

Stigma and Discrimination Threats to Living Positively with Human Immunodeficiency Virus



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KEYWORDS

- Human immunodeficiency virus • AIDS • Stigma • Discrimination • Positive Living
- Disclosure

KEY POINTS

- Over the past 2 decades, the number of individuals remaining healthy and living longer with human immunodeficiency virus (HIV) has increased dramatically.
- With the advancement of HIV treatment, individuals with HIV are living longer and enjoying a higher quality of health.
- If individuals are to have the opportunity to live positively with HIV, it will be necessary to challenge aggressively the beliefs and attitudes that result in stigma and discrimination against this population.

Thirty years into the HIV epidemic, we still have major discrimination and stigma related to HIV, as well as laws and law enforcement that drive people away from HIV services. Such situations are undermining the HIV response across the world. This will only change if we make major investments in programmes to reduce such stigma and increase access to justice for those affected by HIV.
—Michel Sidibe, UNAIDS Executive Director, 2011¹

Over the past 2 decades, the number of individuals remaining healthy and living longer with human immunodeficiency virus (HIV) has increased dramatically. In addition, the number of new cases of HIV, AIDS-related deaths, and HIV infections in children has decreased globally.² These changes are a direct result of advances in treatment and the development and availability of more effective antiretroviral medications.^{2–4} Despite such treatment advances, individuals with HIV continue to confront challenges to living positively, including being subject to stigma and discrimination. The following is a historical overview of the concept of stigma and an exploration of the causes and consequences of multilevel stigma for individuals with HIV. In addition, strategies individuals and societies use to manage stigma and avoid negative experiences are discussed.

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UNDERSTANDING STIGMA

To understand HIV-related stigma, it is first necessary to examine the concept of stigma and its origins. Goffman⁵ defined stigma as a characteristic or attribute that discredits an individual or a group. Society and its related culture establish what is considered normal or acceptable.⁵ Stigma denotes a negative variation or departure from what are considered normal characteristics or attributes of individuals or groups. Variance from normal expectations often results in prejudice, discrimination, stereotyping, and distancing.^{5,6} The ancient Greeks used the term *stigma* to refer to a sign or mark that was cut or burned into the body to indicate that the bearer was a slave, criminal, or traitor—that is, a blemished person who is ritually polluted and to be avoided, especially in public places.⁵ In modern usage, the word usually refers to marks that are unseen.

Stigma and the negative responses to individuals thought to be different or unworthy—a phenomenon common in humans and animals—have continued over the centuries and across cultures and geographic regions. Individuals and groups can be stigmatized for a variety of reasons, including physical characteristics, ethnic or racial group membership, socioeconomic status, lifestyle, and medical conditions.⁷

Fear often underpins stigma. Individuals or groups who are perceived to pose a threat are targets for stigmatizing behaviors and negative actions. The act of stigmatizing an individual or a group allows and justifies actions such as discrimination, ostracization, and economic and social violence toward the stigmatized, actions that would otherwise be unacceptable. By stigmatizing the individual or group, it becomes acceptable to blame the individual or group for possessing the stigmatizing attribute, which in turn supports the concept of punishment for the stigmatized.⁸

HUMAN IMMUNODEFICIENCY VIRUS STIGMA

Not surprisingly, when HIV—a life-threatening illness with an unknown transmission source—was identified in the early 1980s,^{9–11} it immediately invoked fear across society. From the start, HIV has been characterized by fear, stigma, and discrimination of people who have or are perceived as being at risk for contracting HIV.^{1,7} HIV stigma results from a complex set of attributes, such as the fear of contracting a contagious, life-altering illness.¹² This fear often is overlaid with negative attitudes and beliefs toward groups or lifestyles thought to be associated with the disease.¹²

The fact that HIV initially was referred to as the “gay plague”¹³ suggests early efforts by society to distance themselves from individuals at risk for HIV (gay men).^{14,15} Furthermore, the term *plague* seemingly provided validity to the notion that HIV was a punishment from God for immoral or deviant behaviors.¹⁶ These efforts also represent a case of *othering*, a process in which individuals subordinate certain peoples they perceived to be inferior in order to create superior identities for themselves.¹⁷ The act of othering has been identified globally in many different cultures and is often based on racism, sexism, or homophobia.^{12,18,19} Part of othering involves using behaviors and attitudes to distance oneself from the illness and its associated negative consequences and attributes, thereby supporting the contention that those individuals with HIV/AIDS are different from me.⁷

Causes and Double Stigmas

When members of one group are stigmatized for one reason, it is all too easy for society to stigmatize them further if they have HIV. First found in homosexual men, HIV later was discovered in Haitian immigrants, intravenous drug users, and people of color.^{9,10} Individuals in these groups often were viewed as immoral and different from

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