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Whom Can You Trust? Exploring Leadership Addressing HIV Risk Prevention in African American Women

Whom Can You Trust? Exploring Leadership Addressing HIV Risk Prevention in African American Women

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ABSTRACT

Within the last decade African American women have experienced serious increases in HIV diagnoses. Almost 40% of all newly diagnosed HIV-positive women in the United States are black women. Furthermore, black women are 23 times more likely to be diagnosed with AIDS than white women. This paper explores some of the underlying socioeconomic factors for high incidence rates of HIV among African American women—including poverty, racism, and stigma—that contribute to this health disparity and discusses current leadership approaches to addressing this problem. One common leadership approach focuses on adapting CDC intervention programs at a local level, a process that presents significant challenges. This paper concludes with a discussion of approaches and leadership theories from thinkers in public health, anthropology, business, counseling, and psychology. These models supported by ethnographic interviews with HIV workers from the city of Tampa allow insight into the strengths of leadership at local, regional, and national levels and ultimately suggest that a holistic and interdisciplinary focus is necessary to address these structural inequalities.

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Introduction

In the summer of 2006, the world observed the 25th anniversary of the first reported cases of HIV/AIDS. HIV has been an epidemic marked by controversy and prejudice with far-reaching ramifications for health education efforts in regards to HIV risk-prevention. In 2006, ABC Primetime aired its reflective special "Out of Control: AIDS in Black America" (Arledge, 2006). This documentary gave a public voice to a major health crisis that had previously only been discussed within academic and public health settings: the growing HIV epidemic in the African American community (Parker, 2002; Singer, 1998; Konkle-Parker, 2008).

Phil Wilson, the executive director of The Black AIDS Institute in Los Angeles enumerated on this situation saying, "In American today, AIDS is virtually a black disease, by any measure" (Yellin, 2006). He points out that many African American leaders have focused their energies on the epidemic in Africa rather than devoting attention towards the crisis in the United States (Yellin, 2006). Today, there is an incessantly growing need for leadership that will address the complexities of this epidemic in the African American population.

The focal point of this epidemic is African American women (Payne, 2008) whose demographic has experienced serious increases in positive HIV diagnoses. Almost 40% of all newly diagnosed HIV-positive women in the United States are black women (Yellin, 2006). Furthermore, according to the Centers for Disease Control and Prevention (CDC) (2005), black women are 23 times more likely to be diagnosed with AIDS than white women.

The focus of this paper is to explore some of the underlying causes for high incidence rates of HIV among African American women—including stigma both within and without the African American community. This stigma serves as a barrier for open communication about HIV risk within the African American community. Structural contributors like poverty further complicate health educators' abilities to educate and motivate African American women in efforts to reduce their HIV risks. Additionally, current leadership approaches for addressing this problem are discussed.

This paper concludes with a discussion about the type of leadership that might be applied to this health crisis with an emphasis on the importance of collaborative work. Several leadership theories will be incorporated in the hopes of gaining insight into how health educators might better help African American women to reduce their HIV risk and to stem the rising tide of HIV incidence among black women.

Significance of the Problem

"Acquired immune deficiency syndrome (AIDS) has emerged as one of the most devastating diseases in human history. The virus that causes AIDS, human immunodeficiency virus (HIV), has spread rapidly throughout the world's human population" (Singer & Baer, 2007, p. 201). In the United States there were 1.1 million Americans living with HIV in 2006, which is an 11% increase from 2003. This is

an encouraging statistic, because it reflects the increased number of people living longer with HIV as a result of available retroviral medications (Fears, 2005).

Public Health workers, however, must address the reality that more individuals living with HIV means more potential agents for spreading the virus and more individuals who need care, support, and medications. The CDC reports infection rates that have consistently remained around 56,000 new infections each year, but as the US AIDS epidemic continues it disproportionately affects minority groups like African Americans. According to the 2000 census, African Americans made up 13% of the U.S. population, but accounted for 49% of new HIV/AIDS diagnoses in 2005 (CDC, 2005). An estimated 141 infants were perinatally infected with HIV in 2006, and of these infants 65% were black. African American's diagnosed between 1997 and 2004 had lower rates of survival at 66% than whites and other minorities (CDC, 2005).

There have been efforts to address the HIV epidemic in the African American community. The Advancing HIV Prevention (AHP) initiative began in 2003 to address HIV in minority populations focusing specifically on barriers to early diagnosis and increased assess of quality medical care (CDC 2004). This initiative, however, does not address specifically address HIV prevention. The CDC also established the African American HIV/AIDS Work Group to focuses specifically on African Americans (CDC 2005). This group has allowed the CDC to create partnerships within the black community as well as to collect important descriptive data about the epidemic, but because of varying state laws regarding testing the group has had little national impact. A Women's Study of black and Hispanic women in the southeastern United States examines relationship dynamics and other factors associated with HIV infection, but while this group supplies important information regarding the underlying factors for the epidemic, it does not address the policies of HIV risk prevention health education CDC 2005).

Research based interventions include SISTA (Sisters Informing Sisters About Topics on AIDS), Healthy Relationships, a small-group intervention for men and women living with HIV/AIDS, and WILLOW (Women Involved in Life Learning from Other Women), which all target African American women. These interventions have faced challenges when implemented locally in the Tampa area because of lack of funding and employees who are not trained in research. A former Tampa area HIV outreach employee reflected on her time working on one such local adaption of an evidence-based CDC intervention, "I was the only one trained in research and I felt like I was continually banging my head against a wall. The budget was tight and so they tried to cut corners on things that were really important parts of the research base. Finally, I had to leave because the funding was going to be allocated somewhere else" (T. Looney, personal interview, 2008).

Almost half of the CDC's domestic HIV prevention budget, which translates to over $300 million (CDC 2005), is allocated towards addressing HIV in African American communities, yet the epidemic appears to continue largely unchecked. The CDC plays a very important role, but it seems clear that leadership to address HIV prevention among African American women must emerge at a local and regional level to augment the CDC's efforts. Furthermore, national policies and political support are vital for making significant reductions in this epidemic.

Factors Related to and Affecting the Problem

Women make up 126,964 of new HIV/AIDS cases, and black women are almost 23 times more likely to receive a positive diagnosis than white women, which means that there is a significant group of black females affected (CDC 2005). What are the underlying causes for this significant disparity?

First, according to anthropologists Merrill Singer and Hans Baer, "disparity in wealth is matched by great disparities in health and most significantly these inequalities often fall along ethnic lines" (pp. 202-203). In the United States wealth is concentrated to about 3% of the country's entire population while nearly 24.4% of African Americans fall below the poverty line, which is the highest rate for any minority (Teather, 2004).

Socioeconomic factors related to poverty increase the likelihood of exposure to many diseases, including HIV. The literature has identified the reasons for this as stress that is associated with poverty, unemployment, population density, lower education levels, and exposure to unsafe environments. Poverty often leads to poor diet. Coping behaviors prompt deleterious behaviors such as abusive drinking and drugs. Furthermore, research has shown that minority women, especially those who are poor often have problems accessing adequate health care and insurance, which has serious implications for women's health (Schneider et al, 2002). In a 2001 survey on health status, African American women were the highest percentage (46%) to report fair or poor health (Bierman & Clancy, 2001). The challenges related to poverty can lead to disproportionate negative effect on health and higher HIV risk for African American women (Singer & Baer, 2007). It is important to note that poverty does

not breed HIV, but the structural challenges provide a definite linkage that must be identified by public health officials.

Racism is another significant social condition that has been linked to higher levels of HIV risk and infection. Racism is especially significant when its presence causes the women to not seek testing or treatment because of fears of racism. Paul Farmer further articulates this point: "the most well demonstrated co-factors [for HIV] are social inequalities, which structure not only the contours of the AIDS pandemic but also the nature of outcomes once an individual is sick with complications of HIV infection" (Farmer, 1999, pp. 51-52). Racism affects willingness to access health care if the client perceives racism among healthcare providers.

In addition to racism, stigma is another important social challenge. Stigma is often linked to HIV and often stops individuals from pursuing HIV testing. Stigma regarding HIV is particularly prevalent in the black community. Researchers have noted that there has been a general unwillingness to address the issue of HIV because perceived reasons for contracting HIV include homosexual activity and unfaithfulness (Konkle-Parker, 2008).

The lack of discourse on HIV risk within the African American community particularly impacts women. Several studies have focused on extramarital activities of these women's partners, including the "down low" activities among African American men, which is a term given to extramarital homosexual activity by men who consider themselves heterosexual males. Women have been negatively affected because many of them believe that they are in committed relationships and, therefore, reject the idea of needing a condom (Miller, 2007).

Implications for Leadership

The underlying causes of HIV prevalence and risk among African American women are nuanced, challenging, and interrelated. Local HIV agencies are groaning under increasing caseloads of HIV positive individuals and increasing demands for testing and risk reduction counseling while continually battling misinformation and stigma. All of this is occurring in a time of finite Ryan White spending and limited funding. Prevalent needs like transportation, childcare, and housing create an environment where addressing risk of contracting or spreading HIV is not high on the client's priority list. One current Tampa HIV worker observes how these structural challenges affect an outreach program:

> There are so many times that I think to myself—I am not making any impact right now because my client is sitting in front of me with her mind a thousand of miles away trying to figure out where she is going to sleep, how she is going to get there, and what she is going to eat once she gets there and I'm frustrated because I know that somewhere out there are services that can help provide these things, but I don't know how to hook my client up with them.

To address this situation, leaders of the campaign against the rise of HIV/AIDS among African American women must outline a direction so that strategies can be brainstormed to accomplish this vision. John P. Kotter outlines the process for creating major change. This change process begins with "establishing a sense of urgency, creating the guiding coalition, developing a vision and strategy, communicating the change vision, empowered broad-base action, generate short-term wins, consolidate gains and produce more change, and anchor new approaches to culture" (R. McDermott, personal communication, September 2008). Especially important to this outline is the concept of "anchoring" an approach within culture. The culture of a client is important because it can influence how the client perceives and respond to the disease and outreach workers. Additionally, an understanding of culture and community helps HIV caregivers identify community structural challenges experienced by individuals in additional to individual needs. This community-based focus cannot be accomplished from afar by agencies such as the CDC, but instead must be addressed by leaders within local agencies.

It is at this level where the disjunction between the implementation of catalogue CDC evidence-based prevention programs and the realities of communities can occur (Kelly et al., 2000). It is here that HIV organization leaders must become *coaches*, as Daniel Goleman suggests, training and encouraging caregivers to feel "competent and motivated in order to lead to long-term improved performance" (R. McDermott, personal communication, September 2008). Leaders must recognize a need for training in research so that employees have the knowledge and confidence needed to make the appropriate changes to adapt CDC evidence-based intervention programs to local communities.

Goleman's presentation of leaders that "create resonance" (momentum) and Komives et al.'s relational leadership model are important because they stress the importance of inter-relationships among HIV organizations. This bottoms-up approach

to change could be effective for addressing gaps in the services available at individual HIV agencies. A Tampa HIV outreach worker highlights the need for inter-agency communication:

> I do casework type things for my clients all the time that are not included in my job description. I make doctors appointments, get them transportation, work on their housing, and help them with the food stamps program. I have to make it up as I go, because I've never been told what resources are out there. We don't have caseworkers in our program.

The ability to form partnerships and work with existing partner relationships is critical to success. These partnerships should not be limited to organizations that specifically focus on HIV/AIDS, but should also include organizations with other service provision focuses like transportation or childcare. Honest conversations about how these organizations can work together to address structural issues and better serve African American women are important to these partnerships.

HIV agencies seem to place great emphasis and responsibility on the individual client rather than the structural issues that have been identified within communities. This lack of acknowledgement of structural challenges translates into daily frustrations for employees that even the best training can never fully meet. Most structural issues are out of these organizations' control, but they can develop in a way that allows them to respond to these issues as effectively as possible. To address this issue, leaders will need to extend organizations conceptualization of HIV/AIDS, but ultimately it is leadership on a national level that is needed to address the endemic structural issues that plague a majority of African American women. This can only be accomplished through communication and cooperation between national and local leaders.

A leader that stays current with HIV/AIDS literature is important. Current HIV/AIDS literature leads to the recognition of the multi-causality and interrelatedness of local, regional, and global systemic factors contributing to HIV issues. Anthropologists introduced the concept of "syndemic" in the early 1990s to conceptualize these interrelationships. Often a biomedical understanding of HIV isolates the study and treatment of the disease as if it were independent from social contexts (Singer & Baer 2007). The syndemic model "directs attention to social and biological interconnections in health as they are shaped and influenced by inequalities within society" (Singer & Baer 2007).

This framework of thinking is clearly important to addressing the issue of risk reduction within African American women. It is a challenge, however, to maintain such a holistic viewpoint, one that is not always supported by funding, and requires leadership that is visionary and that creates "resonance." The challenge is how to collectively address a monumental problem like HIV risk among African American women. The solution will require creative collaboration among many individuals and groups.

Leaders in research must be willing to step forward and actively engage this issue using their knowledge, skills, and resources to address a pressing health related issue as well as to personally interact with HIV caregivers. Leaders at a national level must address HIV policy and structural issues, but efforts should also be focused at regional and community levels where small local agencies can insert themselves into the community and provide feedback to national leaders. It is the ASTDHPPHE & SOPHE Leadership Model that comprehensively summarizes these qualities through their list of: "visionary leadership, sense of mission, effective change agent, have political competencies, is a key players in organizational dynamics, can social forecast and market, has team leadership competencies, and facilitates team and work groups" (R. McDermott, personal communication, September 2008). This model ultimately addresses all level of community: local, regional, national, and even international, as well as stressing the need for collaboration.

By embodying the leadership principles outlined in these leadership theories, leaders in the local community may make successful progress in addressing HIV risk among African American women.

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