



Invited paper

Keeping Our Hearts from Touching the Ground: HIV/AIDS in American Indian and Alaska Native Women

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A B S T R A C T

HIV/AIDS is a critical and growing challenge to American Indian and Alaska Native (AIAN) women's health. Conceptually guided by the Indigenist Stress-Coping Model, this paper explores the historical and contemporary factors implicated in the HIV epidemic among AIAN women and the co-occurring epidemics of sexual violence and substance abuse. The authors also outline multiple indicators of resiliency in AIAN communities and stress the need for HIV prevention interventions for AIAN women to capitalize on cultural and community strengths.

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A people is not defeated until the hearts of its woman are on the ground.

—Cheyenne proverb

In traditional indigenous cosmologies, the feminine spirit is often regarded as that which sustains life. Even the earth, often referred to as “Mother Earth,” is assigned a feminine identity and provides all that sustains human needs. Women and their bodies are representations of this life-sustaining force, and, in many indigenous cultures, women are regarded as agents of cultural and community preservation. As poetically articulated in the traditional Cheyenne proverb above, a nation cannot be vanquished while the women remain strong enough in body and spirit to carry and protect not only physical but also cultural and spiritual survival. As such, survival of American Indian and Alaska Native (AIAN) cultures can be seen as integrally linked to Native women and this reality frames the need to protect their overall health and wellness, which is currently in a state of crisis.

In June of 2010, the Office of Women's Health (OWH) convened a forum of experts to respond to the National HIV/AIDS Strategy Implementation Plan so that effective strategies for

gender-responsive programming for women and girls could be recommended for integration into a national plan. The OWH Forum produced some important recommendations for consideration in addressing the unique and nuanced needs of diverse communities of women and girls. Several of these recommendations have particular relevance for addressing HIV/AIDS in AIAN communities, including the need to:

- consider gender-based violence and substance abuse as linked to HIV risk;
- consider the use of holistic approaches to understanding and addressing programming; and
- prioritize the use of community-based participatory research (CBPR) approaches in investigating research and practice.

This article supports these particular recommendations by considering the current critical and growing challenge that HIV/AIDS poses to Native women's health. Conceptually guided by the Indigenist Stress-Coping Model (Walters & Simoni, 2002), we explore the historical and contemporary factors implicated in the HIV epidemic among AIAN women and the co-occurring epidemics of sexual violence and substance abuse. We conclude with an emphasis on resiliency in this community and the need for HIV prevention interventions among Native women to capitalize on cultural and community strengths.

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HIV/AIDS in AIAN Women and Adolescent Girls

Although the number of AIDS cases among AIANs reported by the U.S. Centers for Disease Control and Prevention (CDC) accounts for less than 1% of the total in the United States, this statistic fails to represent the actual impact on AIAN communities. Before the breaking-out of multiple race and Native Hawaiian/Pacific Islanders as categories of surveillance, AIANs ranked third in rate of diagnoses behind African Americans and Hispanics (CDC, 2008a). Since the changes to race/ethnic surveillance data, AIAN now rank fifth in diagnoses behind African Americans, Hispanic/Latinos, Native Hawaiian/Pacific Islanders, and persons identifying as multiple races; however, the report advises caution when interpreting this data because the numbers of Native Hawaiian/Pacific Islanders is small and consequently unstable (CDC, 2009b). Further complicating these data is the reality that Native Hawaiians/Pacific Islanders are indigenous peoples and share similar historical and contemporary experiences related to colonization, ongoing discrimination, and persistent health disparities. Additionally, many multiple race persons also include AIAN and other indigenous identities. As such, although the overall data reflect disparate rates of HIV/AIDS diagnoses, the larger contextual picture, including multiplicity of indigenous identity and experience, may be obscured. Additionally, although the overall estimated number and rate of AIDS diagnoses decreased between 2006 and 2009, it remained stable in AIAN communities (CDC, 2009b). In this same time period, HIV diagnoses increased despite an overall population decrease (CDC, 2009b) and this may be a better indicator of the HIV/AIDS risk in AIAN communities. Moreover, recent rates of infection among AIANs have increased more rapidly than in any other racial/ethnic group. In 1990, 223 cases were reported and in 2001, 2,537 cases, a 900% increase (Dennis, 2009). Among individuals diagnosed with AIDS between 2001 and 2005, AIAN had shorter survival times than Whites, Asian and Pacific Islanders, those of multiple races, and Hispanics (CDC, 2009b).

AIAN women are increasingly affected by HIV. Indeed, the percentage of female HIV/AIDS diagnoses among AIANs rose from 19% in 2000 to 29% in 2008 (CDC, 2008a). Although the primary mode of exposure for AIAN women was heterosexual contact (67%), 32% of AIAN women contracted HIV through intravenous drug use (CDC, 2008a). Moreover, AIAN women were 2.4 times more likely to be diagnosed with HIV infection than White women (6.9 vs. 2.9/100,000). The rate of AIDS diagnosis for AIAN women was 2.6 times the rate for White women (4.6 vs. 1.8/100,000). Additionally, AIAN women were 3.4 times more likely to die from AIDS than White women. In fact, HIV/AIDS is the eighth leading cause of death among AIAN women aged 35 to 44. Finally, although HIV/AIDS diagnoses among U.S. girls and women between 15 and 39 years old is decreasing; diagnoses within this age cohort is increasing among AIAN girls and women.

Even more alarming, the statistics on AIDS among AIAN are likely underestimates. HIV surveillance data in several states, including those with the largest AIAN populations, were not collected by the CDC before 2004 because these states resisted the adoption of name-based HIV registries, preferring to use anonymous, unique codes instead of names to avoid the risk of civil liberties violations (Forbes, 1996). California, New York, and Washington, for example—all states with relatively large AIAN populations—only recently began to submit name-based HIV surveillance data (the only kind that the CDC will accept) within the past few years. Their decision was affected by the fact that

their refusal to submit name-based data put them at risk of losing their Ryan White CARE Act funding.

Other factors also contribute to the undercount of AIAN women in HIV/AIDS statistics. Many AIAN women do not have health insurance (U.S. Commission on Civil Rights, 2003) and cannot afford to pay out-of-pocket for HIV testing. Many more live in the rural areas where access to health facilities is limited. Even when HIV testing is free and available, AIAN women living in rural areas or tribal communities may avoid having an HIV test in a setting where they are well known or likely to encounter other tribal members. For those who have been tested, racial misclassification by health care providers can also contribute to lower official rates of HIV cases among AIAN women. For example, according to a study done in Los Angeles, 56% of AIAN with AIDS diagnoses were misclassified as having a different race (CDC, 2008b; Hu, Harlan, & Frye, 2003).

The data on sexually transmitted infections among AIAN women also suggest the statistics on HIV/AIDS are underestimates. Specifically, AIAN women have the second highest chlamydia and gonorrhea rates in the United States—4.5 times higher than the rates among White women. This indicates that AIAN women are engaging in unprotected sex that places them at high risk for HIV exposure and transmission (CDC, 2009a; Vernon, 2007).

The Indigenist Stress-Coping Model: Historical and Contemporary Context

As delineated in the Indigenist Stress-Coping model (Walters & Simoni, 2002), multiple co-occurring stressors provide the context for understanding how HIV has come to impact AIAN women (see Figure 1). Specifically, over the last several hundred years, AIAN communities have endured historically situated traumas including massacres, boarding schools, forced removal, and prohibition of spiritual and cultural practices, as well as ongoing exploitation of bodies and lands. Additionally, contemporary AIAN communities suffer from an ongoing barrage of negative stereotypes and micro-aggressions that disparage and undermine AIAN identity (Walters, Simoni, & Evans-Campbell, 2002) and the strength of AIAN women roles in their traditional societies (Smith, 2005). In recent years, indigenous scholars have hypothesized that experiences of historical trauma and ongoing discrimination are linked to communal and individual contemporary health and health behaviors including those associated with HIV risk, such as interpersonal violence and substance abuse (Duran et al., 1998; Vernon & Thurman, 2009; Walker et al., 1996; Walters et al., 2002).

“Indian Love”: Interpersonal and Sexual Violence in AIAN Women

The OWH Forum recommendations point out that, although there is mention of gender-based violence in the National HIV/AIDS Strategy, there is no reference to prevention or monitoring in the National HIV/AIDS Strategy implementation plan. These aspects are of considerable importance to understanding the complexity of HIV/AIDS risk for AIAN women and girls. AIAN communities experience greater rates of interpersonal violence than any other racial and ethnic group (Tehee & Esquada, 2008). The National Violence Against Women Survey shows the highest rates of all forms of violence occur among AIAN women, with 34.1% of AIAN women experiencing rape, 61.4% physical assault, and 17.0% reporting stalking during their lifetime (Tjaden &

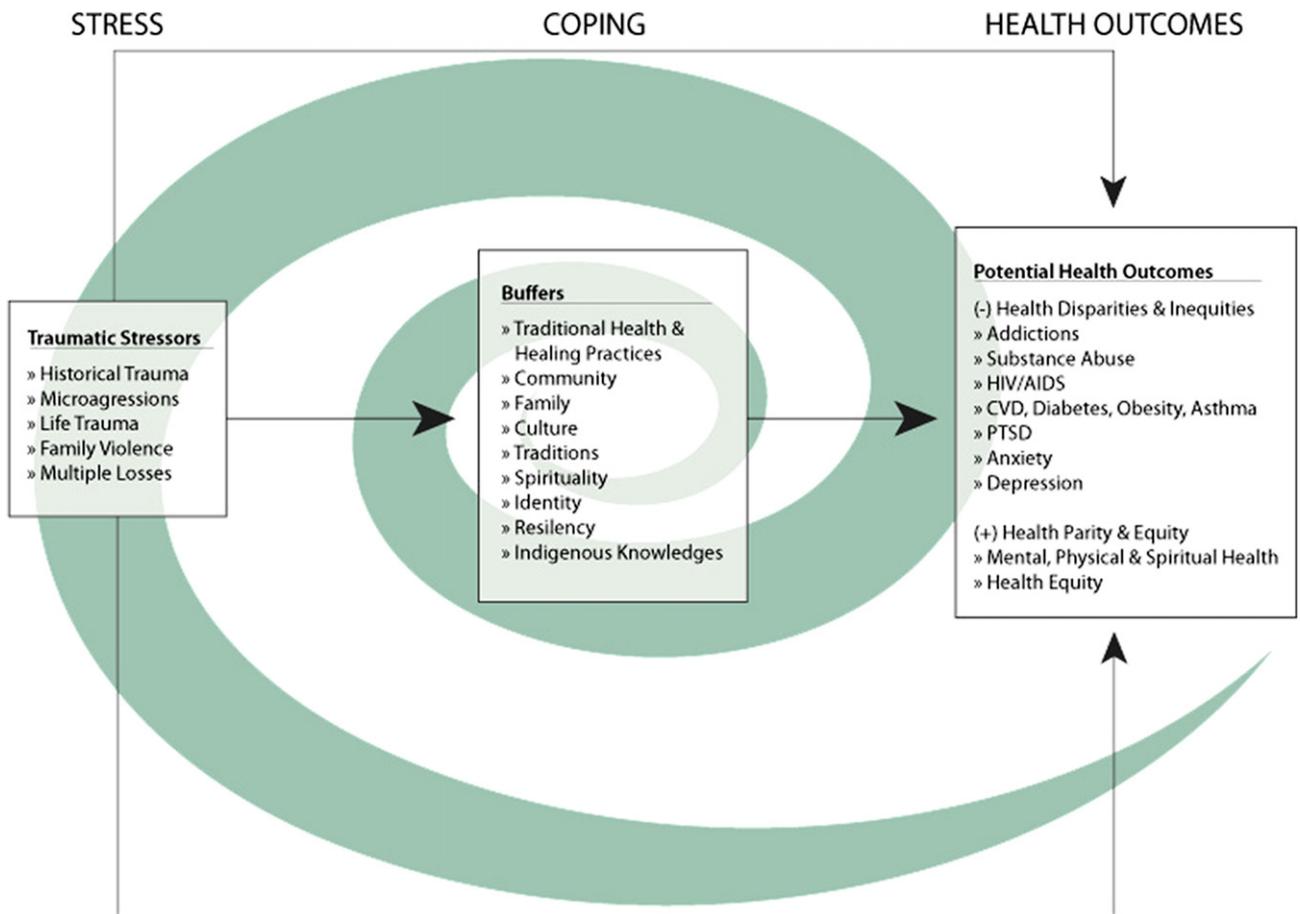


Figure 1. Adapted Indigenist Stress Coping Model (adapted from Walters & Simoni, 2002).

Thoenes, 2000a). Further research suggests that AIAN women have a higher rate of victimization through violent crime (Greenfeld & Smith, 1999) than non-Native women and they may be disproportionately represented among domestic violence homicides (Arbuckle et al., 1996; Tjaden & Thoennes, 2000b).

Many women who experience domestic violence have histories of abuse, as do their partners (Tehee & Esquada, 2007). A distressing sign that domestic violence is widely viewed as a commonplace experience for AIAN women is illustrated by the slang term "Indian love"—an expression implying that violence is simply a way that Native people demonstrate their love to each other (Tehee & Esquada, 2007). Domestic violence can often lead to serious injuries and AIAN women seek medical treatment for domestic violence-related wounds more frequently than any other group. Data from our own studies show a consistent pattern emerging where a "triangle of risk" factors—trauma, substance use, and HIV risk behaviors—place AIAN women at heightened risk for poor health outcomes and HIV exposure. In a community sample of 112 urban AIAN women, 28.2% had experienced childhood physical abuse, 48.2% had been raped, and 40.0% indicated that, as adults, they had experienced assault from a spouse or romantic partner. Further, those who had experienced any type of interpersonal violence were substantially more likely to engage in HIV sex risk behaviors (ranging from 94% to 96.6%, depending on the type of violence history) than women with no history of interpersonal violence (72.2%; Evans-Campbell, Lindhorst, Huang, & Walters, 2006). Studies

indicate that women who have been sexually assaulted are much more likely to engage in high HIV risk behaviors, including having sex with multiple partners, not using condoms, and substance abuse (Vernon & Thurman, 2009).

Sexual minority AIAN women are at particularly high risk for trauma and HIV. In our six-site national study of gay, lesbian, bisexual, and transgender AIAN health (HONOR Project; R0165871), 152 sexual minority AIAN women reported disturbingly high prevalence of both sexual (85%) and physical (78%) assault, both of which were associated with worse overall mental and physical health (Lehavot, Walters, & Simoni, 2009). Moreover, self-reported rates of HIV (8%) were unusually high for these women, suggesting that they may represent a subgroup of AIAN women at increased heightened risk.

Substance Abuse Among AIAN Women

Another OWH Forum recommendation calls for holistic approaches to programming and research so that multiple factors associated with HIV/AIDS risk for women and girls can be addressed effectively through integrated approaches. Alcohol and drug use are critical co-factors associated with HIV/AIDS risk for women and girls and, along with trauma, form a "triangle of risk" that must be addressed holistically for effective HIV prevention interventions (Simoni, Sehgal, & Walters, 2004). Along with high rates of gender-based violence, AIAN women in particular experience high rates of alcohol or drug abuse, which is

also associated with HIV risk (Walters & Simoni, 1999; Simoni et al., 2004). Alcohol is the most common psychoactive substance used by AIANs. By the twelfth grade, 96% of boys and 92% of girls report having used alcohol. AIAN communities tend to drink earlier, more, more often, and with more devastating consequences than other groups (Walters et al., 2002). In investigating HIV risk behaviors, Bertolli and colleagues (2004) found that the number of AIAN who met the criteria for alcohol dependence was nearly twice the rate of non-AIAN counterparts (42% vs. 24%) and illicit non-injection drug use rates were also higher (80% vs. 70%). The 2005 National Survey on Drug Use and Health reported that current illicit drug use was higher in AIANs than in any other racial or ethnic group (CDC, 2008a).

Research among AIAN illustrates the link between substance abuse and HIV risk behaviors. In a study of AIAN living in New York City, respondents who had used alcohol or other drugs recently were over four times more likely to engage in high-risk sexual behaviors than those who had not (Walters, Simoni, & Harris, 2000). In a study of AIAN drug users, Baldwin and colleagues (2000) found that half of the respondent had episodes of drinking until drunk and engaging in unprotected sex during blackout periods. A survey of 68 American Indian women in New York City—conducted to inform community-based HIV prevention approaches—revealed that few respondents had ever injected drugs, and 54% had been tested for HIV (Walters & Simoni, 1999). However, 38% had used alcohol or other drugs in the last 6 months and, among the 59% who reported sexual activity in this period, 80% had had unprotected sex. Alarming, 44% of these women reported lifetime trauma, including domestic violence (25%) and physical (27%) or sexual (27%) assault by a family member or stranger. Consistent with a postcolonial theoretical framework, this trauma was a better predictor of HIV risk behavior than social cognitive variables.

Analyses have also indicated that the use of alcohol or other drugs can mediate the relationship between non-partner sexual assault and sexual risk behaviors. In a community sample of 155 urban AIAN women, respondents reported high rates of lifetime sexual (39%) and physical assault, which was generally associated with lifetime sexual and drug risk behaviors (Simoni et al., 2004). Injection drug use mediated the relationship between non-partner sexual trauma and high risk sexual behaviors. Once again, we see the “triangle of risk”: Trauma, substance use, and HIV risk are critical co-factors that shape AIAN women's risk and resiliency.

Resiliency and Culture-Centered Approaches to HIV Prevention

Although AIAN women suffer from overall poor health status, there are tremendous resiliencies and strengths that have supported the survival and regeneration of Native cultures. CBPR approaches not only build on the strength of participant communities, but also empower communities to generate knowledge and solutions that are culturally meaningful and healthful. The OWH forum participants clearly articulated the importance of CBPR approaches, particularly with respect to development of community-based treatment models. Utilizing CBPR approaches for research as well as developing community-based treatment models by and for AIAN women are particularly liberating strategies given the history of abusive research and “health care” practices AIAN women have endured (e.g., sterilization of Native women without proper consent).

Several indigenous scholars have identified numerous important protective mechanisms that may buffer the impact of trauma on AIAN women's health and HIV/AIDS risk. These include spirituality and traditional health practices; enculturation (Duran & Walters, 2004; Walters et al., 2002); and a strong commitment to tribal community (Evans-Campbell & Walters, 2006). Emphasizing these resiliencies, the Indigenist Stress-Coping model articulates how cultural protective factors work to buffer the effects of multiple forms of violence and risk and has helped to generate a recent focus on culture-centered approaches to HIV/AIDS in AIAN communities. Significantly positive outcomes were achieved during work with HIV-positive AIs in a rural southwest mental health treatment setting, for example, by the adoption of culture-based case management—an approach that integrates traditional cultural practices into the recommended evidence-based treatment practices offered (Duran et al., 2010). Building on strengths and resources available and sustainable in tribal communities (Thurman, Vernon, & Plested, 2007) and looking to AIAN communities, themselves, to identify their own specific prevention needs (Wiechelt, Gryczynski, & Johnson, 2009) is essential in moving toward healthier bodies and spirits and, thus, in the preservation of Native cultures. Centering this work around women's knowledge is one of the key aspects of this preservation (Vernon & Thurman, 2009).

Globally and locally, AIAN women have been rendered nearly invisible in the public discourse and the development of interventions to fight against the HIV pandemic. Most of the targeted interventions for women focus on women taking control over their *personal* sexual health via condom use and negotiation skills. Such practices place the onus of responsibility for women's risk on their shoulders without critically analyzing or interrogating the conditions under which indigenous women live. This approach ignores and, at worst, replicates the inequities that place indigenous women at risk for HIV exposure in the first place. Indeed, AIAN women live their lives in “the dangerous intersections of gender and race” (Smith, 2005). Within dominant national and global HIV prevention movements, women of color are often told that they must control the sexual situation, control “their” men, and place under control their sexual selves and bodies to prevent HIV transmission. Thus, many public health interventions have been inadequate for addressing HIV prevention needs among women of color and AIAN women in particular.

The urgency is not simply to cognitively or behaviorally increase personal knowledge, motivation, or behavioral skills in condom use; rather, the HIV pandemic for AIAN women must be contextualized within historical and contemporary structural realities that are rooted in colonialism, racism, and gendered violence against AIAN women at multiple levels. These have served to perpetuate and exacerbate HIV risk for indigenous women globally and locally. To have a real impact, HIV prevention efforts must take these structural factors into account and address them explicitly. Effective prevention efforts must start here, before the hearts of Native women touch the ground.

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