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## **Lower Income African American Women and HIV/AIDS: The Effect of Contexts on Identity Incorporation**

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**Abstract:** The purpose of this study was to explore how contexts affect the incorporation of the HIV/AIDS identity into the self for lower income African American women. Eleven in-depth interviews were conducted. Situational factors predisposed women to contracting HIV/AIDS and delayed the turning point from their initial emotional reaction. Support from family and friends helped the integration process whereas stigma delayed integration. Race and class negatively affected some women's experience of living with HIV/AIDS. These findings have implications for health educators.

Keywords: African American women, HIV/AIDS, class, identity, contexts

In 2006, the rate of HIV infection was 15 times higher for Black women than for White women in the United States (HIV among African Americans, 2010). Black women account for 12% of the United States population of women but comprised 64% of AIDS diagnoses in 2009 (HIV/AIDS Policy Fact Sheet, 2011). Eighty-five percent of African American women diagnosed with HIV acquire the virus through heterosexual sex (HIV among African Americans, 2011).

Because an increasing number of heterosexual African American women are living with HIV/AIDS, it is important to explore their experiences. Specifically, it is helpful to know how the incorporation of the HIV/AIDS identity is affected by various contexts including the sociocultural (e.g. race, class, gender), interpersonal (e.g. support and stigma), temporal (historical time and developmental phase) and situational (e.g. pregnancy) (Ickovics, Thayaparan, & Ethier, 2001). Scholars have investigated the incorporation process of the HIV/AIDS identity into one's self (e.g. Awa & Yamashita, 2009; Dozier, 1997; Gurevich, 1996), but the populations in these studies have included very few lower income African American women and have not explicitly considered the effect of various contexts on the process. Therefore, the purpose of this study was to explore how various contexts affect the incorporation of the HIV/AIDS identity into the self for lower income African American women.

### **Theoretical Framework and Literature Review**

Living with a chronic illness such affects the self. Identity theorists assert that the self is comprised of multiple identities (Burke & Stets, 2009). These role identities are formed through interaction with others and they comprise the stable self (Burke & Stets, 2009). Individuals live in "networks of social relationships" and they perform different roles in different networks (Burke & Stets, 2009, p. 47). The commitment to an identity depends on the number of persons one is related to through an identity and strength of ties to others based on that identity (Burke & Stets, 2009). The more committed one is to a particular role identity, the greater salience it has in a person's salience hierarchy (Burke & Stets, 2009). "John" might have a highly salient artist identity. He is employed as a graphic artist at a company and he talks about being an artist to his friends, family, and new acquaintances. He also mentors aspiring young artists through a

community program. His identity as a hospice volunteer is less well-known since he does not discuss that role identity with others and only the hospice patients and the hospice coordinator know him as a hospice volunteer.

The studies that mention the effect of various contexts on HIV/AIDS identity incorporation consist primarily of participants who are White gay men or White heterosexual women. With the exception of one study (Baumgartner & David, 2009), participants were largely diagnosed before the advent of life-extending medications such as protease inhibitors. Findings from these studies suggest that stigma prevented or delayed disclosure to others which was integral to the incorporation process (e.g. Awa & Yamashita, 2008; Baumgartner & David, 2009) and individuals immersed themselves in the HIV/AIDS community to cope with the stigma (e.g. Sandstrom 1990). The support of family, friends, and support groups helped integration (e.g. Awa & Yamashita, 2008; Baumgartner & David, 2009). Regarding historical time, the increased availability of information about HIV/AIDS and the effect of life-extending medications on identity incorporation were mentioned briefly (Baumgartner & David, 2009).

Clearly, interpersonal and sociocultural contexts affect African Americans' experience of living with HIV/AIDS (Ickovics, Thayaparan, & Ethier, 2001). Researchers note that African Americans and poor individuals perceived discrimination with health care providers when being treated for HIV/AIDS (Bird, Bogard, & Delahanty, 2004). African Americans living with HIV/AIDS tended to believe they were more discriminated against or morally judged for having HIV/AIDS whereas Whites feared interpersonal rejection (Rao, Pryor, Gaddist & Mayer, 2008). What is not known is how various contexts affect the incorporation process for lower income heterosexual African American women.

### **Data Collection and Analysis**

The data from this study was derived from a larger study on HIV/AIDS and identity incorporation. Participants were age 18 or older and were living with HIV/AIDS for a year or more at the time of the interview. This gave respondents sufficient time to begin to integrate the HIV/AIDS identity into the self.

Eleven of the 36 participants interviewed for the larger study self-identified as African American women. These women ranged in age from 30 to 60 at the time of the interview. The average age was 47. Their education level ranged from 8<sup>th</sup> grade through attending college. Eight of the 11 women earned less than \$10,000 per year. Two participants earned \$10,000-\$20,000 a year and one person earned \$ 20,000 to \$ 30,000 annually. Eight individuals were diagnosed after the widespread use of life-extending medications including protease inhibitors in 1996. All respondents were diagnosed between 1994 and 2003.

Data collection consisted of 11 one and one-half to two hour interviews using a semi-structured interview guide. Data were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967). Member checks, rich thick description, and an audit trail were utilized to enhance reliability and validity (Merriam, 2009).

### **Findings**

It is important to briefly discuss the HIV/AIDS identity incorporation process for these women prior to revealing the effect of the contexts on the process. The four step process was: 1) diagnosis followed by an emotional reaction of denial, depression, fear, shock and anger that coincided with excessive alcohol and drug use; 2) a turning point from that emotional reaction;

3) immersion in the HIV/AIDS community which consisted of becoming involved in HIV/AIDS-related activities and outreach through an AIDS Service Organization and 4) integration of the HIV/AIDS identity. Disclosure to others occurred throughout the process and was vital to integration.

The aforementioned incorporation process was affected by situational, interpersonal, and sociocultural contexts (Ickovics, Thayaparan, & Ethier, 2001). Sexual abuse and chemical dependency were situational contexts that put some of these women at a higher risk for acquiring HIV/AIDS. Their incorrect beliefs about HIV/AIDS delayed their turning point from their initial reaction. A third situational context, their coping with other chronic diseases, made the HIV/AIDS identity less salient than other illnesses. The interpersonal contexts of support and stigma affected the turning point and integration phases and the sociocultural contexts of race and class affected access to information and increased stigmatization which ultimately delayed their turning point from their initial emotional reaction.

### **Pre-diagnostic situational context: Abuse and chemical dependency**

Physical, sexual and verbal abuse in childhood was a common finding among the participants. Seven of the 11 women were chemically dependent prior to diagnosis. Four were molested or raped prior to diagnosis. Research shows these factors put women more at risk for HIV/AIDS (Bensley, Van Eenwyk & Simmons, 2000) so although these situational contexts predated diagnosis, they arguably contributed to these women being more at risk for HIV/AIDS than individuals who did not experience sexual abuse and chemical dependency. Linda's 30-year drug dependency began as a young adult. She noted,

My parents partied. We did the cleaning up. We also did the cleaning up of the alcohol. When I got to high school, I experimented with marijuana and my husband died at 48 of alcoholism. You thought I would have learned, but I didn't. I got worse with my drug habit. I moved back [to the Midwest] in 2001 and I really, REALLY, got out of control.

Four women were molested or raped by family members or neighbors. Levon stated,

My dad was abusive to me. Verbally abusive. Sexually abusive, too because when I was young, in my teens, I was 17...maybe 15. I got molested by my father. I was trying to tell my mother that. She didn't believe me. That went on 2-3 months and then she finally woke up and realized that I wasn't lying [but] by then my dad had passed.

### **Pre-diagnostic situational context: Beliefs about HIV/AIDS prior to diagnosis affected turning point from initial emotional reaction**

Eight of the 11 were diagnosed HIV-positive or with AIDS in 1996 or later when there was the widespread use of life extending medications. Because women relied on outdated information about HIV/AIDS from their neighbors and relatives many believed that HIV/AIDS was a disease that afflicted gay men only and that death was imminent upon diagnosis. This lack of correct information affected their emotional reaction to their diagnosis and delayed their turning point from their initial emotional reaction. Tina was diagnosed with HIV and AIDS in 2003. Her beliefs about HIV/AIDS were typical:

I thought it was gay, White man's disease. I actually was like in shock when they told me that I had it because I didn't really believe it. I was familiar with the story of Ryan White, you know, how he contracted it but it was through a blood transfusion so, you know, I was in shock because they were saying I had HIV and I'm like, 'Please.' I'm like, 'They are making some kind of mistake' . . . First thing I'm thinking when they say that [I have HIV] is, 'I'm not gay and I'm not White so please.' [laughter]

As a result, Tina alternated between living in denial about having the disease and believing she was dying. It was not until months later when her mother encouraged her to learn more about HIV/AIDS by attending a support group that she overcame her initial emotional reactions of denial and fear of imminent death.

### **The Interpersonal Contexts: Support and Stigma affected turning point and integration**

Support from family, friends, helping professionals and HIV/AIDS support groups was a turning point from the initial reaction to the diagnosis. Support from others also enhanced the immersion and integration phases. Pearl describes her turning point from her initial emotional reaction to her diagnosis. Her response is typical of those who were chemically dependent when they were diagnosed with HIV or AIDS.

I entered a recovery home. And the recovery home was for people who was dealing with HIV and substance abuse so I was around a lot of people like myself. In that process, we went to a lot of—I did---I went to a lot of support groups where we could just sit around and talk about—and sometimes it just didn't seem so bad. Sometimes, no. So you sit around these group of women of all races, sexual preferences and they all have the same thing—HIV. We talk about medications and different things. I still do that today.

All the women related stigmatizing experiences that affected their disclosure to others which inhibited the incorporation process. Disclosure was integral to gaining support from others around the disease. At the time of the interview, Mother chose not to tell her friends because she thought she'd be stigmatized. She stated,

Yeah. I don't tell none of my friends . . . Only people that know is my pastor and my family and the support group. As far as friends, I don't let nobody know none of that. They find out so be it. But I'm not going to tell them. . . I only talk to my pastor. I ain't going to talk to the ones in my church. I got a lot of people at church but I'm not going to talk to them about this situation. Everybody looks at you like, "Ohhhh!" I'm not ready to deal with that yet. I just keep it to myself.

### **The Sociocultural Contexts: Race and class**

Four women believed that HIV/AIDS was more stigmatized in the Black community, access to AIDS Service Organizations and HIV/AIDS information was limited in their predominantly poor, African American neighborhoods. They contended that White individuals and gay men were treated better than others in the HIV/AIDS community and discussions about heterosexual African American women's issues were lacking by comparison. Misses summed up the discrimination based on race:

[White gay men] get more opportunities. You get more access to health. You get more access to money. You get more access to services. Simple as that. I wouldn't have had to go to do so much research and finding out stuff on my own. And it's sad, and don't misunderstand me, I don't hate them--I mean we've been living with these kind of prejudices for years. I think it's sad and it really needs to stop because it's a bunch of crock when the numbers that are coming up aren't their [White, gay male] numbers no more. The Black people's numbers don't get counted. . . It's sad. A part of us just doesn't exist.

Three of the 11 women mentioned that their low economic status affected their experience with HIV/AIDS. They thought about their disease more because they relied on federal and state programs for medications and support. One individual believed she would not use support groups and instead rely on a private therapist if she were wealthier. Chanel noted that being poor also is stressful which lowers one's immunity.

### **Post-diagnostic situational contexts: Other Chronic Illness**

Seven of the 11 women mentioned that they were coping with other chronic illnesses such as herpes, hepatitis C, depression, emphysema and high blood pressure. They were more concerned about the effect of those illnesses on their health than HIV/AIDS. Consequently, the focus was on the other chronic conditions for some and their HIV/AIDS identity was less salient. Misses stated, "I think the more [important] chronic illness is COPD and the sinus stuff I am going through now. I woke up today and didn't have any voice. I'm like, 'What the hell!'"

### **Discussion**

In many ways, the contexts affecting lower-income African American women's incorporation of the HIV/AIDS identity reflected the findings of the study's larger population. Participants relied on neighbors for information about HIV/AIDS and poor individuals of all races reported not being treated well by the larger HIV/AIDS community. Support from family, friends and support groups helped with the integration of the HIV/AIDS identity.

Physical abuse and molestation was reported by a greater percentage of lower income African American women than those from other demographics. Some African American women's experiences were somewhat different. They mentioned a lack of attention to their issues in the larger HIV/AIDS community. They reported having to navigate the system and needing to fight for what they needed more than individuals from other groups. Others did not mention any differences in treatment by the medical profession or HIV community because of race, class or gender but noted they had to be very proactive with medical professionals. These individuals tended to blame individuals for not taking action instead of systemic racist, classist and sexist practices in organizations.

African American women are increasingly contracting HIV/AIDS. Health educators and other helping professionals need to know the special concerns poor, heterosexual African American women have in coping with HIV/AIDS in the context of their families and children and in navigating a racist and sexist medical community. These contexts affect integration of the HIV/AIDS identity.

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