

How does stigma affect HIV prevention and treatment?

What is HIV stigma?

HIV-related stigma is a significant problem globally. HIV stigma inflicts hardship and suffering on people living with HIV and interferes with research, prevention, treatment, care and support efforts.

HIV-related stigma refers to negative beliefs, feelings and attitudes towards people living with HIV, their families and people who work with them. HIV stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many vulnerable populations who are disproportionately affected by HIV (such as the stigma of homosexuality, drug use, poverty, migration, transgender status, mental illness, sex work and racial, ethnic and tribal minority status) predates the epidemic and intersects with HIV stigma, which compounds the stigma and discrimination experienced by people living with HIV (PLWH) who belong to such groups.¹

HIV-related discrimination, also known as enacted HIV stigma, refers to the unfair and unjust treatment of someone based on their real or perceived HIV status. Discrimination also affects family members and friends, caregivers, healthcare and lab staff who care for PLWH. The drivers of HIV-related discrimination usually include misconceptions regarding casual transmission of HIV and pre-existing prejudices against certain populations, behaviors, sex, drug use, illness and death. Discrimination can be institutionalized through laws, policies and practices that unjustly affect PLWH and marginalized groups.¹

How do people cope with stigma?

Several factors help individuals cope with HIV-related stigma, and respond to feelings of worthlessness, depression, and anger associated with their diagnosis. Many people learn to manage or cope with stigma quite well and have very positive relationships not impacted greatly by stigma, especially if they have supportive family and friends.

Social support. For many PLWH, social support can help buffer the impact of any stigma. A study of African American PLWH found many had experienced stigma and discrimination, but the impact was softened by having non-PLWH in their social networks express interest and take the initiative to offer help. Connection with other PLWH gave them an opportunity to share their feelings and to fight for their rights.² A study of young African American men who have sex with men (MSM) found that stigma of racism and homophobia was associated with delayed HIV testing, but that men with peer support tested earlier.³

Adapting and coping. Although it can be difficult for persons in already stigmatized communities to identify as HIV-positive, many PLWH do accept their HIV status and successfully form an identity of being pro-active and choosing to live. Adequate treatment for depression and anxiety, along with acceptance of one's diagnosis, provide a protective buffer against stigma and promote acceptance of lifelong HIV treatment.⁴

How is HIV stigma harmful?

Stigma and discrimination add barriers which weaken the ability of people and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

To persons living with HIV. Fear of stigma, discrimination and potential violence, may keep people from disclosing their status to family, friends and sexual partners. This can increase isolation and undermine their ability to access and adhere to treatment, and undermine prevention efforts such as using condoms and not sharing drug equipment. Enacted stigma can result in losing housing and jobs, being ostracized by family, and being treated badly in healthcare facilities, among other effects.

To vulnerable populations. The way people experience stigma varies across countries and communities. Stigma discourages people from seeking information and programs, for fear it will make others think they have HIV, are promiscuous or unfaithful, or are members of populations associated with HIV, like people who inject drugs, sex workers and gay men. It can make people less likely to get tested for HIV, use condoms, ask their partners about their status, use clean needles and injection equipment, or access biomedical prevention options such as male circumcision and pre-exposure prophylaxis (PrEP).

How is HIV stigma addressed?

Stigma exists, and should be targeted at multiple levels: individual, interpersonal (family, friends, social networks), organizational, community and public policy.⁵ Involving PLWH in the design, creation, implementation and evaluation of stigma reduction programs is critical to success.

Individual level

Increasing individual knowledge about HIV transmission, prevention and care, as well as access to services and legal rights is important. One study in South Africa found that while some PLWH experienced stigma through insults and arguments with family members during conflict, they knew that disclosing someone's status without their consent was a crime. In these instances, threatening to go to the police, or sometimes actually calling the police, allowed PLWH to fight back and maintain their self-esteem.⁶

Interpersonal level

The We Are Family campaign from Greater Than AIDS and the Georgia Department of Public Health, reinforces the importance of social support for PLWH. The video campaign features a grandmother and her grown son, a college student and his parents, a pastor and his congregation, a recovering addict and his mother, a transgender woman and her sister, and childhood best friends, all supporting one another following an HIV diagnosis.⁷

Organizational level

Healthcare providers are often named by PLWH as important sources of stigma.⁸ Programs for training healthcare workers⁹ should address culturally-specific stigma drivers, including personal fears of infection, prejudice towards vulnerable groups, and misconceptions or lack of knowledge about HIV transmission, prevention, treatment and universal precautions.¹⁰ Programs also should address how the effect of stigma, discrimination, breaches of confidentiality and negative attitudes can negatively impact patients' lives, health, and ability to follow treatment regimens.

Biomedical and behavioral approaches to HIV prevention, such as PrEP, routine HIV testing, starting treatment soon after diagnosis (test and treat), and treatment for PLWH to viral suppression, have been successful in the US and several countries in reducing new HIV infections and improving the life and health of PLWH. However, HIV stigma and discrimination can greatly impact the success of these interventions. Stigma surrounding PrEP use, including assumptions about promiscuity, can negatively affect PrEP access and uptake.¹¹ Prejudice among healthcare workers may result in drug users, young adults, women¹² and other marginalized populations not being offered either PrEP or HIV testing.

Community level

The Let's Stop HIV Together campaign, launched by the Centers for Disease Control and Prevention (CDC), raises awareness about HIV and its impact on the lives of all Americans, and fights stigma by showing that persons with HIV are real people—mothers, fathers, friends, brothers, sisters, sons, daughters, partners, wives, husbands, and co-workers. The campaign offers facts about HIV, links to testing sites across the US, guidance for taking action against stigma, and online stories about PLWH, and the people who care for them.¹³

Policy level

In Ghana, the Commission on Human Rights and Administrative Justice, the Ghana AIDS Commission and the Health Policy Project developed a web-based mechanism for PLWH to report discrimination in employment, health care, education and other areas. Reports can be anonymous, and all reports result in mediation, investigation and legal resolution by human rights and legal organizations.¹⁴

What needs to be done?

Both the US White House and UNAIDS reports recommend focusing on key populations that have high and disproportionate rates of HIV, and are at higher risk for transmitting and acquiring HIV.^{1, 15} Reducing stigma for other conditions common among persons at risk for or living with HIV—such as substance use, mental health problems, sex work and homelessness—and addressing homophobia are important efforts to improve health outcomes. However, promotion of disclosure of HIV status must be accompanied by protections for PLWH. This calls for a continued commitment to civil rights enforcement.

Says who?

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Special thanks to the following reviewers of this Fact Sheet: Sarah Calabrese, Barbara Green-Ajufo, Cynthia Grossman, William Holzemer, Sebastian Kevany, and Daryl Mangosing, Cynthia Tucker. Reproduction of this text is encouraged; however, copies may not be sold, and the University of California San Francisco should be cited as the source. Fact Sheets are also available in Spanish. ©2016, University of CA. Comments and questions about this Fact Sheet may be e-mailed to CAPS.web@ucsf.edu.

This publication is a product of a Prevention Research Center and was supported by Cooperative Agreement Number **5U48DP004998** from the Centers for Disease Control and Prevention.