

HIV / AIDS Stigma – from Wikipedia: <http://en.wikipedia.org/wiki/AIDS#Stigma>

Stigma



 AIDS Awareness Sign. [Ho Chi Minh City, Vietnam](#) (August 2005). Photo by Peter Rimar.

AIDS stigma exists around the world in a variety of ways, including [ostracism](#), [rejection](#), [discrimination](#) and [avoidance](#) of HIV infected people; compulsory HIV testing without prior [consent](#) or protection of [confidentiality](#); violence against HIV infected individuals or people who are perceived to be infected with HIV; and the [quarantine](#) of HIV infected individuals.^[118] Stigma-related violence or the fear of violence prevents many people from seeking HIV testing, returning for their results, or securing treatment, possibly turning what could be a manageable chronic illness into a death sentence and perpetuating the spread of HIV.^[119]

AIDS stigma has been further divided into the following three categories:

1. Instrumental AIDS stigma—a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness.^[120]
2. Symbolic AIDS stigma—the use of HIV/AIDS to express attitudes toward the social groups or lifestyles perceived to be associated with the disease.^[120]
3. Courtesy AIDS stigma—stigmatization of people connected to the issue of HIV/AIDS or HIV- positive people.^[121]

Often, AIDS stigma is expressed in conjunction with one or more other stigmas, particularly those associated with [homosexuality](#), [bisexuality](#), [promiscuity](#), and intravenous drug use.

In many [developed countries](#), there is an association between AIDS and [homosexuality](#) or [bisexuality](#), and this association is correlated with higher levels of sexual prejudice such as [anti-homosexual](#) attitudes.^[122] There is also a perceived association between all male-male sexual behavior and AIDS, even sex between two uninfected men.

Those most likely to hold misconceptions about HIV transmission and to harbor HIV/AIDS stigma are people with high levels of religiosity, conservative political ideology and less educated people.^{[120][122][123]}

For more details on this topic, see [Stigma and HIV-AIDS, A review of the literature](#)^[124]

Stigma and access to care

The literature devoted to stigma and access to care falls roughly into three categories. Most of the literature deals with barriers to care that HIV-positive individuals encounter across the continuum from HIV diagnosis to end of life. The next largest category of studies documents the reluctance of health care providers to treat individuals with HIV infection. Finally, a few studies cover the stigma experienced by providers of ancillary and support services to people living with HIV/AIDS.

INDIVIDUALS

HIV/AIDS-related stigma affects issues related to HIV testing including delays in testing, the effect of delay on further transmission of HIV, and individuals' responses to testing positive (Chesney and Smith, 1999). Early detection of HIV infection is important. Knowledge of one's HIV seropositivity can lead to earlier treatment and improved outcomes (Herek, 1990). Knowledge of seropositivity also can lead to changes in risk behaviors that can reduce or eliminate the risk of HIV transmission.

A Kaiser Health Poll report (2000) suggested that fear of being stigmatized by HIV/AIDS has some relationship to people's decisions about getting tested for HIV. One-third of survey respondents said that if they were tested for HIV, they would be "very" or "somewhat" concerned that people would think less of them if they discovered that they had been tested. In addition, 8 percent of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to have the test.

Studies provide evidence that stigma is associated with delays in HIV testing among individuals who are at high risk of being infected with HIV (Myers et al., 1993; Stall et al., 1996). In a study of gay and bisexual men who were unaware of their HIV status,

two-thirds of the participants expressed a fear of discrimination against people with HIV and said it was a reason for not getting tested (Stall et al., 1996).

Earlier in the epidemic, HIV stigmatization was shown to influence the way in which at-risk populations approached HIV testing. People at risk for HIV infection were more likely to seek testing that was offered anonymously (i.e., no names were recorded) than testing that was offered confidentially (i.e., names were kept in confidential files) (Fehrs et al., 1988; Johnson et al., 1988).

HIV/AIDS-related stigma also influences individuals' responses to testing positive: It aggravates the psychological burden of receiving a positive HIV test (Chesney and Smith, 1999). Earlier in the epidemic, there were reports of severe psychological responses to notification, including denial, anxiety, depression, and suicidal ideation (Coates et al., 1987; Ostrow et al., 1989). Over time, studies have shown a decrease in severe reactions to being notified of positive test results; however, research continues to show that notification is associated with high distress. Distress is greatest immediately after notification and typically declines within 2 to 10 weeks (Ironson et al., 1990; Perry et al., 1990).

Stigma also affects the care of HIV-positive individuals. After a person tests positive, he or she faces decisions that include how to enter and adhere to care and whether to disclose HIV seropositivity to partners, friends, family, colleagues, employers, and health care providers (Chesney and Smith, 1999). At each level, a decision to disclose seropositivity may either enhance access to support and care or expose the individual to stigmatization and potential discrimination.

HEALTH CARE PROVIDERS

Accessing health care can be a challenge for people who are HIV positive, because the health care system itself is often a source of stigma. Health care professionals, particularly those who infrequently encounter HIV-positive people, can be insensitive to their patients' concerns about stigma. In addition, health care professionals are not always knowledgeable about appropriate procedures for maintaining patient confidentiality (Herek et al., 1998).

The literature on caregiving reveals that stigmatization is evident among health care providers. Fear of contagion and fear of death have clear negative effects on health care providers' attitudes toward and treatment of HIV-positive patients (Gerbert et al., 1991; Weinberger et al., 1992).

Health care providers also may fear stigmatization themselves because of their work with HIV-positive patients (Durham, 1994). Caregivers, whether professionals or volunteers, risk what Goffman called "courtesy stigma," in which they are stigmatized as a result of their association with HIV/AIDS and people living with HIV disease. That stigma may influence their willingness to work with people with HIV or may make their work more difficult (Snyder et al., 1999).

PROVIDERS OF ANCILLARY AND SUPPORT SERVICES

Throughout the course of the HIV/AIDS epidemic, volunteers have been important participants in the nationwide response to the disease. Volunteers have worked to educate the public about HIV transmission and prevention, provided assistance to people living with HIV, donated money and resources to organizations that provide care and treatment for people living with HIV, and raised funds for research on treatment for HIV (Snyder et al., 1999).

Snyder et al. (1999) discussed stigmatization as a barrier to HIV/AIDS volunteerism and noted the power of stigma to actually punish volunteers for their good deeds. Like health care workers, HIV/AIDS volunteers may experience courtesy stigma.

Research reveals that volunteers and nonvolunteers consider HIV/AIDS volunteerism more stigmatizing than other forms of volunteerism (Snyder et al., 1999). Reports of having been made to feel embarrassed, stigmatized, or otherwise uncomfortable in connection with their volunteer activities are more common among HIV/AIDS volunteers than other types of volunteers (Omoto et al., 1998). Volunteers who had been unexpectedly stigmatized reported being less satisfied and more burned out than volunteers who expected to be stigmatized (Snyder et al., 1999). Reports of actual stigmatization predicted HIV/AIDS volunteers' burnout from their work and hastened their decision to quit (Snyder et al., 1999).

One study hypothesized that volunteers' association with HIV/AIDS and people living with the disease is responsible for their feelings of stigmatization (Snyder et al., 1999). Findings support the hypothesis that potential volunteers perceive HIV/AIDS volunteer work to be different and more stigmatizing than cancer volunteer work (Snyder et al., 1999). Potential stigmatization also prevents nonvolunteers from helping AIDS organizations.

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Violence

Violence, defined here as physical assault, is common in the United States. Although men are victims of violent crime more often than women are, women are 5 to 8 times more likely to be victims of assault in the context of intimate relationships. Studies indicate that the epidemiology of physical assault within personal relationships mirrors the epidemiology of HIV infection in women. Risk factors include poverty, unemployment, drug use, childhood sexual and physical abuse, being younger than 30 years old, and homelessness (Zierler et al., 1996; Zierler and Krieger, 1997).

Most women living with HIV—as well as those at highest risk for HIV infection—are poor and members of a minority group. They suffer violence throughout their lives that is beyond what women of higher socioeconomic status generally experience. This background of violence, along with poverty, drug use, and the burden of caring for

themselves and others, creates a number of potential obstacles or barriers to care for HIV disease and coexisting conditions (Vlahov et al., 1998).

Hate crimes are criminal actions intended to harm or intimidate people because of their race, ethnicity, sexual orientation, religion, or other minority group status (Herek, Gillis, and Cogan, 1998).

The literature indicates that violence and HIV/AIDS may be linked in other ways. Some researchers have suggested that disclosure of HIV positivity may provoke violence in intimate relationships (Gielen et al., 1997; Zierler, 1997).

One study examined the proportion of HIV-positive adults who had been assaulted by a partner or someone important to them since their HIV diagnosis and the extent to which they reported their HIV-positive status as a cause of the violence (Zierler et al., 2000). Participants were a nationally representative probability sample of 2,864 HIV-positive adults who were receiving medical care and were enrolled in the HIV Costs and Service Utilization Study. A total of 20.5 percent of the women, 11.5 percent of the men who reported having sex with men, and 7.5 percent of the heterosexual men said they had experienced physical harm since HIV diagnosis. Nearly half of that group reported HIV seropositive status as a cause of violent episodes. Factors most strongly associated with partner and relationship violence were drug dependence, homelessness, and unemployment. It follows that HIV prevention and treatment programs are appropriate settings for violence assessment and sexual assault counseling services for women and men living with or at risk for HIV infection (Vlahov et al., 1998; Zierler et al., 2000).

HIV-related stigma may contribute to victimization based on sexual orientation. Men are at higher risk for victimization than women, and people who are open about their sexual orientation are at higher risk than people who try to conceal their sexual orientation (Herek et al., 1998). People who identify themselves as gay, lesbian, or bisexual, and others who are at risk for HIV, may experience extreme stigma in the form of hate crimes.

Hate crimes have been defined as criminal actions intended to harm or intimidate people because of their race, ethnicity, sexual orientation, religion, or other minority group status (Herek, Gillis, and Cogan, 1998). Survivors of hate crimes that are based on sexual orientation are more likely than other respondents to regard the world as unsafe. Survivors may also view people as malevolent and may experience personal setbacks.

Research findings support the hypothesis that experiencing hate crimes links the victim's feelings of vulnerability and powerlessness with his or her sexual orientation and personal identity (Herek, Gillis, and Cogan, 1998). Victims may believe that their sexual orientation puts them at a higher risk for all kinds of negative experiences. Victims of hate crimes based on sexual orientation have been found to suffer greater psychological distress than victims of non-bias-related crimes (Herek et al., 1998).