framework can help drive policy initiatives that significantly impact the efficacy of HIV prevention programs for older minority women. The creation of specific, initial policies to effectively address the HIV prevalence and incidence in racial/ethnic older adult communities may also need to go beyond just testing. Structural barriers, stereotypes, and lack of awareness about HIV are formidable challenges.

Public media education campaigns can help increase HIV risk awareness among midlife and older racial/ethnic women. Older women, raised before “safe sex” became a buzzword among youth, are less likely to see the importance of using condoms, and the fact that most women over 50 are unconcerned with pregnancy may make them less likely to consider condom use. Policies that have created public awareness campaigns in communities already exist for younger populations and need only be tailored in culturally sensitive and socially appropriate ways for aging minority women. These policies would break ground in changing social norms, making the subject of HIV and sexuality in general less taboo among older adults from racial/ethnic communities.

Voluntary HIV testing is an important element in preventing the transmission of HIV (DiFranceisco, Pinkerton, Dyatlov, & Swain, 2005; Marks, Crepaz, Senterfitt, & Janssen, 2005). The counseling that accompanies an HIV test affords an opportunity to reach HIV-negative individuals who may engage in activities that put them at increased risk for HIV and help these persons to reduce their risk (Centers for Disease Control, 2000). For example, health care providers can offer HIV testing as a part of health screening along with routine tests related to aging (e.g., mammogram, bone density test). Making HIV tests readily available and salient in health care and community settings involves environmental changes in which HIV tests are easily accessible, affordable, and socially acceptable to older minority women. HIV-testing mobile vans (as used in sites where other high-risk groups are found, such as gay bars and streets where sex workers avail themselves) can facilitate testing for older women by offering services where these women live and congregate. Routine HIV testing should be a universal standard of care and should be reimbursed by insurance companies and applicable government health programs. Every women aged 50 or older in substance abuse clinics, jails, STD clinics, institutes for mental health disease, community mental health clinics, hospitals, emergency rooms, and health clinics should all have rapid HIV tests available. Colleges and universities should be encouraged to promote HIV testing among their nontraditional “older” student populations.

Although testing HIV-positive will not cause legal immigrants to lose their existing immigration status, it does present a significant obstacle for those who wish to change their current status, especially those who seek lawful permanent residence in the U.S. Further, INS officials may remove HIV-positive people if they entered without INS permission, although, technically, any illegal immigrant could be removed from the U.S. for that reason alone (McKinnon & Kemp, 2006). This poses an added barrier to testing among immigrant populations; older women might fear deportation if they are discovered to have the virus.

Public health guidelines exist to target certain settings for HIV testing, such as National HIV Testing Day. This annual event encourages persons at risk for HIV infection to get tested. As there are no policies or political landscapes that address targeting any population of women aged 50 and older for testing, implementation of voluntary testing programs for midlife and older women should expand currently active testing policies that target younger populations. This would avert the need to formulate brand-new policies, which may prove to be difficult or time intensive.

Constituents must be involved in the drafting of policies at the implementation level. A coalition consisting of stakeholders, politicians, lawmakers, advocates for the aging, funders, community members, and older minority women can be effective in revising old policies or writing new ones. Women in middle and later life need to have a voice in HIV/AIDS legislation, policies, and program directions to address the lack of commitment to incorporate HIV issues in the aging service network. This strategy incorporates Freire's dialogical (empowerment) theory into the implementation phase of adapted exiting policies, utilizing input from community members to establish new or adapted criteria for an already approved and funded intervention.

## CONCLUSION

Women of all ages from racial/ethnic communities continue to be disproportionately affected by HIV/AIDS. The lack of sufficient targeted HIV outreach, education, and prevention strategies means that in all likelihood the level of HIV infection among older women will continue, particularly among poorer older racial/ethnic minority women. An organized network of older women and community professionals needs to be developed to form the basis for a range of activities, including staff training and development, client advocacy, and system-wide prevention initiatives to address funding and program development. There is an urgent need to address underlying multilevel determinants of HIV transmission in midlife and older minority women through sound HIV prevention policies.

## NOTES

1. The term *HIV/AIDS* refers to three categories of diagnoses collectively: (a) a diagnosis of HIV infection (not AIDS), (b) a diagnosis of HIV infection with a later diagnosis of AIDS, and (c) concurrent diagnoses of HIV infection and AIDS.

2. The term *AIDS* refers to persons diagnosed with AIDS.

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