HIV-related Stigma Among an Urban Sample of Persons Living With HIV at Risk for Dropping Out of HIV-oriented Primary Medical Care

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HIV-related stigma is one of the greatest barriers to preventing and ending the HIV epidemic. The purpose of our study was to examine HIV-related stigma among urban adults voluntarily seeking HIV-oriented primary medical care and at risk for dropping out after enrolling. The baseline cross-sectional analysis of perceived HIV-related stigma upon enrolling in care examined the level of HIV-related stigma and its sub-domains: personalized, disclosure, negative self-image, and public attitudes. Our study also identified precursors of HIV-related stigma and associated outcomes. HIV-related stigma continues to be a significant problem for persons living with HIV; those perceiving higher levels of HIV-related stigma reported a poorer quality of life, both physically and mentally. The relationship between HIV-related stigma and mental health was closely connected in our sample.

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The HIV epidemic continues to be a domestic and global health crisis despite the advent of antiretrovirals that have dramatically transformed HIV into a manageable, chronic disease. According to the Centers for Disease Control and Prevention (CDC, 2012), more than 1.1 million persons are living with HIV in the United States. Of those, nearly one in five is unaware of being infected with HIV (CDC, 2012) and 42% are living with AIDS (CDC, 2013). Since the beginning of the epidemic, transmission patterns have changed from affecting primarily White, gay men to men who have sex with men of all races and ethnicities, heterosexuals, persons of color, women, and persons with mental health, addiction issues, and unstable housing (CDC, 2013).

One of the greatest barriers to preventing and ending the HIV epidemic is the stigma associated with the disease and its associated risk behaviors (The White House Office of National AIDS Policy, 2010). Among both sexes, across racial and ethnic groups, and regardless of sexual orientation or geographic location, HIV-related stigma is a common experience among persons living with HIV (PLWH; Logie & Gadalla, 2009; Relf, Mallinson, Pawlowski, Dolan, & Dekker, 2005; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Wolitski, Pals, Kidder, Courtnay-Quirk, & Holtgrave, 2009).

Stigma is a complex, multidimensional phenomenon characterized by an attribute that spoils a person's social identity, making him or her different from what society expects or anticipates in a person or group

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(Goffman, 1963; Scambler, 2009). Persons with such spoiling attributes–the mentally ill, substance users, commercial sex workers, men who have sex with men, transgender persons, individuals from diverse racial and ethnic groups, and PLWH–are stigmatized because they deviate from what is considered to be normal by mainstream society. The personal experience of stigma is subjective and is partly dependent on the stigmatizing condition and the social circumstances of the individual (Fife & Wright, 2000).

Regardless of the attribute, stigmatized people are frequently devalued, shunned, and negatively viewed by society (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Fife & Wright, 2000; Herek & Glunt, 1988; Kalichman et al., 2009; Scambler, 2009). The most detrimental aspect of stigma occurs when it is internalized. This form of stigma occurs when an individual accepts or shares the same beliefs about the attribute or self as the stigmatizer (Kalichman et al., 2009). Courtwright (2009) further explicated this crucial aspect of stigma in a manner that conveyed the serious impact the phenomenon could have on the day-to-day lives of PLWH. He contended:

> When you stigmatize someone, your aim is not to merely respond to a trait that *you* find undesirable but to mark that person in such a way that *they* find the trait undesirable … It encourages the stigmatized person to hide part of himself from the world; to disguise what is marked because it is perceived – by others and then by self – as *disgusting.* (Courtwright, 2009, p. 91)

It is the internalized disgust that makes one feel deeply ashamed, turns the person on self, and ultimately results in a profound alienation from the self (Courtwright, 2009). The alienation, inferiority, shame, and internalized hate caused by this aspect of stigma ultimately creates changes in behavior. These changes can be manifested as a fear of HIV testing, poor adherence to medical appointments and medications, and not disclosing one's HIV status to others (Vanable, Carey, Blair, & Littlewood, 2006).

In many cases, PLWH have already experienced some form of stigma prior to being diagnosed with HIV. Preexisting stigma is frequently a result of other personal attributes such as mental illness, being from a minority racial or ethnic group, self-identifying as gay or bisexual, being poor, and/or living as a transgender person. It can also be a result of risk factors associated with HIV transmission, including engaging in same-sex relationships, having multiple sexual partners, injecting drugs, and/or engaging in commercial sex work. Preexisting stigma may have already led to perceived feelings of being devalued and shunned by society, which is exacerbated by a diagnosis of HIV. Understanding how specific personal attributes and risk factors are associated with HIV-related stigma is important for designing future stigma-reducing interventions.

HIV-related stigma is unlike other types of health-related stigmas in its nature and severity. HIV-related stigma appears to be more severe than other health-related stigmas such as those associated with tuberculosis, epilepsy, or cancer (Mak et al., 2006; Scambler, 2009; Vanable et al., 2006). The stigma associated with HIV is different because the illness is associated with deviant behavior and HIV is contagious. Because some people view same-sex sexual behaviors and/or having multiple sexual partners as immoral or religiously sanctionable, HIV-infected persons are often blamed for becoming infected. Further, risk for HIV remains poorly understood by society and death from HIV is undesirable. Despite treatment advances, widespread public education and prevention campaigns, and changing societal views about homosexuality, HIV still arouses negative responses and remains a highly stigmatized condition in the United States (Vanable et al., 2006).

HIV-related stigma is associated with individuals delaying HIV testing, accessing treatment inconsistently or late in the disease process, unnecessary disability and/or death, nonadherence to antiretroviral therapy, a loss of productivity, and a diminished quality of life (Mallinson et al., 2005; Sayles et al., 2009; The White House Office of National AIDS Policy, 2010). For many, HIV-related stigma increases the difficulty of disclosing one's HIV status to members of the social network, sexual partners, and even health care providers (Deacon & Boulle, 2007; Relf et al., 2009). Overall, HIV-related stigma impedes the ability of the infected person to self-manage the disease, exacerbating health care disparities in vulnerable populations (Courtwright, 2009).