

AIDS and Stigma

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Ever since the first cases were detected in the United States in 1981, people with AIDS (PWAs) have been the targets of stigma. Press accounts and anecdotal reports from the early 1980s told the stories of PWAs, and those simply suspected of having the disease, being evicted from their homes, fired from their jobs, and shunned by family and friends. Early surveys of public opinion revealed widespread fear of AIDS, lack of accurate information about its transmission, and willingness to support draconian public policies that would restrict civil liberties in the name of fighting it (Altman, 1984; Blake & Arkin, 1988; Clendinen, 1983; Herek, 1990).

After nearly two decades of extensive public education about HIV, one could hope that AIDS-related prejudice and discrimination are now relics of the past. Unfortunately, this is not the case. In 1998, an 8-year old New York girl with HIV was unable to find a Girl Scout troop that would admit her once her infection was disclosed ("HIV-positive girl," 1998). In a 1997 national telephone survey, more than one-fourth of the US public expressed discomfort about being near a person with AIDS in a variety of circumstances (Herek & Capitano, 1998). In 1996, federal legislation was enacted that singled out HIV-positive military personnel for discharge while ignoring other active-duty personnel with comparable serious medical conditions (Shenon, 1996).

Nor is the problem of AIDS stigma confined to the United States. In South Africa, an HIV-infected volunteer recently was beaten to death by neighbors who accused her of bringing shame on their community by revealing her HIV infection (McNeil, 1998). In India, AIDS workers report that people with HIV have become new "untouchables," who are often shunned by medical workers, neighbors, and employers (Burns, 1996). In rural Tanzania, having AIDS is often attributed to witchcraft and PWAs are frequently blamed for their disease (Nnko, 1998).

These are examples of *AIDS-related stigma*, a term that refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated (Herek et al., 1998; see also Alonzo & Reynolds, 1995; Crawford, 1996; Herek, 1990; Pryor & Reeder, 1993). The present paper briefly describes current knowledge about AIDS stigma in the United States. Because of space limitations, it is not intended to provide a thorough literature review, but instead highlights some major findings about AIDS stigma and cites representative studies.

Manifestations of AIDS Stigma in the United States

AIDS is a global pandemic, and persons with HIV (PWHIVs) are stigmatized throughout the world to varying degrees. AIDS stigma around the world is expressed through social ostracism and personal rejection of PWHIVs, discrimination against them, and laws that deprive them of basic human rights (Mann et al.,

1992; Panos Institute, 1990). Although AIDS stigma is effectively universal, it takes different forms from one country to another, and its specific targets vary considerably. This variation is shaped in each society by multiple factors, including the local epidemiology of HIV and preexisting prejudices within the culture, with stigma often expressed against unpopular groups disproportionately affected by the local epidemic (Goldin, 1994; Mann, Tarantola, & Netter, 1992; Panos Institute, 1990; Sabatier, 1988).

In the United States, a significant minority of the public has consistently expressed negative attitudes toward PWAs since the epidemic began and has supported punitive and coercive measures against them, including quarantine, universal mandatory testing, and even tattooing of infected individuals. Such attitudes have fluctuated in their prevalence, with the greatest support for punitive policies in the late 1980s (e.g., Blake & Arkin, 1988; Blendon & Donelan, 1988; Blendon et al., 1992; Herek & Capitanio, 1993; Herek & Glunt, 1991; Herek, 1997; Schneider, 1987; Singer & Rogers, 1986; Stipp & Kerr, 1989).

Although diminished, many of the same attitudes persist today. In a 1997 national telephone survey, support for measures such as quarantine and intentions to avoid PWAs in various situations were lower than in previous years (Herek & Capitanio, 1998). Compared to a similar survey conducted in 1991, however, more respondents in 1997 overestimated the risks of HIV transmission through casual contact and perceived PWAs as deserving their condition. Approximately one-third expressed discomfort and negative feelings toward PWAs (for more findings from the survey, see Capitanio & Herek, this issue; Herek & Capitanio, this issue).

AIDS-related discrimination in employment, health care, insurance, education, and other realms has been widely reported since the early days of the epidemic. PWAs have been fired from their jobs, evicted from their homes, and denied services (e.g., Gostin, 1989, 1990; Gostin, Curran, & Clark, 1987; Hunter & Rubenstein, 1992; Jackson & Hunter, 1992; Turner et al.,

1989). Discrimination continues to occur despite legal precedents and protective legislation (e.g., Burris, this issue; Gostin & Webber, 1998).

Stigma is manifested in its most extreme form when people perceived to be infected with HIV are physically attacked. In a 1992 survey of 1800 people with HIV or AIDS, 21.4% of respondents reported that they had experienced violence in their communities because of their HIV status (National Association of People With AIDS, 1992; see also National Workshop on HIV and Violence, 1996).

The Social Psychology of Stigmatizing AIDS Attitudes

A considerable amount of empirical research has focused on attitudes of the uninfected toward people with AIDS and AIDS-related policies. In these studies, AIDS stigma is conceptualized as a psychological attitude or as a facet of public opinion. Even a cursory examination of the literature in this area quickly reveals that AIDS-related attitudes have been conceptualized in multiple ways, including affective reactions to PWAs, attributions of blame and responsibility to PWAs, avoidance of interpersonal contact with PWAs, and support for various public policies related to AIDS (e.g., Capitanio & Herek, this issue; Herek & Capitanio, this issue; Pryor et al., this issue).

A variety of social, psychological, and demographic variables have been found to correlate with AIDS-related attitudes. Among the most consistent correlates have been age, education, personal contact with PWAs, knowledge about HIV transmission, and attitudes toward homosexuality (e.g., Gerbert, Sumser, & McGuire, 1991; Herek & Capitanio, 1997; Price & Hsu, 1992; Stipp & Kerr, 1989). Younger and better educated respondents consistently manifest lower levels of AIDS stigma than, respectively, older respondents and those with lower levels of education. Similarly, respondents who personally know a PWA tend to manifest less AIDS stigma than others. Attitudes toward PWAs tend to be more favorable and attitudes toward AIDS-related policies less restrictive to

the extent that respondents are knowledgeable about the lack of risk of HIV transmission through casual social contact, and more favorable attitudes toward homosexuality (see also Capitanio & Herek, this issue; Herek & Capitanio, this issue; Pryor et al., this issue).

Some data suggest that racial and ethnic differences exist in AIDS stigma. Members of racial and ethnic minority groups – mainly African Americans and Hispanic Americans – appear more likely than Americans of European descent to overestimate the risks of HIV transmission through casual contact and to endorse policies that would separate PWAs from others (Alcalay, Sniderman, Mitchell, & Griffin, 1989-1990; Herek & Capitanio, 1993, 1997, 1998; Herek & Glunt, 1991; McCaig, Hardy, & Winn, 1991). Such patterns may reflect differences in the credibility that minority group members attach to official AIDS information (Herek & Capitanio, 1994) which, in turn, reflect multiple cultural and historical factors (e.g., Herek & Glunt, 1993; Stevenson, 1994; Turner, 1993).

As a disease, AIDS manifests at least four characteristics likely to evoke stigma (Goffman, 1963; Jones et al., 1984). First, stigma is more often attached to a disease whose cause is perceived to be the bearer's *responsibility*. To the extent that an illness is perceived as having been contracted through voluntary and avoidable behaviors – especially if such behaviors evoke social disapproval – it is likely to be stigmatized and to evoke anger and moralism rather than pity or empathy (Weiner, 1993). Thus, because the primary transmission routes for HIV – sexual intercourse and sharing of infected needles – are widely perceived to be voluntary and immoral behaviors, people infected with HIV are regarded by a significant portion of the public as responsible for their condition and consequently are stigmatized (e.g., Herek & Capitanio, this issue).

Second, greater stigma is associated with illnesses and conditions that are *unalterable* or *degenerative*. Since the earliest days of the epidemic, AIDS has been widely perceived to be

a fatal condition (Blake & Arkin, 1988). Being diagnosed with such a disease is often regarded as equivalent to dying and those who are diagnosed may represent a reminder – or even the personification – of death and mortality (e.g., Stoddard, 1994). Despite the development of increasingly effective therapies, AIDS will probably continue to be perceived as a fatal disease by most of the US public for the foreseeable future. The new drug regimens are not effective for all who take them, and many PWHIVs do not have access to antiviral drugs.

Third, greater stigma is associated with conditions that are perceived to be *contagious* or to place others in harm's way. Perceptions of danger and fears of contagion have surrounded AIDS since the beginning of the epidemic (Herek, 1990). Its continuing prominence is evident in Americans' continuing overestimation of the risks posed by casual contact (Herek & Capitanio, 1998, this issue) and the passage of laws that criminalize acts that might transmit HIV, such as unprotected sexual intercourse (xx). Finally, a condition tends to be more stigmatized when it is readily *apparent* to others – when it actually disrupts a social interaction or is perceived by others as repellent, ugly, or upsetting. The advanced stages of AIDS often dramatically affect an individual's physical appearance and stamina, evoking distress and stigma from observers (e.g., Klitzman, 1997).

Given these characteristics, AIDS probably would have evoked stigma, regardless of its specific epidemiology and social history. Yet the character of AIDS stigma in the United States derives from the association of HIV with particular groups (especially gay/bisexual men and injecting drug users) in popular perceptions. Recognizing this fact, social psychologists have postulated several two-factor theories of AIDS stigma (Herek, 1999; Pryor et al., this issue). Many of these models describe two sources for individuals' AIDS stigma: (1) *instrumental* fear of AIDS as an illness, and (2) *symbolic* associations between AIDS and groups identified with the disease.

Instrumental AIDS stigma results from the

communicability and lethality of HIV; it reflects the fear and apprehension likely to be associated with any transmissible and deadly illness. It is perhaps best illustrated by the experiences of hemophiliacs and others who acquired HIV through receiving blood products. Compared to gay men and drug users, such individuals were not previously highly stigmatized by society (although many faced some degree of illness-related stigma). After the onset of AIDS, however, many faced rejection and isolation because of fears about the spread of HIV through casual contact (e.g., Kinsella, 1989).

Symbolic AIDS stigma results from the social meanings attached to AIDS. It represents the use of the disease to express attitudes toward the groups associated with it or the behaviors that transmit it. Currently, much of the American public continues to equate AIDS with homosexuality to a significant extent. Not surprisingly, symbolic AIDS stigma in the United States has focused principally on male homosexuality (Herek, 1999; Herek & Capitanio, this issue). At the same time, some segments of society have had different experiences with HIV and, consequently, have different symbolic associations for AIDS. In the African American community, for example, AIDS has affected not only gay and bisexual men but also a substantial number of injecting drug users, with the consequence that symbolic AIDS attitudes are closely related to attitudes toward the latter as well as the former (Capitanio & Herek, this issue; Fullilove & Fullilove, this issue).

The Personal Impact of AIDS Stigma

In the 1997 national survey mentioned above, more than three-fourths of respondents expressed the belief that people with AIDS are unfairly persecuted in our society (Herek & Capitanio, 1998). The widespread expectation that PWHIVs will face stigma, coupled with actual experiences with prejudice and discrimination, exerts a considerable impact on PWHIVs, their loved ones, and caregivers. It affects many of the choices that PWHIVs make about being tested and seeking assistance for

their physical, psychological, and social needs (Alonzo & Reynolds, 1995; Chesney & Smith, this issue; Hays et al., 1993; Klitzman, 1997; Lester et al., 1995; Lyter et al., 1987; Siegel & Krauss, 1991). For example, fears of AIDS stigma and its attendant discrimination may deter people at risk for HIV from being tested and seeking information and assistance for risk reduction (Chesney & Smith, this issue).

Apart from outright experiences of rejection and persecution, perhaps the greatest impact of AIDS stigma is its effect on PWHIVs' willingness to disclose their health status to others. Fearing rejection and mistreatment, many PWAs keep their diagnosis a secret from others, which may cause them to be socially isolated. Such isolation, in turn, prevents them from receiving social support and can contribute to their heightened psychological distress (Crandall & Coleman, 1992; Johnston, Stall, & Smith, 1995). In addition, some people with AIDS internalize societal stigma, which can lead to self-loathing, self-blame, and self-destructive behaviors (Herek, 1990; Klitzman, 1997).

The loved ones of PWAs also are at risk for AIDS stigma and its negative effects. They, too, often face ostracism and discrimination because of their association with a PWHIV. This courtesy stigma (Goffman, 1963) can often leave them without adequate social support (Folkman, Chesney & Christopher-Richards, 1994; Folkman et al., 1994; Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996; Paul et al., 1995; Poindexter & Linsk, 1999). Caregivers and advocates for PWAs, whether professionals or volunteers, also risk a courtesy stigma, which may deter them from working with PWHIVs entirely or make their work more difficult (Snyder et al., this issue).

AIDS Stigma and Public Policy

The politics of AIDS stigma have hindered societal response to the epidemic (Panem, 1988; Shilts, 1987). Mass media were initially slow to report on the epidemic, probably because of its prevalence among already stigmatized groups (Albert, 1986; Baker, 1986; Kinsella, 1989).

Extensive resources that might otherwise have gone to prevention instead were needed to respond to punitive AIDS legislation whose purpose was primarily to stigmatize and punish PWAs (Epstein, 1996; Herek & Glunt, 1993). Despite empirical data showing that needle exchange programs are likely to be effective, AIDS stigma and the stigma attached to injecting drug use have prevented the enactment of such programs (Capitanio & Herek, this issue; Stryker & Plant, this issue). Federal law and policy have consistently prevented AIDS educators from providing clear and explicit risk reduction information to individuals at risk (Bailey, 1995; Epstein, 1996; Shilts, 1987).

Recognition of the negative consequences of AIDS stigma for individuals and for public health led to enactment of statutory protections for PWHIVs (Burris, this issue). In addition to barring most discrimination based on HIV status, HIV was exempted from traditional public health practices such as partner notification and contact tracing, a pattern that was labeled *AIDS exceptionalism* (Bayer, 1991). In addition, whereas AIDS is a reportable disease in all 50 states, requirements for reporting HIV infections vary across states.

With the development of more effective treatments for HIV disease and a widespread perception that AIDS stigma has diminished substantially, support for AIDS exceptionalism has diminished. National reporting of the names of HIV-infected persons is now strongly advocated by many leaders in public health (Gostin, Ward, & Baker, 1997). Given the persistence of widespread perceptions that people with AIDS are unfairly persecuted (Herek & Capitanio, 1998), however, a rush to institute the reporting of names of PWHIVs may have deleterious consequences for increasing HIV testing among the individuals at greatest risk for infection, many of whom already distrust the government and anticipate rejection and discrimination of seropositive individuals.

Conclusion

The association of stigma with disease is not

a new phenomenon. Throughout history, the stigma attached to epidemic illnesses and to social groups associated with them have often hampered treatment and prevention, and have inflicted additional suffering on sick individuals and their loved ones (e.g., Brandt, 1987; Defoe, 1960; McNeill, 1976; Rosenberg, 1987). In this sense, the AIDS epidemic has many parallels to older epidemics of cholera and plague. What differentiates AIDS from the older epidemics is that we now have the collective insight to recognize the impact of stigma on individual lives and public health, as well as the technology to scientifically study stigma and seek to reduce it (Devine et al, this issue). One of the great challenges of the AIDS epidemic in the new millennium will be to bring our insight and technology to the problem of eradicating AIDS stigma.

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