Illness, Stigma, and AIDS

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Imagine a disease that arouses great fear throughout the United States, especially in New York and other large cities where it is rampant. Imagine that the disease has no cure and is fatal to most people who manifest its symptoms. Physicians prescribe a variety of treatments but with little success.

Imagine that people who get sick are widely assumed to have engaged in immoral behaviors – probably related to sexual behavior or consumption of drugs. Imagine that the illness strikes especially seriously among Blacks, ethnic minorities, immigrants, and the poor. Many members of these groups even believe the epidemic to be the product of a conspiracy against them by the powerful of society. If someone famous gets sick or dies from the illness, considerable speculation arises about that person's secret life.

Imagine that the lack of effective treatments leads society to focus on prevention efforts. Attempts are made to change "immoral" behaviors that are thought to predispose people to disease. A movement arises to shut down public establishments where such behaviors occur, for they are viewed as breeding grounds for the disease. Imagine that many people explain the disease as a punishment from God for sin, while others claim it is Nature's retribution for maladaptive behavior. Some commentators regard the epidemic as fortunate: It has provided a dramatic opportunity for battling unnatural and unhealthy behaviors.

Imagine that, despite assurances by public health authorities and physicians, the general public assumes the illness to be highly contagious. Consequently, the sick are viewed as dangerous. Calls arise for their quarantine. Hospitals are reluctant to accept them because of the public outcry by neighborhood residents. Some medical professionals refuse to treat them. Physicians refrain from reporting cases out of a desire to protect their patients from public stigma.

Imagine that some tolerance emerges from the horrors of the epidemic, as the public observes a stigmatized group taking care of its own who are sick. Other benefits also emerge, including notable advances in medicine, science, and public health.

The events described here all occurred in the United States during the 1832 cholera epidemic (Rosenberg, 1962/1987). The similarities between cholera in the 1830s and AIDS in the 1990s are striking. In both epidemics, the social meanings of a disease included stigmatization of those who manifested its symptoms. Historically, other illnesses have displayed similar patterns. In this paper, I shall discuss some of the cultural, social, and psychological processes through which an illness

becomes stigmatized, and the consequences of these processes for individuals with the disease.

Stigma and Illness: Historical and Cultural Background

History and Usage

Originally, the term *stigma* referred to a visible marking on the body, usually made by a branding iron or a pointed instrument.[1] The mark signified social ostracism, disgrace, shame, or condemnation. Its bearers typically were considered criminals or villains. Stigma also could refer to nonphysical characteristics. A 1907 textbook of psychiatry described a form of psychopathology known as a Stigmata of Degeneration, for example, and the Oxford English Dictionary (OED) notes a reference in 1859 to the "stigmata of old maidenhood." The OED also records that the word was used in 1597, apparently humorously, to describe the mark bestowed upon a person by an academic degree. In none of these cases was the word's meaning limited to a physical mark or blemish.

Stigma also has carried positive connotations. For Christians, stigmatic markings could signify special grace. Catherine of Sienna and other Catholic saints reportedly manifested wounds on their own bodies corresponding to those of the crucified Jesus. Some of these wounds regularly appeared or bled in conjunction with important feast days. For example, The 13th century saint, Francis of Assisi, was said to have received the stigmata while praying during the Feast of the Exaltation of the Cross.

Modern social scientists have used stigma to denote a socially undesirable characteristic and have been interested primarily in its effects on social interactions. A recent review, for example, identified stigmatized individuals as members of social groups "about which others hold negative attitudes, stereotypes, and beliefs, or which, on average, receive disproportionately poor interpersonal and/or economic outcomes relative to members of the society at large due to discrimination against members of the social category" (Crocker & Major, 1989, p.609).

In what is perhaps the best known and most enduring theoretical analysis of stigma, Goffman (1963) defined it as "an attribute that is deeply discrediting within a particular social interaction" (p.3). He described stigma as a special discrepancy between social expectations and reality. Stigma arises during a social interaction when an individual's *actual social identity* – the attributes she or he possesses – falls short of normative expectations about what that individual should be – her or his *virtual social identity*. This discrepancy is in an unfavorable direction; the individual is perceived, whether accurately or not, as unable to fulfill the role requirements of ordinary social interaction with "normals," and consequently is "reduced in our minds from a whole and usual person to a tainted, discounted one" (p.3). According to Goffman, stigma spoils an identity by preventing the stigmatized person from meeting expectations for particular kinds of social interaction. Goffman stressed that stigma is not inherent in an attribute itself, but rather in social interactions where the attribute is relevant to the participants' expectations about what the other person should be. Being Black is a source of stigma at a social gathering of White supremacists, but not in an African-American church congregation. Having AIDS is a source of stigma in many settings, but not in an AIDS support group.

Because a discrepancy between virtual and actual social identities can appear in many ways, various dimensions have been proposed on which different stigmas can be ordered. One of them is a stigma's *concealability*, the extent to which the stigmatized condition is hidden or obvious (Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984). More concealable conditions permit their holder to avoid stigma with greater ease. The physical manifestations of cerebral palsy and advanced Kaposi's Sarcoma are readily evident in social interactions, and consequently these conditions are low on concealability. Being gay or asymptomatically infected with HIV, in contrast, are usually concealable. A second important dimension on which to locate any stigma is its level of *disruptiveness* (Jones et al.,

1984) or *obtrusiveness* (Goffman, 1963), i.e., the extent to which it interferes with the normal flow of social interaction. Characteristics that are disruptive elicit high levels of stigma. A third, closely related dimension is that of *aesthetic qualities*; the more that others perceive the condition as repellent, ugly or upsetting, the more stigma is attached to it. A fourth dimension is the circumstance of the condition's *origin*, including the bearer's perceived responsibility for its cause or maintenance; observers may attach less stigma to a condition whose cause is perceived to be beyond control. A fifth dimension is the *course* of the stigma over time, with less acceptance extended to those whose condition is unalterable or degenerative. Finally, perceived *peril* from the stigmatized condition is important; others manifest more negative attitudes toward a stigmatized person to the extent that they believe they can be physically, socially, or morally tainted by interaction with him or her (Goffman, 1963; Jones et al., 1984).

At least five areas of analysis are necessary for understanding any specific instance of stigma. First, we must understand the characteristic or condition that provides the basis for stigmatization. In the case of physical disease, this means understanding its etiology, symptoms, and course. Second, we must examine the processes through which the culture attaches stigma to the condition, i.e., the cultural construction of an ideology of stigma. Third, we must analyze the formation, expression, and maintenance of attitudes toward the stigmatized by those socially defined as "normal." Fourth, we must analyze the subjective experience of having the stigma: How it is interpreted and understood, how one negotiates socially around it, and how one constructs an identity that incorporates it. Fifth, at the interpersonal level, we must analyze the interaction processes through which stigmatized individuals are identified, and through which the nonstigmatized and stigmatized negotiate their respective roles in a social interaction. These five areas of analysis can be useful in considering further the 19th century American epidemic of cholera.

A Case Study: Cholera in the United States

Prior to 1800, cholera was endemic in some parts of India and regularly was spread throughout the country by Hindu pilgrims and religious travelers. By the early 19th century, traders and military troops from Britain and other nations intercepted the traditional routes of transmission and spread cholera throughout the world. The epidemic reached the United States in 1832, and again in 1849 and 1866, probably carried by Irish emigrants travelling to Canada. Cholera is

> "caused by a bacillus that could live as an independent organism in water for lengthy periods of time. Once swallowed, if the cholera bacillus survives the stomach juices, it is capable of swift multiplication in the human alimentary tract, and produces violent and dramatic symptoms – diarrhea, vomiting, fever, and death, often within a few hours of the first signs of illness. The speed with which cholera killed was profoundly alarming, since perfectly healthy people could never feel safe from sudden death when the infection was anywhere near. In addition, the symptoms were peculiarly horrible: radical dehydration meant that a victim shrank into a wizened caricature of his former self within a few hours, while ruptured capillaries discolored the skin, turning it black and blue. The effect was to make mortality uniquely visible: patterns of bodily decay were exacerbated and accelerated, as in a time-lapse motion picture, to remind all who saw it of death's ugly horror and utter inevitability...." (McNeill, 1976, pp. 230-231).

Rosenberg's (1962/1987) history of three 19th-century cholera epidemics in the United States clearly illustrates the evolution of the social construction of disease. Cultural understanding of cholera shifted from viewing it as a moral punishment for sinners in the 1832 epidemic to, by 1866, an understanding of it as

the result of poor sanitation and public health practices.

When the 1832 epidemic struck, neither physicians nor the general public understood the bacterial transmission of the disease. Physicians believed that cholera was caused by the introduction of poisons into the atmosphere, e.g., from decaying matter. Certain conditions were thought to predispose people to succumb to these poisons. Excessive sexual activity, for example, was viewed as a predisposing factor for cholera because it "left its devotees weakened and 'artificially stimulated,' their systems defenseless against cholera" (Rosenberg, 1962/1987, p.41). Prostitutes and their customers, consequently, were considered to be at high risk.

The poor, Blacks, and immigrants all comprised additional "risk groups" for cholera. Many members of the upper and middle classes explained the poor's susceptibility to cholera as a consequence of idleness and intemperance. In reality, it resulted chiefly from living in crowded and unsanitary conditions without clean water. Rosenberg reported that so few deaths occurred in Paris outside of the lower classes that the poor regarded the epidemic as "a poison plot fomented by the aristocracy and executed by the doctors" (p.56).

In the case of Black Americans, who suffered disproportionately both from poverty and from cholera, victim blaming was complemented by racism. "Whether he was free or slave, [White] Americans believed, the Negro's innate character invited cholera. He was, with few exceptions, filthy and careless in his personal habits, lazy and ignorant by temperament. A natural fatalist, moreover, he took no steps to protect himself from disease..." (Rosenberg, 1962/1987, pp. 59-60).

Newly arrived European immigrants, the majority of whom were Catholic, also were feared. Many were kept out of the country, condemned to wander "starved and half-naked along the Canadian border" (p.62). Nevertheless, although they often were viewed as ignorant, superstitious, and distasteful, immigrants also were pitied by many Americans. The work of

priests and nuns to care for sick Catholic immigrants may even have moderated anti-Catholic prejudice, if only temporarily.

Because no effective treatment was available for cholera, public attention centered on prevention efforts, which often took a highly moralistic tone. A Connecticut physician, for example, demanded that boards of health have "the power to *change the habits of the sensual, the vicious, the intemperate*" (Rosenberg, 1962/1987, p.96). Temperance reformers argued with some success that if consumption of alcohol predisposed one to cholera, then the saloons were legally dispensing poison and should be closed. This moralism interfered with scientific observation. Physicians who could detect no clear differences in susceptibility between drinkers and nondrinkers did not broadcast their observation "for the sake of temperance and good order" (Rosenberg, 1962/1987, p.97).

To their credit, many Americans perceived the epidemic as revealing a disturbing extent of poverty, which they blamed on society rather than God or the poor. For most, however, cholera seemed to demonstrate the power of God and the futility of earthly values. It functioned to "'promote the cause of righteousness, by sweeping away the obdurate and the incorrigible,' and 'to drain off the filth and scum which contaminate and defile human society.' The great majority of those who fell before the destroyer were the enemies of God" (Rosenberg, 1962/1987, p.43). Many who did not view cholera as a direct punishment from God viewed it as the consequence of failure to observe Nature's laws. "Cholera was caused by intemperance and filth and vice – liberals emphasized – conditions which had never been imposed by God. Just as the misuse of a machine must inevitably damage it, so any abuse of our bodies would bring its inescapable punishment" (p.45).

Although physicians proclaimed (incorrectly) that cholera was not contagious, many members of the public disregarded them and responded to the epidemic by attacking and

avoiding sick persons. "In Chester, Pennsylvania, several persons suspected of carrying the pestilence were reportedly murdered, along with the man who had sheltered them. Armed Rhode Islanders turned back New Yorkers fleeing across Long Island Sound. At Ypsilanti, the local militia fired upon the mail stage from cholera-infested Detroit. Everywhere there were stringent quarantines" (Rosenberg, 1962/1987, p.37).

Hospitals for cholera patients also provoked protest. Workers in a shipyard adjoining a cholera hospital "left work so unanimously and precipitately at its establishment that their employers were unable to fulfill their contracts" (p.87). "Neighbors resorted to everything from humble petitions to arson in their efforts to have them removed. Not that respectable folk opposed cholera hospitals. Everyone agreed they were necessary – but on someone else's street" (p. 94).

In the subsequent 1849 and 1866 cholera epidemics, public attitudes changed as scientific understanding of the disease increased. Once the cholera bacillus was known to spread primarily through the vomitus and excrement of infected individuals, massive public health campaigns were mounted to destroy contaminated bedding and clothing, to improve sewage disposal and purify public water supplies, and to clean up cities. Outmoded moralistic conceptualizations of the disease yielded to a new respect for public health and medicine as Americans realized that purely material practices could prevent the spread of cholera. As Rosenberg pointed out, this shift in the paradigm for cholera did not reflect the culture's decrease in piety; rather, it was based on advances in scientific understanding that made the moralistic approach to cholera increasingly irrelevant.

Stigma and the Social Construction of Illness

In his discussion of cholera, Rosenberg (1962/1987) observed, "A disease is no absolute physical entity but a complex intellectual construct, an amalgam of biological state and social definition" (p. 5n). In other words, illnesses are socially constructed. Symptoms are noticed, correlated, and categorized as related or unrelated to the illness; the disease is labeled; theories of cause, transmission, prevention, and cure are formulated, promulgated, criticized, and revised. This process involves a series of social interactions among epidemiologists, physicians, patients and their loved ones, journalists, insurance companies, government officials, and others.

In addition to identifying symptoms and naming the disease, the social construction of illness typically includes four components. The *origin* of the disease is identified; frequently, as knowledge about it accrues, increasingly complex systems of causes are articulated. In this process, *responsibility* for the disease frequently is assigned. Simultaneously, the "*victim*" or "patient" is constructed as guilty or innocent, dangerous or benign, heroic or pitiful. Finally, *responsibility for cure* is assigned. These four components of the construction of illness can be identified both for individual manifestations of illness and for illness as a societal phenomenon. Specific sources of infection as well as ultimate or evolutionary origins are identified. Responsibility is assigned to individuals for their own illness and to groups for bringing the disease onto the community or society. Cultural images develop of individual patients as well as communities of victims. Responsibility for an individual's cure as well as responsibility for eradicating the illness from society are assigned.

During this definitional process, the culture imbues the disease with meaning by integrating it into a larger ontology. At least two dimensions of conflict pervade this constructive process. The first is a conflict between moralistic and secular worldviews. In his historical account of American reactions to venereal disease, Brandt (1987) labeled these competing views *moralism* and *secular rationalism.* In my own empirical research, I have labeled them *moralism* and *pragmatism* (our research is described below). Moralists seek to define illness as a manifestation of spiritual or supernatural forces in the material world. Disease is viewed as

divine punishment or as a test from God; the appropriate response, therefore, is increased piety, adherence to religious teachings and, in some cases, expiatic rituals. The secular or pragmatic construction, in contrast, views disease as the result of purely physical processes which threaten the public welfare and can be eliminated through direct intervention; the appropriate response is to do whatever is necessary to interfere with the disease process, e.g., through the use of drugs or vaccines, behavior change, or elimination of hazardous environmental conditions.

The moralistic construction of cholera, for example, identified it as a punishment inflicted on sinners and prescribed virtuous behavior (e.g., temperance, abstention from excessive sexual activity) as the proper prevention. Pragmatists, in contrast, identified the sources of cholera in the unsanitary living conditions of its victims; once the cause of the disease was understood, they instituted procedures that laid the groundwork for many modern public health practices, e.g., removal of garbage from streets and maintenance of sanitary water supplies (Rosenberg, 1962/1987). The pragmatic construction of illness should not be automatically equated with science and medicine, however, since medical approaches to disease often have been infused with moralism, especially in the early constructions of disease before scientific knowledge has advanced. Similarly, moralists may well understand and accept the scientific explanations of disease, but may consider them to be incomplete. For example, a leading physician offered the following comment on venereal disease in 1950.

"Mere treatment of venereal disease is certainly not the answer. And were it the answer, and were venereal diseases wiped out, it is now clear that the accomplishment would have heavy costs in the social, moral, and material life of man. A world of accepted, universalized, safeguarded promiscuity is something to look at searchingly before it is accepted" (Brandt, 1987, p.172).

The conflict between moralism and secular rationalism in public discourse on venereal disease was described by Brandt (1987). Advocates of a secular rationalist approach typically accepted sexual behavior outside of marriage as inevitable; they sought to reduce the incidence of venereal disease through distribution of prophylactics and, when effective antibiotics became available, through nonjudgmental treatment of infected individuals. Moralists, in contrast, have advocated abstinence, and have appealed both to moral values and fear of disease to encourage it; they have considered venereal disease to be symptomatic of deeper social disorder.

The ongoing conflict between moralism and secular rationalism has been apparent in contemporary debates about preventing the spread of AIDS through distributing condoms, instituting needle exchange programs, and developing safer sex educational materials for gay and bisexual men. Proponents of these policies take a nonjudgmental stance toward risk behaviors, accept that they occur, and focus on the primary goal of preventing HIV transmission. Opponents, in contrast, reject the interventions as promoting or condoning what they feel is immoral behavior; their solution is summarized by the "Just say no" slogan of the Reagan administration. For those who subscribe to this moralistic view, "the way to control sexually transmitted disease is not through medical means but rather through moral rectitude. A disease such as AIDS is controlled by controlling individual conduct" (Brandt, 1987, p.202). The primary goal of the secular rationalists is to prevent disease; the primary goal of the moralists is to prevent behavior that they consider sinful or wrong.

A second conflict pervading the social construction of illness concerns the appropriate response to persons identified as ill. Should they be cared for with compassion by the community, or should they be excluded and viewed as dangerous? This conflict is not necessarily related to that between moralism and pragmatism. Compassionate care for the sick

can be justified on either moral or pragmatic grounds, as can ostracism and retribution against them. Social constructions concerning responsibility for an illness are especially salient in this conflict. As Brandt (1987) framed the question: Is disease "merely the result of an individual's willful exposure, or should external, environmental, and social factors that might contribute to a tendency to exposure be considered?" (p.169). Writing about herpes, whose mention disappeared from the mass media when the implications of the AIDS epidemic were recognized, Brandt (1987) noted that when a disease results from voluntary behavior, victims often are viewed as having gotten what they deserve. He pointed to our culture's underlying assumption that behavior is entirely voluntary and that, once informed about risks, individuals should modify their behaviors. "The assumption that an individual's behavior is free from external forces – that life style is strictly voluntary – is explicit" (p.202).

Many Americans, including psychologists, take this highly individualistic view of human beings as rational and agentic. We have two reactions when people don't change their riskful behavior: Puzzlement and hostility. We are puzzled that everyone who "learns the facts" does not immediately alter her or his behaviors. We assume that prevention (of AIDS, lung cancer, heart disease) is both a possibility and priority for all individuals, that it takes precedence over all other physical, psychological, social, and cultural needs. We attribute responsibility entirely to the individual, ignoring the situation and culture in which that individual lives. We ignore historical relationships between communities of the ill and the larger society, disregarding the possibility that communities "at risk" may not trust or believe medical experts and government officials, or may have different priorities for which problems must be solved. After our puzzlement abates, we relegate those who cannot (or will not) change to their fate, and sometimes tolerate punitive actions against them. I shall return to these two dimensions of public debate about prevention later in my discussion of individual attitudes toward people with AIDS.

AIDS AND STIGMA

Keeping in mind these common themes in the cultural construction of illness and stigma, we now can turn to a more systematic discussion of AIDS-related stigma.[2] As used here, *AIDS-related stigma* refers to all unfavorable attitudes, beliefs, behaviors, and policies directed at persons perceived to be infected with HIV, whether or not they actually are infected and regardless of whether or not they manifest symptoms of AIDS. I purposely avoid using terms that imply individual pathology, such as "AIDS Phobia" or "AIDS Hysteria" because such labels inappropriately individualize and pathologize this social phenomenon. Instead, I propose that individuals' hostility toward people with AIDS can best be understood through psychological and sociological perspectives on stigma, prejudice, and attitudes. Individual manifestations of AIDS-related stigma represent the intersection of psychological processes with the cultural construction of the illness.

AIDS-related stigma is manifested in a variety of ways. HIV-infected people continue to be rejected by friends and relatives, fired or forced to resign from their jobs, and subjected to violent assault. Calls still are issued for their quarantine. As the number of people requiring medical care increases exponentially, making ever larger demands on already limited health care and government funds (Bloom & Carliner, 1988; Hay, Osmond, & Jacobson, 1988; Scitovsky, Cline, & Lee, 1986; Scitovsky & Rice, 1987; Seage et al., 1986), we can only expect that the problem of AIDS-related stigma will be further exacerbated. It can best be discussed by considering each of the five areas of analysis discussed earlier: The biomedical manifestations of AIDS, the cultural construction of AIDS, attitudes of the nonstigmatized, experiences of the stigmatized, and social interactions between the two groups.

The Biomedical Perspective[3]

Acquired Immune Deficiency Syndrome is diagnosed when infection with the Human Immunodeficiency Virus (HIV) has caused a person's immune system to break down to such a degree that he or she manifests conditions caused by various viruses, fungal infections, and parasites – organisms that people with healthy immune systems are able to repel successfully. Most common among these are a protozoan infection of the lung, called *Pneumocystis Carinii Pneumonia* (PCP) and *Kaposi's Sarcoma* (KS), a previously rare form of cancer that appears as purplish lesions on and in the body.[4] HIV also frequently infects the brain, with the consequence that many persons with advanced cases of AIDS display marked neurological impairment.

The amount of time between infection with HIV and diagnosis of PCP or KS can be perhaps as long as ten years. In the interim, symptoms such as chronic lymphadenopathy, night sweats and oral thrush are used to diagnose *AIDS-Related Complex*, or *ARC*. Many physicians now question the medical usefulness of ARC as a diagnosis, however, and instead have begun to think in terms of *HIV-disease*, which ranges along a continuum from initial infection to frank AIDS. This shift in terminology emphasizes that HIV infection itself signals a disease state, regardless of whether symptoms have appeared. It reflects both pessimism that, in the absence of effective therapies, most people infected with HIV will progress to frank AIDS, as well as optimism that early identification and intervention may be effective in slowing or preventing breakdown of the immune system.

The history of AIDS in the United States is usually traced to 1981, when several cases of PCP and KS were reported in previously healthy gay men (see, e.g., Fettner & Check, 1985; Shilts, 1987). HIV-infection probably has been with the human race for considerably longer, however. In some parts of Africa, HIV appears to have been endemic for decades, although the lack of medical care in those areas, along with worldwide indifference, prevented AIDS from being noticed there. When the U.S. Public Health Service, through its Centers for Disease Control (CDC), began to name the puzzling phenomenon around 1982, they initially, called it GRID: Gay-Related Immune Deficiency (Shilts, 1987). The name eventually adopted, however, was Acquired Immune Deficiency Syndrome: *acquired* because the people who had it were previously healthy – it was not congenital; *immune deficiency* because the condition was characterized by immunological weakness; *syndrome* because the immune deficiency left people vulnerable to a cluster of infections and KS.

HIV is transmitted when infected blood or semen is introduced directly into a healthy person's bloodstream. This can occur during unprotected anal or vaginal (and possibly oral) sexual intercourse, as well as when drugs are injected intravenously with apparatus that already contains another person's AIDS-infected blood (many IV drug users share their needles and syringes). Infections also have resulted from transfusions with contaminated blood or blood products, although new screening procedures have drastically reduced transmission through this route. Additionally, a fetus or neonate can be infected by its mother.

By the end of 1989, the Centers for Disease Control had recorded 117,781 diagnosed cases of AIDS in the United States. Among the 115,786 adults reflected in that statistic, most (61%) were men who were infected through unprotected homosexual behavior, probably anal intercourse in most cases. The second-most common route of HIV transmission in adult US AIDS cases has been through sharing intravenous needles for illegal drugs (21%). Another 7% of adult cases fit both categories. This pattern differs from that observed in Africa, where most adult transmission appears to have occurred through heterosexual intercourse. The vast majority of the 1,995 cases of pediatric AIDS reported in the United States by the end of 1989 apparently resulted from infection by the mother (81%); 11% were linked to blood transfusions and

another 5% to recipients of blood products for coagulation disorders.

In the United States, Blacks and Hispanics are disproportionately represented in all transmission categories except hemophiliacs. Although African Americans comprise only 12% of the U.S. population, they represent 16% of adult AIDS cases among gay or bisexual men, 50% of the adult cases among IV drug users, 26% of the adult cases among drug-using gay or bisexual males, 62% of the adult cases traced to heterosexual contact, and 53% of pediatric AIDS cases. Similarly, Latin/Hispanic Americans comprise 6% of the population, yet they account for 11% of adult AIDS cases among gay or bisexual men, 29% of the adult cases among IV drug users, 14% of the adult cases among drug-using gay or bisexual males, 17% of the adult cases traced to heterosexual contact, and 25% of pediatric AIDS cases (HIV/AIDS Surveillance, January, 1990; see also Hopkins, 1987; Peterson & Marin, 1988; Rogers & Williams, 1987). In addition to those already diagnosed, the CDC now estimates that approximately one million Americans are infected with HIV (e.g., "Estimates of HIV Prevalence," 1990; see also Garrison, 1990).

Individuals diagnosed with AIDS in the United States have a median life expectancy of about 18 months. This estimate is potentially misleading, however, because it combines individuals who have access to high-quality medical care with those who have no resources for treatment. Currently, therapy with AZT, aerosolized pentamidine, and other drugs can considerably prolong life expectancy after diagnosis. As new treatments become available in the near future, AIDS is likely to become less a fatal illness and more a chronic, treatable condition (for regular updates on new treatments, the reader is referred to *AIDS Treatment News* and other resources listed in Appendix 1). Nevertheless, an individual's chances for survival will depend to a large extent on her or his access to good medical care. More than 70,000 of the Americans diagnosed with AIDS

by the end of 1989 have died (HIV/AIDS Surveillance, January, 1990).

The Cultural Construction of AIDS

As an illness, AIDS is a likely candidate for high levels of stigmatization. Although asymptomatic HIV infection is concealable and unlikely to be disruptive, the symptoms of AIDS-related illnesses often are visible, are perceived by others as repellent, ugly, or upsetting, and can interfere with an individual's social interactions, e.g., by reducing mobility, stamina, and endurance. Further, both AIDS and HIV infection are widely viewed as incurable and progressive (*negative course*), and as posing a risk to others through transmission (*high peril*). Additionally, engaging in homosexual intercourse and injection of illegal drugs are widely perceived as willful, riskful behaviors; HIV contracted through these routes is assigned a blameful origin (I shall consider so-called "blameless victims" presently).

The intensity of AIDS-related stigma, however, cannot be accounted for solely on the basis of the characteristics of HIV disease. Of considerable additional importance is that the American epidemic of AIDS has occurred primarily among marginalized groups, especially gay men, and that the epidemic has been defined socially as a disease of these groups. Consequently, the stigma attached to AIDS as an illness is layered upon pre-existing stigma and, to some extent, is equated with it. AIDS has become a symbol; reactions to AIDS are reactions to gay men, drug users, racial minorities, or outsiders in general.

The frequent use of the phrase "the general public" as a counterpart to "risk groups" conveys this distinction between dominant in-group and stigmatized out-group; gay men, IV drug users, and their sexual partners are not part of "the general public." Similarly, persons who did not contract AIDS through homosexual behavior or drug use often have been categorized as "innocent victims" (Albert, 1986). A *Newsweek* caption early in the epidemic, for example, described a teenage hemophiliac and

an infant with AIDS as "the most blameless victims" ("Social Fallout From an Epidemic," 1985). The opposite of a blameless victim, of course, is a "blameable" victim; guilt is assigned if HIV-infection occurred during stigmatized behavior.

In the past, the treatment and prevention of epidemic diseases often have been hampered by stigma attached to the illness and to social groups manifesting it. Social ostracism and hostility toward bubonic plague in the 14th century, for example, encouraged diseased persons to hide their illness from members of their own community or to flee to other towns, spreading infection in the process (e.g., Defoe, 1960). Plague-inspired anti-semitic riots drove healthy and infected Jews alike to eastern Europe, often spreading illness (McNeill, 1976). In a similar fashion, AIDS-related stigma, layered upon preexisting prejudice against gay men and others, has hindered effective societal response to the epidemic in several ways. Negative reactions have shaped the behavior of policy makers, legislators, caregivers and infected individuals, and have limited the effectiveness of prevention efforts. The Centers for Disease Control, for example, withheld funding for educational programs that included explicit instructions for engaging in male homosexual behavior without transmitting HIV (Panem, 1987). The United States Senate twice endorsed an amendment by Jesse Helms (R-NC) that prohibited federal funds for AIDS education materials that "promote or encourage, directly or indirectly, homosexual activities" ("Limit Voted on AIDS Funds," 1987). By constricting the scope of risk-reduction education, such actions contribute to the epidemic's spread.

The use of AIDS as an ideological and political issue was exemplified by the comments of columnist Patrick Buchanan (1987): "There is one, only one, cause of the AIDS crisis – the willful refusal of homosexuals to cease indulging in the immoral, unnatural, unsanitary, unhealthy, and suicidal practice of anal intercourse, which is the primary means by which the AIDS virus is being spread through the `gay' community, and,

thence, into the needles of IV drug abusers" and to others. Buchanan further suggested that the "Democratic Party should be dragged into the court of public opinion as an unindicted co-conspirator in America's AIDS epidemic" for "seeking to amend state and federal civil rights laws to make sodomy a protected civil right, to put homosexual behavior, the sexual practice by which AIDS is spread, on the same moral plane with being female or being black." AIDS and gay rights were thus equated and linked to the opposition party.

The federal government's slow responses to AIDS can be understood in part as a response to the politics of stigma. Anti-gay sentiment appears to have played an important role in the Reagan administration's failure to confront the epidemic. Shilts (1987) documented in painful detail the federal government's refusal to respond to AIDS during the Reagan administration – the cutbacks in funding to the CDC, followed by refusals to allocate resources to AIDS research, followed by refusals to request congressional funding for AIDS research, followed by refusal to spend the funds that Congress had allocated over the Reagan administration's objections (see also Panem, 1987).

Then-President Reagan did not even make explicit public statements about AIDS until 1987 – more than five years and tens of thousands of lives into the epidemic. The Administration's reasoning was evident in remarks made at the 1985 International Conference on AIDS by then-Secretary of the Department of Health and Human Services, Margaret Heckler: "We must conquer AIDS before it affects the heterosexual population and the general population....We have a very strong public interest in stopping AIDS before it spreads outside the risk groups, before it becomes an overwhelming problem" (quoted in Shilts, 1987). Although AIDS already afflicted more than 9000 people at the time, and more than 4000 had died – most of them gay or bisexual men – Heckler and the Reagan administration did not see it as an "overwhelming problem" because it had not affected the

"general population" (which did not include gay men).

A similar pattern can be seen in responses by the news media to the epidemic. Initially, AIDS received very little press coverage. When it did, it often was referred to as a "gay plague" (VerMeulen, 1982). The *New York Times* published only six stories about AIDS during 1981 and 1982, a period when 634 Americans had been diagnosed with AIDS, and 260 of them had died, most of them in New York; none of the six stories made the front page. In contrast, the *Times* printed 54 stories in 1982 about the discovery of poisoned Tylenol capsules in Chicago in October of that year, four of them on the front page; only seven people died from poisoned Tylenol (Shilts, 1987). In 1983, however, infected individuals were discovered outside of the "risk groups" of homosexual/bisexual men and IV-drug users. AIDS was reported in female partners of IV drug users, blood transfusion recipients, and babies born to women with AIDS. Around this time, scientists also realized that infected people could "carry" and transmit the virus without themselves manifesting any physical symptoms of AIDS. In other words, AIDS had "innocent" victims. Suddenly, the previously minimal AIDS coverage in the *New York Times* (measured by number of stories devoted to AIDS each week) took a major jump (Baker, 1986; Panem, 1987). As Shilts (1987) argued, the epidemic was virtually ignored by the non-gay media as long as it was merely a "story of dead and dying homosexuals" (p. 191).

Reactions of the Nonstigmatized

The cultural construction of AIDS as a stigmatized condition of stigmatized groups is clearly expressed in the behaviors and attitudes of many nonstigmatized individuals. Healthy people make hurtful and insensitive remarks; tell or laugh at AIDS jokes; reject or isolate people with AIDS; vote for quarantine laws or for politicians who support them; and perpetrate or tolerate discrimination, harassment, and even violence (see Herek & Glunt, 1988). Survey

research consistently shows that a significant minority of the American public endorses quarantine of HIV-infected persons, universal mandatory testing, and even such draconian measures as tattooing of infected individuals, even though public health officials consistently have argued against such measures as ineffective and repressive (e.g., Blendon & Donelan, 1988; Schneider, 1987; Singer & Rogers, 1986; Stipp & Kerr, 1989). People with AIDS are more negatively evaluated than are persons with other diseases, even by health care workers (Katz et al., 1987; Kelly, St. Lawrence, Smith, Hood, & Cook, 1987; Triplet & Sugarman, 1987). Avoidance of people with AIDS and overestimation of the risks of casual contact are common among caregivers (Blumenfield, Smith, Milazzo, Seropian, & Wormser, 1987; Kelly et al., 1987; Knox, Dow, & Cotton, 1989; Mejta, Denton, Krems, & Hiatt, 1988; O'Donnell, O'Donnell, Pleck, Snarey, & Rose, 1987; Rubin, Reitman, Berrier, & Sacks, 1989; Wallack, 1989; Wertz, Sorenson, Liebling, Kessler, & Heeren, 1987; Wiley, Heath, & Acklin, 1988). Two complementary social psychological approaches to understanding such attitudes and behavior are discussed here. The first approach is drawn from social cognition research and decision-making theory. The second derives from research on attitudes and prejudice.

AIDS, Anxiety, and Social Cognition

The first approach suggests that many seemingly irrational reactions to AIDS reflect simple errors of judgment, inappropriate use of cognitive heuristics, and stress-related defective decisionmaking. This approach begins with several observations about the AIDS epidemic: AIDS is a new illness that is uniformly fatal; it is caused by an unseen infectious agent that can remain latent in the body for an unknown period of time; the epidemic is perceived as both out of control and potentially catastrophic. Because such perceptions are likely to arouse anxiety (Slovic, 1987), they are likely to affect public reactions to AIDS in several ways. They lead to perceptions of ever higher levels of risk

associated with AIDS and to a strong desire to have that risk reduced; this, in turn, can lead to a willingness to impose strict regulation to achieve such a reduction (Slovic, Fischoff, & Lichtenstein, 1981). Personal decisions made under the influence of such anxiety are likely to be defective, i.e., they fail to consider available information adequately, to seek needed new information, and to evaluate the likely consequences of any proposed action in terms of the full array of one's short-term and long-term goals (Herek, Janis, & Huth, 1989; Janis & Mann, 1977).

One pattern of defective decisionmaking that probably occurs in connection with AIDS is *hypervigilance* (Janis & Mann, 1977). Consider the following example. A person learns that one of her coworkers has been diagnosed with AIDS. She knows that AIDS is a life-threatening disease. She has been bombarded with public education messages that AIDS is incurable but preventable. She believes these messages but is unclear about exactly *how* to prevent HIV infection. Lacking a clear understanding of how HIV is transmitted, she recalls other viral illnesses with which she has experience, e.g., influenza. She recalls also that experts never say that casual transmission (e.g., through saliva) cannot occur; they simply say that such transmission hasn't been observed. She calculates her own risk of infection from her coworker as high. She feels that she must do something to protect herself but perceives serious drawbacks to every alternative that she can call to mind (e.g., she could quit her job but would suffer financially; she could continue to interact with her coworker but might get infected this way). Discovering that some other employees are demanding that the coworker with AIDS be forced to take a disability leave and fearful that she will become infected unless she does *something*, she joins the protest. When challenged with expert opinion and company policy concerning nondiscrimination on the basis of HIV status, she states her newly-adopted guiding rules: "Better safe than sorry" and "You can't be too careful."

This example includes the key antecedents of hypervigilance. The decision-maker experienced intense stress due to several simultaneous perceptions: a) That severe losses are imminent if she does nothing; b) that losses also are imminent if she takes action; c) that a satisfactory solution is possible; but d) that she must do something now – sufficient time is not available to search carefully for a solution. Time pressures also led the woman in our example to use the *availability* heuristic inappropriately: Lacking information about AIDS, she relied on comparisons to easily recalled situations with which she had experience, i.e., influenza (Tversky & Kahneman, 1974). Janis (1989) summarized the hypervigilant pattern as "Try anything that looks promising to get the hell out of this agonizing dilemma as fast as you can. Never mind any other consequences" (p. 80). Hypervigilance may underlie a "do something" syndrome observed in some public opinion surveys about AIDS, a willingness to endorse any AIDS-related policy that promises action regardless of its likely costs, consequences, or effectiveness (Schneider, 1987).

AIDS, Attitudes, and Prejudice

Along with anxiety, AIDS evokes prejudice. Social psychological research on attitudes, therefore, also is relevant to understanding AIDS-related stigma. In the sections below, I discuss the cognitive dimensions along which AIDS-related attitudes appear to be organized, the motivations underlying those attitudes, and the relationship of AIDS-related attitudes to anti-gay prejudice.

The Dimensions of Attitudes Concerning AIDS. In my own research with Eric Glunt at the Graduate Center of the City University of New York (Herek & Glunt, 1988, 1990), I have found that public reactions to AIDS appear to be organized along two principal psychological dimensions. These dimensions, which have emerged repeatedly in factor analyses of responses from different samples, correspond to the two levels of conflict that Brandt (1987) observed in the history of public response to sexually transmitted diseases in the United

States. One factor focuses on issues of blame and responsibility, as well as the conflict between compassion and coercion in perceptions of people with AIDS; we labeled it the COERCION/COMPASSION dimension of AIDS-related attitudes. The other factor includes items that pit the opposing philosophies of moralism and secular rationalism against each other; we labeled it PRAGMATISM/MORALISM. These two dimensions of AIDS-related attitudes are not highly correlated, suggesting that an individual's position on one dimension does not predict her or his position on the other.

Although the same two dimensions emerged in separate analyses of responses from White and Black respondents, we observed racial differences in the variables that predict individuals' positions on the dimensions. Among Whites, individual attitudes toward gay men were among the best predictors of responses to the attitude items. Whites who expressed general prejudice against gay men also were more likely to view people with AIDS as responsible for their illness and to endorse measures such as quarantine for dealing with AIDS (elements of the COERCION/COMPASSION dimension), and to reject governmental policies such as distributing condoms and clean needles (elements of the PRAGMATISM/MORALISM dimension). Blacks' reactions to AIDS, in contrast, appeared to reflect deep distrust of scientists and the government, as well as a perception of the epidemic in terms of its effect on the African-American community. Whites' attitudes appeared to be premised on an "outsiders'" view of the AIDS epidemic whereas Blacks' attitudes reflected the perspective of "insiders." This did not seem to result from some affinity between Black respondents and gay people; indeed, we suspect that many of the African Americans in our sample equated "gay men" with "gay *White* men." Rather, Blacks focused on the disproportionate representation of African Americans among people with AIDS. Many Black males with AIDS, of course, contracted HIV through unprotected homosexual behavior, but our data do not permit us to assess whether the African American respondents in our sample were aware of this fact. Because of the relatively small representation of African-Americans in our research to date, all of our conclusions about their attitudes must be stated provisionally here; data-collection with a larger national Black sample currently is in progress.

From these findings, we concluded that public attitudes concerning AIDS reflect conflicts that have been present in policy debates concerning other illnesses, especially sexually transmitted diseases. We also concluded that the attitudes of Whites and Blacks may have different antecedents. Understanding AIDS-related stigma among White Americans requires understanding the social psychological bases for heterosexuals' attitudes toward gay people. Understanding AIDS-related stigma among African Americans, in contrast, requires an analysis of individuals' perceptions of how AIDS fits in the historical context of African Americans' treatment by White society.

Two Conceptualizations of Attitudes. At least two social psychological conceptualizations of attitudes are relevant to understanding AIDS-related stigma. The first is exemplified in the work of Fishbein and Ajzen (1975; Ajzen & Fishbein, 1980). Their theory of reasoned action conceives of behavior as shaped largely by the intention to behave, which results from attitudes toward the specific behavior that, in turn, are shaped by beliefs about the utility of the behavior for meeting personal goals and by perceived social norms governing the behavior. Within this framework, attitudes are assumed to be primarily instrumental, i.e., strategies for organizing thought and behavior based on the inherent benefits or detriments associated with the attitude object. Broader ideologies or general attitudes are assumed to have minimal immediate relevance to understanding specific behaviors.

A contrasting perspective can be derived from research on symbolic politics, which generally has focused on racial attitudes (e.g., Kinder, 1986; Kinder & Sears, 1981, 1985; see

also Sniderman & Tetlock, 1986a, 1986b). Symbolic racism is conceptualized to be a general ideology, abstracted from specific situations and specific calculations of an individual's own self-interest. Its origins lie in the "preadult acquisition of traditional values (particularly individualism and self-reliance), and of racial fears and stereotypes" (Kinder, 1986, p.154). It is not simply racism, but rather the conjunction of racism with traditional values. An example would be Whites' anti-Black attitudes based on the belief that Blacks receive unfair preferential treatment in affirmative action hiring programs.

Applied to AIDS, each perspective emphasizes different variables as antecedent to attitudes. The reasoned action perspective highlights the importance of concerns about personal health and safety, e.g., fear of becoming infected with HIV. The symbolic politics perspective highlights the importance of AIDS as a symbolic issue that juxtaposes fears and stereotypes of out-groups (gay men, IV drug users, racial minorities) and traditional American values (e.g., sexual morality, beliefs that people get what they deserve). Using these two perspectives in a series of empirical studies, Pryor, Reeder, and Vinacco (1989) examined two kinds of reactions to AIDS: Willingness to have one's own child in a classroom with a child with AIDS and willingness to be enrolled in a course with a professor with AIDS. They observed that their respondents' AIDS-related attitudes included both symbolic (operationalized as attitudes toward homosexuality) and instrumental components.

Such a finding inevitably raises the question of how the relative importance of symbolic and instrumental issues differs among individuals. In this regard, I have found the *functional approach* to attitudes to be very useful. It is based on the premise that people hold and express particular attitudes because they derive psychological benefit from doing so, and that the type of benefit varies among individuals. Attitudes are understood according to the psychological needs they meet – the functions

they serve. These functions are different for different people. Two people can hold the same attitude for very different reasons (see Herek, 1986, 1987; Katz, 1960, 1968; Katz & Stotland, 1959; Sarnoff & Katz, 1954; Smith, 1947; Smith, Bruner, & White, 1956).

In my own research, I have found that attitude functions can be classified into two broad types. Instrumental attitudes, those that benefit people primarily by helping them to organize the various objects of the world according to their own self interests, serve *Evaluative functions*. These functions derive from the actual characteristics of the attitude object, i.e., whether it provides rewards or punishments. Alternatively, the functions of symbolic attitudes derive principally from consequences of their *expression* – that is, speaking them aloud, writing them down, communicating them to another person, or even simply articulating them to oneself. In the case of *Expressive functions*, the attitude object is a means to an end. By expressing a particular attitude, the person receives psychological benefit: Increased self-esteem from affirming values central to self-concept (the *Value-Expressive* function), increased social support from expressing opinions consonant with those of important others (the *Social-Expressive* function), or a reduction in anxiety (the *Defensive* function).

Applied to AIDS, the Evaluative functions are most clearly related to concerns about personal risk of exposure to HIV. The Expressive functions are associated with the metaphorical (Sontag, 1988) or symbolic aspects of AIDS. These functions are not always distinct. Consider, for example, parents' attitudes about sending their children to school where an HIV-infected student is enrolled. At first glance, such attitudes clearly involve Evaluative functions; they reflect the parents' assessment of the risks faced by their children in the classroom with an infected child. Such attitudes probably also serve Expressive functions. They provide an opportunity for parents to affirm their feelings of love for their children as well as an

occasion to assert to the community, "I am a good parent." If other parents are banding together to respond to the infected student (whether to protest the child's presence or to welcome her or him), the parent can receive support by expressing socially-approved sentiments.

Attitude functions are affected by characteristics of the person and the situation. Someone with a strong need for affiliation, for example, is likely to hold attitudes concerning AIDS that increase his or her acceptance by friends, while someone else who is strongly committed to a political ideology is likely to hold attitudes about AIDS that reinforce that commitment. Additionally, situational cues can increase the salience of individual needs and thereby affect attitudes. A situation that makes personal values salient will lend itself to a Value Expressive function more than will a situation that highlights intrapsychic conflicts (Herek, 1986).

***AIDS and Attitudes Toward Gay People*.** Because of the ways in which AIDS has been socially constructed in our culture, most individuals do not respond to AIDS simply as a lethal and transmissible disease. Rather, they respond to it as a lethal and transmissible disease *of gay men and other minorities*. AIDS thus provides many with a metaphor for prejudice – a convenient hook upon which to hang their preexisting hostility toward out-groups. Approximately one-fourth of the respondents to *Los Angeles Times* polls, for example, consistently have agreed that "AIDS is a punishment God has given homosexuals for the way they live" – 28% on 12/5/85, 24% on 7/9/86, and 27% on 7/24/87[5] (see also Blendon & Donelan, 1988). Respondents who express negative attitudes toward gay people are more likely than others to be poorly informed about AIDS and are more likely to stigmatize people with AIDS (D'Augelli, 1989; Goodwin & Roscoe, 1988; Herek & Glunt, 1990; Pryor, Reeder, & Vinacco, 1989; Stipp & Kerr, 1989). Further, gay men with AIDS are more likely to

be negatively evaluated than are heterosexuals with AIDS (Triplet & Sugarman, 1987).

Anti-gay hostility has long existed in the United States. Despite their achievement of greater visibility and acceptance in recent years, lesbians and gay men continue to be targets of widespread institutional prejudice. Whereas racial, ethnic, and religious minorities also suffer from such prejudice, gay people are unique in that overt discrimination and intolerance against them are officially condoned by governmental, religious, and social institutions. Discrimination in housing and employment on the basis of sexual orientation currently is prohibited by statute only in two states, Wisconsin and Massachusetts. Lesbian and gay male couples generally are denied the community recognition, legal protection, and economic benefits accorded to married heterosexual partners. Indeed, sexual intimacy between same-sex partners remains illegal in one-half of the states, and the constitutionality of such laws was upheld by the United States Supreme Court in 1986 in the case of *Bowers v. Hardwick* (Melton, 1989).

This climate of condemnation fosters anti-gay attitudes and behavior among heterosexuals, and discourages gay women and men from disclosing their homosexual orientation to those around them. Yet, great variability can be observed in the attitudes expressed by individuals in American culture. Some heterosexuals are much more hostile toward gay people than seems to be required by social norms. Others defy the norms and accept gay people. These differences can be explained in part through examination of the psychological functions served by attitudes toward lesbians and gay men (see Herek, 1984, 1987).

Given the empirical relationship between AIDS-related stigma and attitudes toward gay people, the psychological functions served by the two types of attitudes might be closely related. For example, people with AIDS may be assigned to a cognitive category already existing for gay people; the affect resulting from negative experiences with gay people then may be transferred to people with AIDS (one of the

Evaluative functions). Negative stereotypes of gay people (e.g., as preying on young people) may be imputed to people with AIDS as well. Alternatively, a fundamentalist Christian might condemn homosexuality as a way of affirming her or his sense of self as a good Christian and thereby increasing self-esteem (a Value-Expressive function). AIDS might be interpreted as God's punishment for homosexuality; expressing condemnation for people with AIDS might similarly bolster self-esteem. Yet another possibility is that a person whose hostility toward gay people is based on unresolved intrapsychic conflicts may experience similar anxieties associated with AIDS. Because AIDS links homosexuality with death, it offers a focus for anxieties associated with both (a Defensive function).

AIDS, Attitudes and Education

The social psychological approaches described here point to the need for AIDS education programs to address variables that interfere with receptivity to factual information about AIDS. Although providing accurate information about AIDS and HIV is absolutely necessary, it is not enough for at least five reasons. First, the audience for educational programs may be unable to utilize the information they receive because of their high levels of anxiety associated with AIDS. One approach to this problem is to address specific types of errors that people are likely to make in thinking about AIDS under conditions of stress. Misuse of the availability heuristic, for example, might be reduced by providing clear information about how AIDS differs from other illnesses easily called to mind, such as influenza. Another important approach is to avoid overstating the risks of audience members for HIV infection. An educator designing an AIDS education program for middle-class White heterosexual college students (a group at fairly low risk of encountering a sexual partner infected with HIV), for example, may be tempted to inflate audience members' risk for HIV infection as a way of increasing their sense of urgency and overcoming their illusions of invulnerability.

Although based on good intentions, this approach may create anxiety levels so high that audience members adopt a hypervigilant pattern for responding to AIDS. If ineffective, it may damage the credibility of the educator with her or his audience.

A second reason why simple information is not enough is that audiences for AIDS education programs may experience conflicts between their own basic values and proposed strategies for preventing HIV transmission. Advocating the use of condoms to people whose religious values strictly prohibit any non-marital sexuality, for example, may be ineffectual or counterproductive. The value conflicts must be recognized by the educator and confronted in the education program (e.g., Rokeach, 1973).

Third, audiences for AIDS education may believe that people with AIDS are only getting what they deserve for engaging in behaviors that are socially condemned. This application of the "just world hypothesis" (Lerner, 1970) probably reflects *a priori* condemnation of gay men and intravenous drug users. It also may represent a need to believe that the epidemic is somehow controllable, that one can be safe by avoiding certain behaviors and following certain rules. In this sense, the notion of "innocent victims" may reflect concern about the loss of control (people can become infected with HIV even if they don't have sex with men or share needles) as much as it reflects condemnation of "guilty victims."

Fourth, audiences for AIDS education may be skeptical rather than ignorant or uninformed. My own observation from focus group discussions about AIDS is that many Americans know the official story that HIV cannot be transmitted through casual contact, but they do not believe it. African Americans and members of other minority groups that historically have reported less trust in the government than Whites (e.g., Howell & Fagan, 1988) may be especially unwilling to trust White-identified government officials and scientific experts concerning AIDS. Effective AIDS education programs must overcome this barrier, e.g., by communicating

16

information through trusted sources (church and community leaders, celebrities).

A fifth reason why information alone is not enough is that, although people are indeed concerned about their own vulnerability to HIV infection, AIDS-related attitudes also serve Expressive functions. Educators must address the symbolic aspects of AIDS, e.g., rejection of persons with AIDS as a way of increasing in-group solidarity. A person whose AIDS-related prejudice serves a Social-Expressive function, for example, might be placed in a situation where acceptance and compassion for persons with AIDS are the norm. In such a setting (e.g., one's own classroom), disparaging remarks or jokes about AIDS would receive social disapproval, and expressing prejudice against persons with AIDS would not bring social support or acceptance. Educators can work to change social norms outside the classroom by teaching their students how to speak up against expressions of AIDS-related stigma by one's friends or family members.

Of all the issues symbolized in AIDS-related stigma, perhaps the most prevalent is that of attitudes toward gay men and, indirectly, attitudes toward lesbians. As described above, the cultural construction of AIDS has focused on the epidemic's early manifestations in the gay male community. The dominant cultural images of AIDS probably will continue to equate it with male homosexuality even as the demographic realities of the epidemic shift to heterosexual people of color. Thus, the linkage between reactions to AIDS and attitudes toward gay men should be addressed explicitly in education programs.

The Experience of AIDS-Related Stigma

I have discussed how stigma has been attached to AIDS at the cultural level, and how that stigma translates into individual attitudes. But what of the experiences of a person who has AIDS, is infected with HIV, or is presumed by others to be infected? For such people, AIDS-related stigma adds an additional layer to the challenges of coping with a chronic and

potentially lethal condition. Sensitivity to the mental health consequences of AIDS-related stigma is important for caregivers, researchers, and policymakers. A review of the vast literature on the psychological ramifications of AIDS and HIV-infection is beyond the scope of this paper (see Kelly & St. Lawrence, 1988, in this regard). Instead, I shall consider some ways in which being stigmatized by AIDS can affect psychological functioning and mental health. (For discussions of mental health interventions with people with AIDS, see Adler & Beckett, 1989; Barret, 1989; Barrows & Halgin, 1988; Dane, 1989; Morin & Batchelor, 1984; Sheridan & Sheridan, 1988.)

Persons with AIDS bear the burden of societal hostility at a time when they are most in need of social support. The stigma attached to the illness also subjects them to suspicion about previously private aspects of their lives. "Indeed, to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain 'risk group,' a community of pariahs" (Sontag, 1989, pp.24-25).[6] Thus, disclosure of HIV infection is likely to lead others to wonder: Is he homosexual? Did she use drugs? Widespread awareness among American gay men of this discrediting process was reflected in an early AIDS joke: "What's the hardest thing about being diagnosed? Convincing your parents that you're Haitian" (Dundes, 1987). People at risk may compromise their own health when they attempt to avoid these multiple levels of stigma. Fears of harassment, job discrimination, and loss of insurance coverage may deter them from being tested for HIV infection, seeking early treatment for symptoms, or securing help from friends, relatives, or AIDS support organizations.

Stigma and Psychological Functioning

Anxiety, anger, and depression, which commonly are experienced by people with HIV disease (Kelly & St. Lawrence, 1988), are likely to be exacerbated by AIDS-related stigma. Anxiety results not only from fears about the physical effects of HIV disease, but also from fears about others' responses; infected and sick individuals appropriately anticipate rejection,

discrimination, hostility, and even physical violence from others who learn of their condition (Herek & Glunt, 1988). Anger at the loss of one's health and mobility can be intensified by perceptions that the federal government, the Catholic Church, and other institutions have failed to respond adequately to the AIDS epidemic because of their hostility toward gay men and other minorities (Herek & Glunt, 1988). Depression can be intensified by self-blame and internalization of societal stigmas concerning AIDS, homosexuality, drug use, and race. Depression also may result from feelings of "universal helplessness," which are likely when people with AIDS perceive themselves as being treated unfairly and attribute the cause to forces that are external, stable, and global, i.e., widespread and enduring prejudice (Abramson, Seligman, & Teasdale, 1978; Crocker & Major, 1989).

Stigma, Self-Concept, and Self-Esteem

In addition to these affective responses, AIDS-related stigma may affect an individual's overall self-concept and level of self-esteem. In general, a stigma is most extensively incorporated into the self-concept when it generates extreme and consistent negative reactions on the part of others, which are most likely to occur when the stigma is non-concealable, aesthetically displeasing, and socially disruptive. A stigmatized characteristic also affects the bearer's self-concept to the extent that it is related to some domain of behavior or experience over which the bearer feels he or she should have control (Jones et al., 1984). AIDS frequently manifests these characteristics.

Nevertheless, members of stigmatized groups appear to use a variety of strategies to safeguard their self-esteem (Crocker & Major, 1989). First, members of stigmatized groups are able to maintain higher levels of self-esteem to the extent that they attribute negative social experiences to their stigma (an external attribution) while attributing positive social experiences to their own qualities or abilities (an internal attribution). A man with AIDS who is fired from his job, for example, will be less likely to have his self-esteem diminished if he attributes his employer's action to prejudice rather than to his own competence. He still must face the problem of being unemployed, but he may be better able to confront this problem if he does not blame himself for bringing it on. A second successful strategy for maintaining self-esteem in the face of stigma is to devalue the abilities or qualities that one is likely to lack by virtue of one's stigmatized condition. After they have been (literally) marked by Kaposi's Sarcoma and other AIDS-related illnesses, for example, many gay men learn to discount the importance of physical attractiveness in defining self-worth. Instead, they may emphasize their capabilities for compassion, sociability, or humor, which are less likely to be impaired by their illness. A third strategy described by Crocker and Major (1989) for maintaining or enhancing self-esteem is to select for social comparison others who are stigmatized. People with AIDS are less likely to feel despair at their physical condition if they compare themselves to others who are sick rather than to healthy friends or to their pre-diagnosis self.

Generally, these three coping strategies are most readily employed by people whose self-concept is structured around the stigmatized group and who have extensive contact with a community of similarly stigmatized individuals. Many communities of people with AIDS, their families, friends, and volunteers exist around the country. In addition to providing services and social support, these groups help people with AIDS to understand and overcome their stigmatization. They provide contexts in which people can formulate alternative analyses of AIDS to counteract those of the larger society. Many sponsor publications in which the ideology of the members is formulated. AIDS organizations present the case of people with AIDS to the noninfected public. They have influenced the terminology attached to AIDS, e.g., by discouraging use of the label "AIDS victim" in favor of "Person with AIDS."

Some people with AIDS have found that the movement absorbs all of their time, that a new career has been thrust upon them. They have become "professionals." They spend much of their time organizing social services and demonstrations, fundraising, attending meetings, and speaking to the public. This professionalization consolidates belief in AIDS or HIV-status as a basis for identity (Goffman, 1963). Professionals, by recounting their own story, offer others with AIDS a doctrine for making sense out of their own stigmatized situation; they provide advice and offer norms for behavior. They often urge others to "come out" with their AIDS diagnosis, and to reject others' negative attitudes. Their prescriptions provide others with guidelines for behavior, the basis for an in-group alignment, and an appropriate attitude toward the self. Membership in an AIDS group even may enable individuals to achieve a level of self-esteem higher than the majority nonstigmatized group; they may turn their diagnosis into a virtue or asset (Jones et al., 1984).

Simultaneously, however, some people with AIDS may feel that membership in the AIDS community also makes change and growth difficult by decreasing the number of alternative views of the self that are available from others; the pressure to be "politically correct" can feel limiting (Jones et al., 1984). Because they have internalized societal attitudes, others may experience ambivalence around their identity as a person with AIDS. They may feel hostility toward others with AIDS who are more obviously stigmatized than themselves. For example, a person who was infected through a blood transfusion may feel contempt for a gay man with AIDS who, in turn, may express hostility toward an IV drug user with AIDS. Or a person with AIDS might feel dislike for AIDS activists because of their visibility and stridency. In each case, the ambivalent individual may simultaneously feel both repulsion at others and subsequent shame at being repulsed (Goffman, 1963).

Psychological Consequences of Acute

Victimization

People with AIDS are at risk for several kinds of victimization, ranging from interpersonal rejection and ridicule to job and housing discrimination to violence (Dalton & Burris, 1987; Dundes, 1987; Herek, 1989; Herek & Glunt, 1988). The aftermath of criminal victimization is likely to be similar to that for other survivors of crime or assault. It may be complicated, however, by several factors. First, physical injuries received in an assault may compound existing health problems of persons with AIDS. Second, trauma related to the assault may interact with the experience of the AIDS diagnosis itself as a major trauma. Third, the dependency that inevitably follows criminal victimization may compound the loss of personal control already experienced by the person with AIDS. Fourth in searching for a cause for their victimization, many crime victims blame themselves; a victimized person with AIDS may feel responsible for her or his victimization, which may magnify feelings of guilt or responsibility for being sick in the first place. Fifth, to be a victim in our society is itself a stigmatized status; thus, the victimized person with AIDS must cope with yet another level of stigma (see generally Bard & Sangrey, 1979; Janoff-Bulman & Frieze, 1983a, 1983b).

Managing Social Interactions

Interactions between people who are infected with HIV (or are presumed to be infected) and nonstigmatized others are shaped by all of the factors previously discussed. Because extensive empirical data about such interactions are not yet available, much of the following section derives from Goffman's (1963) impressive theoretical discussion. A starting point is his distinction between the *discredited* (those whose HIV status is known to other parties in the interaction) and the *discreditable* (those whose HIV status is hidden from one or more parties). A discreditable person who is "passing" must concentrate on managing information about her or his stigma. The primary focus of an interaction involving a discredited person, in

contrast, is upon managing discomfort and tension. Each of these situations will be discussed in turn.

Managing Information: The Experience of Passing

In addition to reasons already mentioned, people with AIDS or HIV infection may wish to hide their status from others because of fears of straining family relationships and friendships, a wish to maintain normalcy in their own lives, and a desire to avoid revealing their homosexuality or use of intravenous drugs (Herek & Glunt, 1988; Kelly & St. Lawrence, 1988). Most people with AIDS regularly find themselves in social settings where passing is more or less necessary. In extreme situations, any disclosure of one's health status would mean immediate expulsion (e.g., some employment or housing situations); Goffman (1963, p.81) refers to these as "forbidden places." At the other extreme are places like the physician's examining room, the hospital, and the AIDS support group, where no need exists to pass. In such "back places," the stigmatized individual, like an actor backstage, can stop playing the role of the healthy person. Between these extremes are "civil places," where others make a visible attempt to treat the person with AIDS as just like anyone else, even though they may remain uncomfortable and do not completely accept or understand her or him.

People with AIDS who are passing face continual hazards. They can be discredited either by information that becomes apparent about them during an interaction or by exposure at the hands of others who already know about their diagnosis. Consequently, they must carefully structure social situations to minimize the risk of exposure. Gay people and others with previous experience at hiding a stigmatized condition are likely to have already developed useful skills in this regard.

Passing is stressful, however, to anyone who must do it. People hiding their diagnosis experience a great discrepancy between their public and private identities. They may feel inauthentic, that they are living a lie (Jones et al., 1984). They may have the distressing experience of being exposed to others' insensitivity or prejudice against people with AIDS. They do not face direct prejudice against themselves; rather, they face unwitting acceptance of themselves by individuals who are prejudiced against people with AIDS (Goffman, 1963). People hiding their AIDS diagnosis also may experience what Goffman called "the Cinderella syndrome" (p.90). They feel that they are living on a leash; that they must stay close to home where medicines can be taken, makeup can be reapplied and, in short, their disguise can be refurbished and they can rest up from having to wear it.

People with AIDS use a variety of techniques in passing. Sometimes they present the signs of their illness as signs of another, less stigmatized attribute; the persistent cough is dismissed as a cold, the lack of energy is attributed to being "stressed out." This process inevitably requires further and further elaboration to prevent disclosure, and can give rise to hurt feelings and misunderstandings on the part of others. A man with KS may alienate his gym buddies in the process of avoiding the exposure of his lesions that would occur if he undressed. The woman who cannot eat solid food without vomiting may offend friends and relatives by refusing their invitations to dinner.

People with AIDS who are passing are likely to divide the world into a large group to whom nothing is told and a small group to whom everything is told. Those who know about their diagnosis are then relied upon for help in keeping the secret. Sometimes these intimates put themselves in the role of protecting the individual from any manifestation of prejudice or rejection by others; in the course of filling this role, they may be more alive to the diagnosis and its attendant problems than even the person with AIDS (Goffman, 1963).

People with AIDS also may find themselves having to rely for help in protecting their secret upon others who, although they are not known personally, are able to detect their condition. These might include other people with AIDS and the "wise," e.g., health care professionals and

lay individuals active in the gay or AIDS communities. The wise are "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan" (p.28). The wise can provide a model for how far normals could go in treating stigmatized people as if they didn't have a stigma.

Obviously, the demands of passing are likely to disrupt relationships. People with AIDS who are passing may find that they consciously create distance in order to avoid disclosing their diagnosis to others. They may avoid social contact with specific others and, when together, keep the conversation at a superficial level. They may develop entirely new friendship networks, consisting of people in the AIDS community and service providers.

Even people with AIDS who are relatively open about their diagnosis may experience problems when they encounter acquaintances or family members who know them from an earlier part of their life. These pre-stigma contacts may have difficulty replacing their preexisting conceptions of the person with an understanding of her or his present situation. They may be unable either to accept the person with AIDS or to respond with formal tact of the sort displayed by strangers (Goffman, 1963).

Managing Interpersonal Tension: Social Interactions After Disclosure

General Characteristics of Social Interactions. Although most people with AIDS have the experience of passing in at least some situations, many also participate in interactions in which their stigmatized status is known to others. Disclosure of their diagnosis may occur against their wishes, e.g., by a breach of confidentiality or by an inadvertent disclosure during an interaction. Alternatively, individuals may voluntarily disclose their status because they reject society's stigma and feel that if they accept and respect themselves they will feel no

need to conceal their condition. Additionally, disclosing one's diagnosis to others increases opportunities for much-needed social support (Adelman, 1989; Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986; Zich & Temoshok, 1987). "Coming out" can be accomplished through direct disclosure or through offering indirect evidence to others (e.g., purposeful slips in the conversation, by displaying the logo of an AIDS organization on a button, badge, or article of clothing).

Once their status has been disclosed, persons with AIDS no longer need worry about passing but new problems are created. They may now feel uncertain as to what others "really" are thinking of them. They probably will feel that they are under closer scrutiny than are others in the same situation. Their minor accomplishments may be considered too remarkable, while minor failings may be interpreted as a direct expression of their illness. Others may stare at them if they manifest lesions or hair loss because of chemotherapy. Strangers may feel free to strike up personal conversations about AIDS or offer unwanted and unneeded help.

Others' reactions will be influenced by their feelings toward the person with AIDS, their beliefs and attitudes concerning AIDS in general, and their beliefs about appropriate behaviors to display in the company of persons with AIDS (Dunkel-Schetter & Wortman, 1982). Some will have unequivocally positive feelings toward the person with AIDS, will be well-informed, unprejudiced, and will have had experience interacting with persons with AIDS. Others will be unequivocally negative and will terminate their relationship with the person with AIDS. From a social psychological perspective, the interactions (or noninteractions) resulting from such unambiguous responses are fairly simple to understand.

More complicated, however, are interactions with those who have no experience with AIDS and who know little about it. These people are likely to experience ambivalence resulting from the clash of their negative feelings

concerning AIDS and their positive (or possibly ambivalent) feelings toward the person with AIDS. Ambivalence may result in exaggerated positive responses to persons with AIDS when they manifest positive characteristics or overly harsh rejections when they display negative characteristics (Katz, 1981). Ambivalent individuals may feel unable to discuss their discomfort out of the belief that they should remain positive and optimistic around the person with AIDS. They may worry about whether they are being overly sympathetic or are making impossible demands in an effort to carry on as though nothing were amiss. They may adopt a cheerful facade in the presence of the person with AIDS, both as a strategy for reducing their own anxiety and in response to their beliefs about how one "should" behave in the presence of a seriously ill person. They may fear that they will break down in the presence of the person with AIDS, or betray their feelings, or say the wrong thing (Dunkel-Schetter & Wortman, 1982). The person with AIDS may wish not to burden her or his family, and therefore may hesitate to express her or his concerns about illness, physical discomfort, and death.

Everyone involved in the interaction may feel so uncomfortable that the healthy individual and person with AIDS alike may arrange to avoid or minimize contact with each other. Alternatively, they may maintain social contact while avoiding open discussion of AIDS. In either case, the person with AIDS feels isolated, and the healthy person does not learn how to interact comfortably with someone with AIDS.

Conflicts also can occur concerning the emergent identity of the person with AIDS. For reasons already mentioned, people with AIDS are likely to derive considerable benefit from incorporating their diagnosis into their identity, and from joining various AIDS support groups and organizations. Well-intentioned healthy people, however, may advise friends with AIDS to downplay their newly-formed identity based on their diagnosis. They may encourage the person with AIDS to help "normals" in dealing with her or his diagnosis by, for example, using

levity to put them at ease. Goffman (1963) summarized society's criteria for "good adjustment:" A stigmatized individual should "cheerfully and unself-consciously accept himself as essentially the same as normals, while at the same time he voluntarily withholds himself from those situations in which normals would find it difficult to give lip service to their similar acceptance of him" (p.121). Goffman noted that, from the point of view of the nonstigmatized, this prescription means "that the unfairness and pain of having to carry a stigma will never be presented to them; it means that normals will not have to admit to themselves how limited their tactfulness and tolerance is; and it means that normals can remain relatively uncontaminated by intimate contact with the stigmatized, relatively unthreatened in their identity beliefs" (p.121).

People with AIDS, strongly in need of social support, may try to fit this prescription for adjustment. They may hide their problems from others, conveying the impression that they are coping well. This covering strategy, however, requires the person with AIDS to present a false front. Others' acceptance is perceived to be based on the self that is presented rather than the true self. Thus, the person with AIDS may continue to feel that she or he is not truly worthy of positive regard.

Interactions with Family Members. Despite these impediments to interaction, most people with AIDS have frequent contact with others, especially with family members. "Family member" here refers to anyone with whom the person with AIDS is involved in a long-term, committed, and caring relationship. This definition includes lovers or life-partners, regardless of the legal status of their relationship, as well as friends. Family members experience considerable anxiety associated with changes in a patient's health status and physical appearance (Greif & Porembski, 1987; Frierson, Lippmann, & Johnson, 1987). Family members who have had unprotected sexual contact with a person with AIDS must cope with their own anxieties about being infected with HIV. Additionally, all family members, whether or not they have had a

sexual relationship with the person with AIDS, are likely to experience stigma themselves (Cline, 1989). This can create additional worries for the person with AIDS. Stigma-related stress is especially likely for same-sex lovers, who often are the primary caregivers for gay men with AIDS but whose status is not legally recognized (Morin & Batchelor, 1984). Stress may be especially pronounced after the person with AIDS has died, leaving the lover and other family members to grieve, often without adequate community supports (Berube, 1988; Martin, 1988; Trice, 1988).

"*Paradoxical Stigma" and AIDS*. To round out this discussion of social interactions between people with AIDS and healthy others, I wish to note a type of interaction that differs from the negative manifestations of AIDS-related stigma discussed throughout this paper. In it, AIDS is treated as a sign of special "holiness," and people with AIDS as "saints" by those close to them or politically supportive of them. I use religious terminology here to draw a parallel between AIDS and the stigmata manifested by certain saints in Catholic teachings. This phenomenon, which I shall refer to as "paradoxical stigma," was illustrated in a column written by Chuck Grochmal, headlined "Patronizing My Disease," in the Toronto magazine, *Xtra* (June, 1989).[7] After noting that, before his diagnosis, agreeing with his friends on a movie or restaurant required extensive negotiation, he described a change that occurred:

> "It dawned on me that my friends were patronizing me or, more correctly, my disease. Because I had aids, in their zeal they were bending over backwards (no dirty comments, please) to make sure my 'remaining time' was pleasant on my terms – not theirs. In the process they were compromising their opinions, a cornerstone of our friendship, and also that special quality only gay men experience, known to us as 'sisterhood.' My friends, John and Jack, being closest to me, were the guiltiest of the lot. When

I would suggest a movie that we might go to see, no matter what they really thought of the idea, they agreed that my selection was brilliant and that's the movie we would go to see....It was the same story when it came to a choice of restaurants for eating out. And on and on *ad nauseam*....I certainly have changed because of aids, but there is no good reason for the changes that Jack and John were inflicting on me. It said to me that they were spineless if they couldn't say 'no' to me any more, especially since I enjoy a good fight over insignificant details. Well, once they grasped what I was trying to beat into them...things improved. I've got a lot of fight left in me and now we're back to fighting" (p. 26).

Our culture tends to portray illness as an occasion for self-transcendence, when the virtuous become more so and the less virtuous get an opportunity to behave well (Sontag, 1978). Goffman (1963, p.28) observed that this "cult of the stigmatized" can cause difficulties for all concerned. Although sainthood may have some appeal, it prevents people with AIDS from being treated simply as normal. Lovers, friends, and colleagues may try to minimize their own relationship needs unrealistically – experiencing guilt when they argue with or criticize the person with AIDS. This in turn may create serious strains for loved ones while the person with AIDS is alive, and serious guilt after she or he has died. This paradoxical form of AIDS-related stigma, like the negative forms to which most of this paper has been devoted, should be considered undesirable.

THE AIDS EPIDEMIC: CHALLENGES AND OPPORTUNITIES

When considering possible future trends in the AIDS epidemic, we inevitably must feel a strange mix of hopeful optimism and overwhelming worry. We can be optimistic based on the amazing pace of scientific progress in understanding AIDS, its etiology and its

natural history. Improvements in treatments mean that persons with AIDS who have access to good medical care today can live longer and better lives than was the case even a few years ago. Although many scientists and activists believe that research to find a cure could proceed more rapidly than has been or is now the case, promising new experimental treatments all justify hope that HIV infection will become a chronic, treatable condition someday soon.

We also can be optimistic based on the social history of AIDS. Despite the worst fears of many, and the best efforts of some, AIDS-related stigma generally has not become the basis for public policy. Calls for quarantine now are widely considered unrealistic and extreme. The fight against universal mandatory testing has been successful to date, although testing continues in the military, prisons, and other settings. Legislation to protect the civil liberties of persons with AIDS and other disabled Americans has been introduced in the Congress with strong bipartisan support and the endorsement of President Bush. Perhaps most important, the American public displays increasingly greater sophistication in its knowledge concerning AIDS. In many places, tolerance and compassion appear to be the social norm, rather than fear and persecution.

Despite these hopeful signs, current trends in the epidemic also justify considerable concern about the future. AIDS is not yet a chronic treatable disease; people continue to die from it every day. Even with advances in treatment and research, the number of people with AIDS soon will increase dramatically. Most of the hundreds of thousands of Americans who now are infected but asymptomatic can be expected to begin to display symptoms within the next five to ten years. This may mean a tenfold increase in the number of AIDS cases over those that have been reported so far during the entire epidemic in the United States. Although early intervention with AZT, aerosolized pentamidine, and other medications may delay or prevent many infected people from developing symptoms, these treatments currently are available only to a

minority. Local hospitals and health care systems, already inadequate for meeting the needs of many Americans, will be more severely stressed by AIDS. Even in San Francisco, which is considered a model of effective community response to the epidemic, the present system is not expected to be adequate for meeting the increased demands placed on it as the number of AIDS cases inexorably rises. And if one looks beyond the borders of the United States to AIDS in developing countries, the future is indeed bleak.

Even if all transmission of HIV were to stop immediately, visions of the coming decade would be frightening. But transmission continues. A remarkable amount of risk reduction has been observed in gay male communities in large cities (e.g., Becker & Joseph, 1988; Martin, 1987; Siegel, Bauman, Christ, & Krown, 1988; Winkelstein et al., 1987). Comparable levels of behavior change are not apparent, however, in smaller cities, towns, and rural areas. Despite increased concern about AIDS prevention among intravenous drug users, transmission of HIV remains largely unchecked among them; available resources and resolve are currently insufficient for dealing effectively with AIDS in this group, which is largely poor and disproportionately of color (Turner, Miller, & Moses, 1989).

The United States soon will face a second wave of the epidemic as the thousands of gay men who now are infected begin to manifest symptoms and require medical care. Then a third wave will break as symptoms of HIV disease appear among more and more IV drug users, their homosexual and heterosexual partners, and their infants. As the third wave washes over us, the epidemic will become more ghettoized among poor Americans, especially those of color.

Today, AIDS in the minds of most Americans is primarily a disease of homosexuality, and it carries the particular stigma attending that perception. As the social profile of the epidemic changes, so too will AIDS-related stigma change. AIDS will continue to be a disease of the Other, but the specific

24

character of that Other will evolve from gay males to the poor and people of color. Unfortunately, the history of prejudice in the United States suggests that this shift in the cultural construction of AIDS will be accompanied by changes in the form and manifestations of AIDS-related stigma, rather than a reduction in its intensity.

How should psychologists respond to AIDS-related stigma? As with so many other areas of human behavior, we should each begin by identifying our own personal relationship to HIV-disease. Even though our training as scientists and practitioners and educators provides us with tools and strategies for approaching phenomena far removed from our own experience, AIDS and AIDS-related stigma are not so removed. They are integral parts of our social reality in contemporary America, whether or not we realize it. I propose, therefore, that we each explicitly recognize our own relationship to the epidemic, recognize how that relationship might limit our perspective, and allow it to enrich our understanding. At the same time, psychologists also should clarify their relationships to the many communities affected by the epidemic. As appropriate, we each must recognize our own ignorance about some or all of these groups and learn about them as a prerequisite for working with them.

Obviously, psychologists who are themselves infected with HIV (or who think they may be infected) have a different perspective on the disease than do their uninfected and unworried colleagues. Those who are not concerned about their own personal HIV status may nevertheless have friends and loved ones who are infected. Or HIV may have touched their professional relationships through colleagues, clients, students, staff, or research participants who are HIV-positive. Some psychologists have not yet been touched directly by AIDS, although that is likely to change. Whatever their personal relationship to the epidemic, psychologists must evaluate how it affects their professional involvement with AIDS. Those most intimately involved may have

the greatest difficulty maintaining sufficient distance and objectivity in their work or they may risk rapid burnout as AIDS touches all parts of their lives. Psychologists more distant from the personal consequences of AIDS may fail to appreciate its intellectual, emotional, and social complexities, which ultimately shape their own attitudes and beliefs, which ultimately affect their research, practice, and teaching.

After clarifying their personal and professional relationship to the epidemic, psychologists can begin to approach AIDS and its attendant stigma in each of the five areas I have described. First, in the biomedical realm, they can educate themselves about the physical realities of AIDS and HIV-disease. Although reading about the medical aspects of AIDS (e.g., Institute of Medicine, 1988) is an important starting point, psychologists also should develop a first-hand understanding for the disease. Psychologists who are themselves infected with HIV or whose loved ones are infected cannot avoid such an understanding. Others may benefit from volunteering to work for a local AIDS service organization, perhaps after first reading one or more personal accounts of the disease (e.g., Monette, 1988; Peabody, 1986; Whitmore, 1988). I am suggesting here that psychologists purposely seek experience with AIDS outside of their professional role. Aside from making us more empathic and compassionate human beings, such experience will vastly increase our understanding of AIDS and AIDS-related stigma, and thereby improve our research, therapeutic, and diagnostic skills considerably.

The second area of my discussion was the cultural construction of AIDS and its stigmatizing properties. I have tried throughout this lecture to "deconstruct" AIDS, to identify some of its symbolic and metaphorical uses. Psychologists should continue this process for themselves, confronting images of AIDS in daily conversations, in popular media and, most importantly, in their own work. Help with this task can be found in the alternative constructions provided in the newsletters and newspapers of AIDS organizations and in the publications of the

gay, African American, and Hispanic communities. As well as deconstructing, psychologists can play important roles in reconstructing AIDS through speaking out as individuals and through professional and academic organizations. Congressional and local lobbying by psychologists, for example, have influenced legislation concerning appropriations, HIV-testing, and discrimination. Additionally, psychologists have confronted AIDS-related stigma by speaking out in court rooms and through mass media.

The third and fourth areas of my discussion were attitudes of the nonstigmatized toward persons with AIDS and the subjective experience of being the target of those attitudes. Here again, one's personal relationship to the epidemic is a starting point in developing a critical understanding of these phenomena. Psychologists infected with HIV already know too well the experience of AIDS-related stigma; nevertheless, they can benefit from using their professional skills to analyze critically the dynamics of that stigma. Some uninfected psychologists can draw upon their experiences as a member of another stigmatized minority (e.g., as a gay person or a person of color) to gain an initial understanding of the consequences of AIDS-related stigma. Others who are not themselves at risk for AIDS nevertheless will experience a degree of stigma when their professional involvement with AIDS becomes publicly known. In all cases, these experiences provide lenses through which existing knowledge and theory can be filtered.

The final area of my discussion focused on interactions between persons with AIDS and others. As elsewhere, psychologists can begin here with their own experiences. Regardless of our own HIV status, how do we feel differently interacting with a person with AIDS in contrast to a person who is not HIV-infected? From this level of questioning, we can move to a critical understanding of the effects of AIDS-related stigma on general social interactions, on relationships between persons with AIDS and

family members, and on family members themselves.

If the AIDS epidemic had never occurred, this lecture might instead have focused on the stigma related to cholera. We might have discussed how the cultural construction of that disease in 1832 affected medical responses to the epidemic and how it inflicted hardships upon the sick. Alternatively, we might have discussed social constructions of some other illness: The plague, or influenza, or cancer. In any of these cases, many of our general observations and conclusions about the nature of illness and stigma would have been similar to those presented here.

But, of course, the AIDS epidemic did occur and continues to shape our reality. As a result, illness-related stigma is not simply an abstract phenomenon to be considered with scholarly detachment. Instead, it impinges upon our daily lives and work. Rather than being interesting historical trends that we can dispassionately discuss, the conflicts between moralistic and secular constructions of disease or between coercive and compassionate responses to it have become literally life and death struggles played out in policy arenas as we watch and, in many cases, participate. A lecture on AIDS and stigma, therefore, cannot be limited to analysis but must also include a call to action.

Today, AIDS-related stigma is itself an epidemic, one that infects individual attitudes, beliefs, behaviors and, ultimately, public policy and the health of society. In many of its broad patterns, AIDS-related stigma resembles past couplings of illness and stigma. In many of its particulars, it is new and different. Because we psychologists can integrate our own subjective experiences of AIDS with our perspectives as researchers, practitioners, and teachers, we can achieve a unique understanding of the many manifestations of AIDS-related stigma described in this lecture. Consequently, we also have unique opportunities and responsibilities to combat not only AIDS, the physical illness, but also AIDS, the stigmatized illness.

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Footnotes

1. My comments on the history and usage of the word *stigma* are based on the 1971 edition of the *Oxford English Dictionary* (OED), p.954.

2. To better understand the social psychological phenomena discussed in the remainder of the paper, readers who lack personal experience with AIDS and AIDS-related stigma may wish to read the accounts provided by Monette (1988), Peabody (1986), and Whitmore (1988).

3. Unless otherwise noted, the information in this section is taken from the Institute of Medicine (1988).

4. Some researchers and physicians have suggested that KS is not a cancer, that it is caused by a sexually-transmitted agent other than HIV, and that it is not necessarily an indication of AIDS (Perlman, 1990).

5. I thank Prof. Bliss Siman, of Baruch College of the City University of New York, for her assistance in obtaining these data through the Roper Center, University of Connecticut at Storrs.

6. Conversely, to be gay or bisexual man, an IV drug user, and, to some extent, Black, or Latin in the United States today is to be

perceived as a member of the "AIDS community," whether or not one is infected with HIV. AIDS constitutes a new master category that subsumes these stigmatized groups. Even lesbians, who are at the lowest risk of anyone for sexual transmission of HIV, are categorized with the AIDS community by virtue of their homosexuality.

7. I am grateful to Barry Adam for this example.

Appendix A:
Resources for
Current Information on AIDS

In addition to general academic and professional journals, psychologists wishing to find the most recent information on AIDS-related issues may wish to consult the following.

Newsletters

AIDS Treatment News (semi-monthly). ATN, c/o John S. James, PO Box 411256, San Francisco, CA 94141.

AIDS/HIV Record (semi-monthly). BioData Publishers, PO Box 66020, Washington, DC 20035.

Treatment Issues (10 times yearly). Gay Men's Health Crisis, 129 West 20 Street, New York, NY 10011.

FOCUS: A Guide to AIDS Research and Counseling (monthly). UCSF AIDS Health Project, Box 0084, San Francisco, CA 94143-0884.

MIRA: Multicultural Inquiry and Research on AIDS Newsletter (quarterly). MIRA Newsletter, 74 New Montgomery Street, San Francisco, CA 94105.

AIDS Journals

AIDS & Public Policy Journal (quarterly). 107 East Church Street, Frederick, MD 21701.

AIDS Education and Prevention (quarterly). Guilford Publications, 72 Spring Street, New York, NY 10012.