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This chapter examines the challenges faced by African American women living with HIV/AIDS and how they learn to live with this chronic illness.

## African American Women and HIV/AIDS

Lisa M. Baumgartner

HIV/AIDS transitioned from an acute terminal illness to a chronic disease in the United States with the advent of life-extending medications (Edelman, Gordon, & Justice, 2011). Although the phrase “AIDS crisis” is rarely heard, a crisis exists for African American women in the United States because AIDS is the third leading cause of death among that population (Henry J. Kaiser Family Foundation, 2012). Although Black women represent 12% of the population, they comprise 64% of “estimated AIDS diagnoses among women” (Henry J. Kaiser Family Foundation, 2013, para. 3) and “account for the greatest share of deaths among women with HIV in 2009 (65%)” (para. 3). The rates of HIV infection for African American women living in large cities such as Baltimore, MD, Atlanta, GA, and New York City rival rates found in the general population in the Democratic Republic of Congo (Conley, 2012).

It is important to know the challenges faced by African American women as regards HIV/AIDS. In this chapter, I discuss risk behaviors and HIV/AIDS in African American women, the sociocultural and interpersonal challenges HIV-positive African American women negotiate, and the learning that occurs as a result of living with HIV/AIDS. Last, I will provide conclusions and recommendations for health educators.

### **HIV/AIDS Risk Factors and African American Women**

African American women face social factors such as “cultural beliefs, values and practices” that might put them more at risk for HIV/AIDS such as an imbalance in the male/female sex ratio and negative attitudes toward condom use (McNair & Prather, 2004, p. 107). Since African American women outnumber African American men, women are afraid to discuss condom use because they fear their partner might pursue relationships with women who do not insist on condom use (McNair & Prather, 2004). Scholars discovered that although African American women stated they *personally* would negotiate condom use, they believed African American women in general did not negotiate condom use because of fear of rejection from their partners (Jackson & Pittiglio, 2012).

Another social factor that African American women face is having sex with men who have sex with men (MSM). In a literature review that discussed bisexual Black men, HIV risk, and heterosexual transmission, the authors found that heterosexual women might be more at risk for HIV infection from Black men who identified as gay and bisexual since 22% of gay-identified men and 61% of the bisexually identified men had had sex with a woman in the last year “compared to 12% of the heterosexually identified black MSM” (Millett, Malebranche, Mason, & Spikes, 2005, p. 545). Black men were less likely to disclose their homosexual behavior to their heterosexual female partners (Millett et al., 2005). Although research concerning African American men on the “down low” (e.g., African American MSM who have sex with heterosexual women and do not disclose that they also have sex with men) and HIV/AIDS transmission might perpetuate racial stereotypes, conflates sexual identity with sexual behavior, and may advance the erroneous idea that Black MSM are a homogenous population (Ford, Whetten, Hall, Kaufman, & Thrasher, 2007), the fact remains that African American men on the “down low,” who also have sexual relations with African American women, put the women at risk for HIV infection.

African American men on the “down low” are not the only source of HIV infection for African American women. African Americans have a smaller social network than Whites given the low male–female sex ratio due to higher rates of African American male incarceration and death (Adimora & Schoenbach, 2002). Higher reported rates of concurrent sexual relationships among heterosexual African Americans may increase infection rates among them (Adimora & Schoenbach, 2002). Additionally, African American women report higher rates of vaginal douching which increases their susceptibility to sexually transmitted diseases and may increase their chances of contracting HIV (Cottrell, 2010).

In addition to personal hygiene practices, other elements may also contribute to an increased chance of HIV infection for low-income African American women. Researchers determined that low-income African American women “who reported higher levels of fatalism, optimistic bias, interpersonal power and financial independence perceived themselves to be at less risk for HIV” (Younge, Salem, & Bybee, 2010, p. 63). Low-income African American women generally knew what put them at risk for HIV. However, an optimistic and fatalistic worldview “decrease[d] risk perception among African American women even in the face of accurate knowledge about HIV risk” (p. 67). Women tended to believe that they would not experience negative events “related to sexual behavior” (p. 67). Although fatalism (e.g., believing that a higher power controls one’s health) and optimistic bias are coping mechanisms for low-income African American women in general, these traits appear to work against them as regards perceived HIV risk.

In addition to social factors, “contextual factors” or “aspects of the environment that influence an individual’s perspective and therefore have import

only for that person” (McNair & Prather, 2004, p. 107) place African American women at risk for HIV/AIDS. These factors include “environmental stress, relationship history, and victimization experiences” (p. 111). Scholars investigated the effect of poverty on HIV-risk factors. They found that 67% of the 524 low-income women had engaged in unwanted intercourse to avoid physical and verbal abuse, loss of shelter, or loss of relationship (Whyte, 2006). Women who engaged in unwanted sex were more likely to have unsafe sex and younger, poorer women had “higher levels of survival sex and [had] less safe sex than older women” (Whyte, 2006, p. 242). Additionally, women who had unwanted sex had a history of physical abuse by a partner and were less likely to request their partners use condoms for fear of being physically hurt (Kalichman, Williams, Cherry, Belcher, & Nachimson, 1998; Wingood & DiClemente, 1997). Women who possessed low relationship power “were far less likely to suggest condoms out of fear of partner violence, anger, and abandonment” (Harris, Gant, Pitter, & Brodie, 2009, p. 343). Additional factors that contributed to HIV risk included African Americans being more likely to live in poverty than Whites (U.S. Department of Health and Human Services, 2012), having less access to affordable healthcare (Peek et al., 2012), and African American women facing the stigmas of race, class, and gender (Berger, 2004).

### **African American Women’s Challenges of Living With HIV/AIDS**

African American women cope with factors that place them at increased risk for contracting HIV/AIDS and also face challenges in living with HIV/AIDS. In this section, I will explore how the intersections of the sociocultural context (e.g., race, class, gender, and culture) and the interpersonal context (e.g., stigma) create challenges for African American women living with HIV/AIDS (Ickovics, Thayaparan, & Ethier, 2001).

HIV-positive African American women experience multiple stigmas due to race, class, and gender. Researchers examined HIV-positive stigma discrimination among African American and White women. White women reported more HIV-related discrimination than African American women but it had no effect on measures of stress, self-esteem, and suicidal ideation (Wingood et al., 2007). In contrast, African American women who recounted HIV discrimination reported increased stress, lower self-esteem, and higher degrees of suicidal ideation. The authors posited that HIV discrimination might have been underreported by African American women due to internalized oppression, having more difficulty talking about HIV discrimination with researchers, or because African American women might have attributed their HIV-discrimination experiences to racial discrimination. The authors concluded that because African American women cope with racial discrimination and some experience poverty that “may enhance their vulnerability to the adverse health outcomes associated with HIV-discrimination” (p. 109).

Melton (2011) noted that HIV-positive Black women were especially stigmatized because of the racist image of African American women being “sexually loose” (p. 300). Participants reported how “intersectional stigma and stereotypes” informed their experiences (p. 303). For example, a participant who lived in a drug-infested, economically challenged area of the city divulged her HIV-positive status to few people because she knew she’d be viewed as a drug addict or sex worker. Melton found that HIV-positive women were “marginalized from the margins” because revealing one’s status could alienate individuals’ Black female networks of friends or “sista’ circles” (p. 308). Consequently, some women did not seek HIV education or care for fear of losing their African American women support networks (Melton, 2011).

In addition to experiencing external stigma such as being seen as promiscuous, scholars discovered that African American women experienced HIV stigma internally as “existential despair” (Buseh & Stevens, 2007, p. 8). Upon diagnosis, they feared death and believed they deserved the disease. They were shunned when their status was revealed (Buseh & Stevens, 2007). Last, institutional stigma occurred when social workers, prison officials, and hospital workers treated participants disrespectfully. Strategies to resist stigma included gaining support from family and friends, finding role models who lived with the disease, using their spirituality to cope with the disease, and advocating for HIV/AIDS-related causes (Buseh & Stevens, 2007).

### **African American Women and Learning to Live With HIV/AIDS**

Learning to live with stigma can be one aspect of learning to live with a chronic disease. As regards chronic illness, learning is implicitly and explicitly discussed in the literature. Specifically, chronically ill individuals engage in self-directed learning although African Americans’ learning experiences are not the focus of the studies (Holland, 1992; Rager, 2006). Alan Tough (1971), who popularized the notion of self-directed learning, examined the self-planned learning of adults in Ontario, Canada. He discovered that adults engaged in learning projects, which he defined as “a highly deliberate effort to gain and retain certain definite knowledge and skill or to change in some way” (Tough, 1978, p. 250). Tough (1978) noted that the learning project had to be seven hours in duration and the learning sessions could occur in several episodes. Learning projects can be undertaken to “gain new knowledge, insight or understanding,” to gain skills, or to change attitudes or behaviors (Tough, 1971, p. 1). Tough (1971) asserted that roughly 70% of all learning projects were planned by the learner who used individuals such as experts and media sources such as books or magazines to learn.

Like men and women living with cancer (Rager, 2006), African American women living with HIV/AIDS engaged in self-directed learning (Baumgartner, 2012). Women learned about HIV/AIDS from talking with individuals such as doctors or caseworkers or peers in HIV/AIDS support groups or seminars sponsored by AIDS Service Organizations (ASOs). Hearing others’ experiences

of living with HIV/AIDS was a preferred way to learn. Women read magazines, online newsletters, and websites such as the Center for Disease Control (CDC) website. Last, although her study was not framed using self-directed learning theory, Schaefer's (2005) investigation of the lived experience of fibromyalgia in African American women showed that participants engaged in self-directed learning as evidenced by searching for information about the disease on the Internet and reading books on the subject.

In addition to self-directed learning, transformative learning can occur as the result of contracting a chronic illness. Mezirow (2000) says that there can be a transformation of one's beliefs or attitudes (meaning schemes) or a transformation of one's entire worldview (perspective transformation). Mezirow (2000) delineates a 10-phase transformative learning process. Critical to this process is the presentation of a disorienting dilemma such as an HIV/AIDS diagnosis. This disorienting dilemma might prompt individuals to critically reflect on their assumptions about the world (what is really important in life?) and decide on new priorities (helping others is more important than amassing material possessions).

Although the transformative learning of individuals living with various chronic illnesses including HIV/AIDS (Courtenay, Merriam, & Reeves, 1998) and multiple sclerosis (Lewis, 2009) has been investigated, the learning experiences of people of color has not been a focus of these investigations. Regarding African Americans' experiences of chronic illness using a transformative learning framework, Ntiri and Stewart (2009) explored "the effect of an education intervention utilizing TL principles on functional health literacy and diabetes knowledge of African Americans" (p. 101). Twenty participants completed the required testing and transformative learning activity. Participants attended six diabetes education sessions, which was the transformative learning intervention, over three weeks. These course sessions motivated participants to search for more knowledge on diabetes and "to improve self-management of their illness" (p. 110).

Informal, incidental, and tacit learning can also occur for individuals living with a chronic disease. Self-directed learning is a type of informal learning where learners intentionally plan and carry out learning projects such as how to build a deck (Merriam, Caffarella, & Baumgartner, 2007). Incidental learning is accidental learning that occurs as "a by-product of doing something else" (p. 36). An example of incidental learning occurred when African American women attended an HIV/AIDS support group to learn more about how the disease was transmitted, and they met long-term survivors and realized that Persons Living with HIV/AIDS (PLWHAs) can live long, productive lives (Baumgartner, 2012). Last, tacit learning is akin to socialization and is not conscious learning although individuals might become aware of this learning at a later date (Marsick & Watkins, 1990). An example of this type of learning happened when study participants realized that ASOs and support groups socialized members into engaging in HIV/AIDS advocacy behavior (Baumgartner, 2012).

Last, individuals learned more about HIV in nonformal settings. Nonformal educational opportunities are “learning opportunities *outside* the formal educational system” (italics in original) and they generally have a curriculum and a facilitator (Merriam et al., 2007, p. 30). HIV/AIDS education programs, HIV/AIDS support groups, and group meetings for recovering addicts living with HIV/AIDS are examples of nonformal education. Since the sample was solicited from ASOs, all participants engaged in nonformal education through support groups and HIV/AIDS trainings at ASOs (Baumgartner, 2012).

## Conclusions and Recommendations

Living and learning with HIV/AIDS occurs in community. Various contexts including interpersonal (e.g., stigma and support) and sociocultural (e.g., race, class, gender, and culture) affect individuals’ experiences of living with HIV/AIDS in the community (Ickovics et al., 2001). Women experience multiple stigmas because of their race, gender, socioeconomic status, and HIV-positive status in the community. However, support services that cater to PLWHAs can mitigate some of that stigma.

Scholars assert that “framing institutions” (Watkins-Hayes, Pittman-Gay, & Beaman, 2012, p. 2028) and “framing agents” (p. 2032) within those institutions greatly influence how African American women cope with HIV/AIDS. Framing institutions “generate language, adaptive skills, and practical knowledge that shape how individuals interpret a new life condition and whether they ultimately see it as a platform for growth” (p. 2030) and include hospitals, clinics, and prisons. Framing agents are “actors within these institutions who individually inform how illness is constructed and addressed, offering explicit and implicit directives for coping” (p. 2030) and include nurses, doctors, and other healthcare professionals. Framing institutions “operate as intermediaries between micro-level perceptions and actions and macro-structural forces and systems positioned between one’s personal response to a new circumstance and the larger set of privileges and disadvantages that she experiences due to [African American women’s] social location” (p. 2030). Researchers interviewed 30 African American women living with HIV/AIDS and found that framing agents and institutions affected how individuals coped immediately after diagnosis and how newly diagnosed participants conceptualized HIV/AIDS (Watkins-Hayes et al., 2012). Framing institutions helped participants learn how to talk about their disease and provided access to resources. Some framing institutions helped participants see their diagnosis in a positive light. African American women less tied to framing agents did not cope as well with HIV/AIDS (Watkins-Hayes et al., 2012). Alternatively, some framing agents did not frame the disease positively (e.g., telling prisoners to remain silent about their diagnosis) which caused participants to engage in maladaptive coping behaviors (Watkins-Hayes et al., 2012).

Depending on how issues regarding living with HIV/AIDS are addressed, framing institutions and framing agents can either empower or disempower

PLWHAs (Watkins-Hayes et al., 2012). It is important that ASOs recognize the multiple stigmas that African American women contend with in order to provide support services for them. For example, support groups that cater to African American women and issues particular to them are needed. Further, programs that focus on sexual assertiveness as regards condom use and the availability of counseling sessions for women who have experienced sexual and physical abuse are needed so women can be empowered to take charge of their intimate relationships with others.

Given that low relationship power predicted a lack of condom negotiation, Harris et al. (2009) recommend that prevention programs should focus on helping women “cognitively restructure the way they approach and define power within their interpersonal relationships with men” (p. 345). High relationship power led to “incredibly powerful reductions in HIV risk and it explains 40% of variance in perceived HIV risk behavior” (p. 346).

Regarding learning, it is clear HIV-positive African American women engage in nonformal education, and self-directed and incidental learning. Many prefer learning about HIV/AIDS from others although they also utilize print materials and the Internet (Baumgartner, 2012). Framing institutions should know that peer support groups, groups led by professionals, and guest speakers are preferred ways for African American women to learn about HIV/AIDS. Seeing and hearing from long-term survivors was especially helpful to HIV-positive African American women.

Last, additional research is needed in a variety of areas. First, additional research is needed to determine whether HIV infection among heterosexual African American women is driven by a smaller group of bisexual HIV-positive men whose risk behavior is unknown or a large group of “exclusively heterosexual black men who have comparatively lower HIV prevalence but high HIV risk behavior” (Millett et al., 2005, p. 575). Second, there is a dearth of research on the experiences of PLWHAs living in rural areas including African American women. Findings from this research could add depth to the extant literature. Third, community-based participatory research has been lauded as a potentially effective research methodology for studies concerning HIV/AIDS prevention, care, and treatment (Rhodes, Malow, & Jolly, 2010). However, more studies using this methodology are needed that discuss the concerns of African American women.

In sum, African American women are more at risk for contracting HIV/AIDS than women from other demographics. They also face special challenges in living with HIV/AIDS in a racist, sexist, and classist society. “Framing institutions” (Watkins-Hayes et al., 2012, p. 2028) such as ASOs and hospitals and “framing agents” (p. 2028) such as social workers and HIV/AIDS educators can provide the language and support necessary for individuals to transition from thinking they will die from HIV/AIDS to living with HIV/AIDS (Watkins-Hayes et al., 2012). HIV/AIDS educators need to recognize the challenging conditions under which African American women live with HIV/AIDS and provide learning opportunities tailored to their preferences. Last, HIV-positive

African American women might be underrepresented at the planning table when various “framing institutions” (Watkins-Hayes et al., 2012, p. 2028) convene program planning meetings, and their voices need to be heard.

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*LISA M. BAUMGARTNER is an associate professor in the adult education and human resource development program in the Department of Educational Administration and Human Resource Development at Texas A&M University.*