

AIDS and Stigma: A Conceptual Framework and Research Agenda

Final Report from a Research Workshop Sponsored by the National Institute of Mental Health

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Workshop Participants

Gregory M. Herek, *University of California, Davis* (Co-Chair)
Leonard Mitnick, *National Institute of Mental Health* (Co-Chair)

Scott Burris, *Temple Law School*
Margaret Chesney, *University of California, San Francisco*
Patricia Devine, *University of Wisconsin, Madison*
Mindy Thompson Fullilove, *New York State Psychiatric Institute*
Robert Fullilove, *Columbia University School of Public Health*
Herbert Chao Gunther, *Public Media Center, San Francisco*
Jeffrey Levi, *Center for Health Policy Research, George Washington University Medical Center*
Stuart Michaels, *University of Chicago*
Alvin Novick, *Yale University*
John Pryor, *Illinois State University*
Mark Snyder, *University of Minnesota*
Timothy Sweeney, *Empire State Pride Foundation, New York*

PREFACE: *On April 12-13, 1996, the Office on AIDS of the National Institute of Mental Health (NIMH) convened a research workshop to consider the problem of AIDS-related stigma, its impact on the epidemic, and priorities for empirical research. The workshop, co-chaired by Gregory Herek and Leonard Mitnick of NIMH, was designed to promote consideration of empirical research and theory-building that would have both basic and applied scientific significance, including implications for policymakers and opinion leaders. The following report summarizes the workshop's discussion and principal recommendations for research priorities in this area. A somewhat different version of this report will appear in the AIDS & Public Policy Journal in 1998.*

AIDS-related stigma (or, more simply, *AIDS stigma*) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV and at the individuals, groups, and communities with which they are associated. It persists despite passage of protective legislation and disclosures by public figures that they have AIDS or are infected with HIV.

Although widely recognized as a problem, AIDS stigma has not been extensively studied by social and behavioral scientists. Empirical research is urgently needed in this area, however. Data are especially needed to inform government leaders, health providers, and the general public

as they debate new policies concerning HIV treatment, prevention, and monitoring. We begin the present paper by providing a conceptual framework for understanding AIDS stigma, and then propose a basic research agenda.

A CONCEPTUAL FRAMEWORK

AIDS stigma represents a set of shared values, attitudes, and beliefs that can be conceptualized at both cultural and individual levels. At the cultural level, AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of persons with HIV (PWHIVs) and those at risk for infection. At the individual level, it takes the form of behaviors, thoughts, and feelings that express prejudices against persons infected with HIV. Such prejudices can be found among PWHIVs as well those who are uninfected.

Because stigma is, by definition, a relational construct, adequately understanding it requires analysis at both cultural and individual levels. In the following section, we discuss stigma first in terms of its cultural context, and then in terms of its manifestations in individuals. The latter level of analysis is further divided into discussions of AIDS stigma from the perspective of its targets (i.e., people with HIV and others who are socially linked to them) and its perpetrators.

The Cultural Context of Stigma

Examples of institutional and cultural manifestations of AIDS stigma include laws and policies that directly punish PWHIVs or promote discrimination against them; electoral campaigns that promote negative attitudes, beliefs, or actions against PWHIVs and their loved ones, associates, caregivers, or advocates; institutional failures to address problems and needs related to AIDS or HIV because of its stigmatized status; and scapegoating of minority communities because of their perceived association with the epidemic.

Although AIDS stigma is a product of the HIV epidemic, the association of stigma with disease is not a new phenomenon. Throughout history, the stigma attached to epidemic illnesses and the social groups linked to them has often hampered treatment and prevention, and has inflicted additional suffering on sick individuals

and their loved ones. In this sense, AIDS stigma displays continuity with many past epidemics. Yet, AIDS stigma must be understood in relation to the specific characteristics of HIV disease and the modern AIDS epidemic. In this regard, four points are particularly important.

First, the nature and intensity of AIDS stigma are shaped by the social construction of the epidemic in different locales. AIDS is a global pandemic, and PWHIVs are stigmatized throughout the world to varying degrees. AIDS stigma around the world is expressed through ostracism of PWHIVs, discrimination against them, laws mandating compulsory HIV testing without prior consent or protection of confidentiality, and even quarantine. Although AIDS stigma is effectively universal, it takes different forms in different countries. The specific groups targeted for AIDS stigma vary considerably across cultures and national borders, as does the extent to which stigmatizing attitudes are enshrined in laws and policies. This variation is shaped in each society by multiple factors, including the local epidemiology of HIV; preexisting beliefs and values surrounding sexuality, disease, gender, and drug use; and prejudices toward specific cultural outgroups. Throughout the world, AIDS stigma has tended to be expressed locally against unpopular and relatively powerless groups disproportionately affected by the epidemic.

Second, in the United States and elsewhere, stigma has been associated with AIDS from the earliest days of the epidemic, documented in the forms of public attitudes, violence, and discriminatory practices. Since the epidemic began, a significant minority of the American public has consistently expressed negative attitudes toward PWHIVs and has supported coercive measures against them, including quarantine, universal mandatory testing, and even tattooing of infected individuals. PWHIVs have been more negatively evaluated than persons with other diseases, even by health care workers and mental health professionals. In some cases, people perceived to be HIV-infected have been physically attacked. Such assaults have also been directed at individuals who — because of their group membership or community affiliation —

serve as a proxy for people with AIDS, such as gay men and lesbians.

In addition, AIDS-related discrimination has been reported since the early days of the epidemic. PWHIVs (and people believed to have AIDS or HIV) have been fired from their jobs, evicted from their homes, and denied services. Such discrimination, which has occurred despite legal precedents and protective legislation, has been especially dramatic in the areas of employment, health care, insurance, and education. Ironically, even some institutional policies and laws designed to protect people with HIV from the effects of stigma can, in part, perpetuate it. Privacy law, for example, assists PWHIVs with managing stigma but may also contribute to the characterization of HIV as a dirty secret. Similarly, protection of PWHIVs from discrimination under disability laws entails classifying even asymptomatic HIV as a handicap.

Third, AIDS stigma has been layered upon preexisting societal stigma toward outgroups affected by HIV. Consequently, cultural AIDS stigma has been closely intertwined with the stigma associated with drug use, homosexuality, poverty, and racial minority status. Indeed, it can be argued that preexisting stigma helped to give rise to the AIDS epidemic by creating social conditions that foster HIV transmission. Societal stigma directed at illegal drug use, for example, helped to create a subculture that included phenomena such as “shooting galleries,” which have facilitated the efficient transmission of HIV and other microorganisms.

Fourth, within a particular society, AIDS stigma can vary across population subgroups. How different communities and groups react to AIDS stigma may vary depending upon how they have been affected by the epidemic. Among the factors likely to shape the forms taken by stigma within different groups are: (1) the predominant patterns of HIV infection in the group, which affect the likelihood both of individuals being infected with HIV and of individuals knowing others who are infected; (2) the immediacy of AIDS relative to the group’s other pressing problems; (3) the group’s history of being stigmatized by the dominant culture, which can

also affect the group’s level of trust for cultural institutions, including the health care establishment; and (4) the group’s shared attitude toward behaviors and subgroups associated with HIV. An important example of intergroup variation involves racial and ethnic differences in AIDS stigma. In the United States, for example, African Americans and Hispanics often score lower than Whites on tests of AIDS knowledge. The belief that HIV is transmitted through casual contact is associated with a greater tendency to stigmatize PWHIVs through personal avoidance and endorsement of public policies such as quarantine. Interracial and interethnic variations in such beliefs may reflect differences in the trust that different groups place in official AIDS information which, in turn, reflect multiple cultural and historical factors.

Intergroup differences in AIDS stigma are important for at least three reasons. First, AIDS stigma within a particular community is likely to shape that community’s response to the epidemic. Indeed, it is likely to be a central factor in the community’s readiness to acknowledge its own risk for HIV in a realistic manner. Second, intergroup variations in stigma can create different experiences for PWHIVs in different communities and cultures. Because of cultural differences in the construction of homosexuality, for example, the amount and type of stigma experienced by a Black gay man with AIDS may differ dramatically according to whether he identifies primarily with a heterosexual African American community, a Black gay community, or a White gay community. Third, cultural differences in stigma may necessitate different interventions for reducing stigma in different communities.

Individual AIDS Stigma

Targets of AIDS Stigma

Primary AIDS stigma. The primary targets of AIDS stigma are individuals with HIV and those who are perceived to be HIV-infected. Fear of becoming a primary target of AIDS stigma also affects individuals whose behavior may place them at risk, regardless of their serostatus.

AIDS stigma creates significant stress for many PWHIVs. It dramatically raises the

personal cost of learning that one has HIV, both because infected people are exposed to the prejudice of others and because they are forced to confront any negative feelings that they might harbor toward their own behavior or identity. Once their serostatus is known to others, persons infected with HIV face social ostracism, stereotyping, and the many types of discrimination and attack described above. They also legitimately may fear that disclosure of their status (“coming out” as an HIV-infected person) will strain family relationships and friendships, make it difficult for them to maintain normal lives, or reveal other aspects of their lives that might lead to further stigma, such as homosexuality or use of intravenous drugs. Stigma can also lead to losses that undermine PWHIVs’ livelihood and quality of life, including restriction of career opportunities and loss of employment.

To avoid discrimination and loss, many PWHIVs attempt to conceal their status, which requires that they continually manage information about their stigmatized status in social interactions. They may decide not to disclose their HIV serostatus to family, friends, employers, and even physicians. This concealment may cause them to be cut off from social support and needed medical and social services. They also may delay in obtaining medical care, or fail to adhere adequately to medical treatment regimens once they enter care. With growing evidence that treatment with combination drug therapies may significantly alter the course of HIV disease — especially when begun during the period of primary infection — such delays may have negative consequences for PWHIVs’ long-term prognosis. In the most serious instances, the stigmatization of HIV illness can result in PWHIVs foregoing valuable social support and medical treatments that could increase their longevity and improve their quality of life.

AIDS stigma can also interfere with PWHIVs’ coping and adjustment. The psychological distress experienced by many PWHIVs is likely to be exacerbated by self-imposed isolation and by experiences with ostracism, hostility, and discrimination.

Internalized stigma also can disempower PWHIVs and those at risk for infection. Individuals may blame themselves for their experiences with stigma, even to the point at which they cease to assert their right to decent treatment and other social benefits. PWHIVs who accept society’s negative characterizations of people with HIV — or of groups disproportionately affected by HIV, such as gay men — may blame themselves for the intolerance of others, feeling that they deserve mistreatment. Laws against discrimination are of little help to people who do not see their mistreatment as an undeserved wrong. In this way, stigma can deprive PWHIVs of the very right to have rights.

Secondary AIDS stigma. The secondary targets of AIDS stigma include PWHIVs’ partners, family members, and loved ones, as well as the professionals and volunteers who work with them or provide AIDS services or advocacy. Using Goffman’s (1963) terminology, these individuals experience a *courtesy stigma* through their close association with AIDS, PWHIVs, and the many stigmatized groups associated with HIV — including homosexuals and drug users. The secondary targets of AIDS stigma also include uninfected members of groups popularly perceived as linked to the AIDS epidemic. In the United States, these groups include the gay and lesbian community, bisexual men, injecting drug users, hemophiliacs, and Haitians. Secondary stigma can leave the loved ones of PWHIVs without adequate social support. It also takes a toll on those who work with PWHIVs. Secondary stigma may deter professional and volunteer caregivers and advocates from working with PWHIVs, or may make their work more difficult and stressful. The experience of stigma appears to affect caregivers’ levels of satisfaction, stress, psychological well-being, and their willingness to continue working with PWHIVs.

AIDS stigma and prevention. AIDS stigma interferes with effective prevention efforts. Fears of stigma represent an impediment to disclosure by PWHIVs of their serostatus to others, including sexual partners, which can interfere with effective risk reduction. In addition, the experience of stigma may represent an ongoing

source of psychological distress that may make effective risk reduction more difficult for PWHIVs. Although empirical research in this area is scant, it also appears that fears of AIDS stigma can deter people at risk for HIV from being tested and from seeking information and assistance for risk reduction. Delays in testing increase the likelihood that infected individuals will transmit the virus to their sexual partners, to those with whom they share needles, and to their offspring. Internalized stigma and fear of stigma from others also may be associated with adverse responses to receiving a positive HIV test result which, in turn, may increase the likelihood of continuing behaviors that transmit HIV.

The politics of AIDS stigma have also hindered societal response to the epidemic. The news media were initially slow to cover the epidemic, probably because of its prevalence among stigmatized groups. Federal legislation and policy have frequently prevented AIDS educators from providing clear and explicit risk reduction information to individuals at risk. For example, opposition to needle exchange programs — despite their apparent effectiveness in reducing HIV transmission rates — has been premised on the need to maintain the stigma associated with illegal drug use. Extensive resources that might otherwise have gone to prevention instead have been needed to respond to punitive AIDS legislation whose purpose was primarily to stigmatize and punish PWHIVs. Such legislation remains a problem well into the second decade of the epidemic. In 1996, for example, federal law briefly singled out HIV-positive military personnel for discharge while ignoring other active-duty personnel with comparable serious medical conditions.

Perpetrators of AIDS Stigma

The perpetrators of AIDS stigma are individuals who express negative attitudes or feelings toward PWHIVs, or who engage in discrimination or other stigmatizing behaviors. Empirical research indicates that a significant minority of adults in the United States manifests AIDS stigma to some degree. These negative reactions seem to derive from two fundamental sources. First, perpetrators may fear certain

outcomes directly related to HIV, resulting in *instrumental stigma*. Second, they may react to the accumulated social meanings associated with HIV and AIDS, resulting in *symbolic stigma*. The bases of instrumental and symbolic stigma represent two separable sets of social and psychological factors.

Instrumental AIDS stigma. AIDS shares many characteristics with other diseases that are typically associated with high levels of stigma. First, AIDS has been widely perceived to be an unalterable, degenerative, and fatal condition (although recent advances in HIV treatments — most notably the successful use of protease inhibitors — might change this perception). Second, AIDS is widely understood to be transmissible; when a disease is contagious, the person afflicted with it is often regarded as dangerous and is avoided. Finally, in the more advanced stages of HIV disease, its symptoms are often readily apparent to others and may be perceived as repellent, ugly, or upsetting. Any disease that is widely regarded as dangerous, contagious, and disfiguring is likely to be stigmatized. Amplifying this reaction to AIDS is a tendency among a significant portion of the public to blame PWHIVs for their illness. This blame stems from the widespread perception that the primary transmission routes for HIV — sexual intercourse and sharing of infected needles — are immoral and voluntary.

Whereas some fear of contagion is not unusual in response to a disease, uninfected people vary widely in their perceptions of danger associated with being around PWHIVs. By the early 1990s, for example, most adults in the United States appeared to understand that casual social contact (e.g., sharing food with or sitting near a PWHIV) posed no risk and were not bothered by it. Others, however, still believed that HIV can be transmitted through various forms of casual contact. The latter group of individuals are the most likely to manifest instrumental stigma.

Symbolic AIDS stigma. In addition to its instrumental roots, the specific character of AIDS stigma in the United States derives from the association of HIV with particular groups in popular perceptions. *Symbolic AIDS stigma*

results from the social meanings attached to AIDS. It represents the use of the disease to express attitudes toward the groups associated with it and the behaviors that transmit it.

Because the American public continues to equate AIDS with homosexuality to a significant extent, symbolic AIDS stigma in the United States has focused principally on male homosexuality. Heterosexuals' attitudes toward gay people are strongly correlated with their AIDS-related fear, knowledge, and stigma. Those who express negative attitudes toward gay people are more likely than others to be poorly informed and excessively fearful concerning AIDS, and are more likely to stigmatize people with AIDS. Furthermore, gay men with AIDS and men who contracted HIV through male-male sex are more likely to be negatively evaluated or blamed than are heterosexuals with AIDS or other illnesses. Even among health care professionals, negative attitudes about homosexuals are associated with unwillingness to work with and negative attitudes toward patients with AIDS.

AIDS stigma is also affected by attitudes toward other stigmatized groups associated with HIV in public perceptions. For example, AIDS stigma has combined with the stigma historically associated with drug use to affect public policy about HIV prevention programs targeting injecting drug users. One of the major consequences has been continuing government opposition to needle exchange programs, despite evidence of their efficacy.

AIDS stigma also has interacted with cultural prejudices, such as sexism and racism, to shape responses to the epidemic. When women and members of other groups — including ethnic and racial minorities, the poor, and the homeless — become infected with HIV or develop AIDS, their already-disadvantaged status subjects them to differential treatment by society. For example, although women were one of the fastest growing sectors of the U.S. AIDS patient population by the early 1990s, cultural sexism interacted with AIDS stigma to make them one of the most invisible groups among PWHIVs at that time.

At the core of symbolic AIDS stigma is the perception of PWHIVs as a social outgroup. This perception, which is perhaps inevitable to some

degree with any serious illness, was reinforced in a variety of ways early in the epidemic, often by well-intentioned researchers and care providers. For example, when the epidemiological construct of “risk groups” was adopted in popular discourse about AIDS, its meaning mutated in such a way that it helped to reinforce perceptions of PWHIVs as an outgroup, and — coupled with the need of many perpetrators of stigma to protect their own social identity — heightened the perception of difference between the ingroup (“us,” i.e., noninfected, nondeviant people) and the outgroup (“them,” i.e., infected, deviant people). As a result, the boundaries between “us” and “them” became rigid and represent a major obstacle in the reduction of AIDS-related stigma.

A RESEARCH AGENDA

Despite the serious consequences of AIDS stigma for persons with HIV, their loved ones and caregivers, and society as a whole, empirical research on this topic has been limited. Much of the available data are drawn from anecdotal reports, studies for which stigma was not the primary focus, or studies of other stigmatized groups. Indeed, AIDS stigma often appears to have been regarded by researchers principally as a backdrop against which the epidemic has occurred rather than as a phenomenon warranting study in its own right.

Because stigma hampers society's ability to respond effectively to AIDS, understanding and counteracting it will remain critical public health objectives into the new millennium. Social and behavioral research can play a key role in providing the information necessary to develop effective programs to combat AIDS stigma. In the following section, we briefly outline a research agenda for AIDS stigma.

As a starting point, we suggest that research on AIDS stigma should be *action research*, that is, it should have the goal of yielding results that are readily applicable to efforts to eradicate AIDS stigma. Whereas basic research also should be encouraged on the social, psychological, and cultural processes that underlie AIDS stigma (and illness-related stigma in general), the primary research focus should be understanding AIDS stigma in order to develop

and test strategies for reducing it in real-world settings.

Research on the Cultural Context of AIDS Stigma

Research is needed to illuminate the cultural context of AIDS stigma. Such research should describe occurrences of stigma as well as resistance to it. Examples of the latter include needle exchange programs; the Americans with Disabilities Act (ADA) and other protective legislation; and the establishment of institutions to fight AIDS such as the National Association of People with AIDS, Gay Men's Health Crisis, and the Names Project. Empirical research should also identify the ways in which stigma directed at the communities most affected by AIDS contributes to HIV transmission, as well as the ways in which community responses to prejudice and discrimination have facilitated an adaptive response to the AIDS epidemic.

Whereas descriptive research is necessary for developing an understanding of the ways in which stigma is manifested in society's institutions, the primary value of research on the cultural context of AIDS stigma will ultimately lie in its ability to generate effective strategies for reducing stigma in society at large. Such interventions must reach policy makers, opinion leaders, and average citizens in order to be effective.

Because AIDS stigma permeates society, delineating a research agenda on its specific cultural manifestations is a daunting task. In the following discussion, we briefly highlight some key research questions related to stigma within several cultural institutions. In each area, some examples can be cited in which the institution has promoted stigma and others in which it has actively challenged stigma or tried to alleviate stigma's consequences. As a general goal, we propose that research on institutional AIDS stigma attempt to identify the conditions under which the latter outcome has been achieved and the former avoided in order to apply models that have been successful in the past to new arenas of stigma.

Law

In the United States, the law has been used

both to promote AIDS stigma and to negatively sanction stigma and protect its targets. Examples of the former include laws that have targeted people with AIDS for special punitive treatment (e.g., military discharge) or have placed special restrictions on AIDS prevention efforts (e.g., restrictions on federal funding for AIDS educational materials that are sexually explicit or that portray homosexuality in a positive light). Empirical research can demonstrate the negative consequences of such laws for the well-being of PWHIVs and those who are at risk for infection, as well as the ways in which such policies may actually promote the spread of HIV by, for example, deterring PWHIVs from disclosing their serostatus to others or preventing individuals at risk for HIV from learning effective prevention techniques. In addition, research on responses to such laws by individuals and organizations — both in the form of attempts to prevent their passage or enforcement, and responses to them once they are in place — could also be useful.

Although numerous attempts have been made to use the law to promote stigma, the law has more often been deployed to address the problem of stigma. This has occurred on two levels. First, the law has been used to regulate the conduct of people who come into possession of HIV-related information about others, requiring them to keep the information confidential and to abstain from discrimination based on HIV status. Second, HIV-related laws address stigma itself by asserting a social norm of respect and equality for PWHIVs and those at risk for contracting HIV. This anti-stigma project in law, widely supported by public health officials, has been constituted in a range and degree of legal protection never before extended to individuals with a communicable disease.

Whereas the assumption that law can help to reduce stigma and stigmatizing behavior — and thereby enhance HIV prevention and treatment — is reasonable in light of present knowledge of law and public health, we know very little about how HIV-related laws actually operate to reduce stigma and its effects. The fact that many people at risk for HIV infection still avoid being tested raises the question of whether the law effectively addresses their concerns. Indeed, for some people

(e.g., drug-using mothers who fear the state may take custody of their children), the law may itself be a source of social risk.

Empirical research, therefore, should identify the impact of existing statutes (e.g., the ADA, local AIDS antidiscrimination ordinances) on the behavior both of the perpetrators and targets of AIDS stigma. Such research should recognize that the effectiveness of laws to protect individuals — and the latter's attitudes toward the law — vary according to many factors, including race and social class. Traditional thinking about stigma and social risk — and the use of the law to address them — may have little relevance to the concerns of people in the groups in which HIV continues to spread most rapidly. Consequently, such research should attempt to identify intergroup differences in the impact of AIDS law.

An emerging area for research derives from recent calls for an end to heightened legal protection of the privacy of PWHIVs, that is, so-called “AIDS exceptionalism.” In the past, an array of policies and laws have had the goals of protecting people with HIV from stigma and increasing the effectiveness of public health responses to the epidemic. Recent arguments proposing to eliminate such protections have typically been premised on the assumption that AIDS stigma is no longer a serious problem and that efforts to avoid it now have a deleterious effect on prevention efforts. However, empirical research is clearly needed to document whether AIDS stigma still constitutes a sufficiently serious problem that it would interfere with HIV testing and risk-reduction if current legal protections were eliminated. For example, would procedures such as aggressive partner notification or reporting the names of all PWHIVs to state and federal government sources actually be effective in reducing HIV transmission? Would people at risk for HIV be less likely to seek testing if they perceive that they cannot do so anonymously or without mandatory partner notification? These questions should be empirically addressed before changing AIDS-related public policy in this area.

Mass Media

The mass media have played a central role in providing information about AIDS and HIV to the US public. As with the law, the media have both engendered AIDS stigma and helped to combat it. Empirical research is needed to document the ways in which the media have influenced AIDS stigma, and the ways in which they can be used to counteract it. One area for research concerns how media dissemination of information about HIV (e.g., how to avoid infection) affects public stigma of PWHIVs. For example, do mass media messages about the importance of taking personal responsibility for avoiding HIV infection inadvertently increase the public's punitive blaming of PWHIVs? Do campaigns that increase audience members' sense of personal risk for HIV also engender heightened stigma of PWHIVs? Another research question concerns how media coverage of personal disclosures by public figures that they have HIV or AIDS affects public attitudes toward PWHIVs in general. In what situations, for example, do disclosures of HIV infection by celebrities have a positive effect on the public's responses to AIDS?

Religion

Religious institutions have displayed a wide variety of responses to the HIV epidemic, with most — though not all — expressing condemnation of AIDS stigma. Nevertheless, because HIV is transmitted by behaviors that are condemned by many religions, the religious response to AIDS has often been conflictual and ambivalent. Empirical research is needed both to describe the variety of responses by organized religion and their evolution over time, and also to prescribe strategies for ways in which the influence of churches, temples, and mosques can be utilized more effectively to eliminate AIDS stigma and its consequences.

The Workplace

Discrimination in the workplace has historically been a primary manifestation of AIDS stigma. At the same time, many employers have developed effective workplace programs for accommodating the needs of employees with HIV while simultaneously educating other workers

about AIDS. With the advent of increasingly effective HIV treatments, new workplace challenges are being created. PWHIVs who can return to work as a result of successful combination drug therapies may find that they are unable to secure appropriate employment or cannot obtain disability insurance, which they are likely to need if their physical health deteriorates in the future. At the same time, uninfected supervisors and employees may need additional education about HIV and the needs of HIV-infected workers. Empirical research should identify the core components of effective workplace programs for addressing such aspects of AIDS stigma.

Health Care

Although the health care system provides care for PWHIVS, it also is often a source of stigma. Many providers express negative attitudes toward PWHIVs and would prefer not to treat them. Health care professionals and support staff — especially those who deal with PWHIVs infrequently — can be insensitive to PWHIVs' concerns about stigma, and are not always knowledgeable about appropriate procedures for maintaining patient confidentiality. Empirical research is needed to identify the best strategies for training and monitoring health care providers to insure that they are sensitive to the problems of AIDS stigma and understand how to minimize its occurrence and address its negative consequences.

Research on the Targets of AIDS Stigma

Primary Targets

Research on the primary targets of stigma typically operationalizes AIDS stigma in terms of thoughts, feelings, and behaviors that occur in reaction to or anticipation of real or imagined stigma. Examples include avoidance of HIV testing or medical care; nondisclosure of one's HIV status to others; avoidance of safer sex or other risk reduction practices because of fears of stigma; and negative psychological states (e.g., low self esteem, self-blame, self-loathing) that result from internalizing societal stigma. Empirical research is needed to address the effect of stigma on persons infected with HIV as well

as persons at risk for HIV infection. Three types of research are especially important.

First, descriptive cross-sectional research is needed to document the ways in which stigma affects PWHIVs, including their perceptions and fears associated with stigma; the impact of stigma on their decisions to be tested, to engage in risk-reduction, to enter medical care, and to adhere to care regimens; and their physical and psychological well-being. Further research is also needed to unravel the possible interrelationships between psychosocial factors and disease progression. Second, longitudinal research is needed to describe the ways in which AIDS stigma evolves in response to the changing nature of the epidemic. In particular, empirical studies are needed to describe new manifestations of stigma that emerge in conjunction with new breakthroughs in treatment of HIV (e.g., new types of workplace stigma), and the ways that these new forms affect PWHIVs — both those who are directly benefiting from new therapies and those who are not. Finally, research is also needed to develop strategies for mitigating the impact of AIDS stigma, and to evaluate their effectiveness.

Secondary Targets

In addition to studying the primary targets of AIDS stigma, empirical research should also describe the impact of AIDS stigma on its secondary targets: PWHIVs' family, loved ones, and professional and volunteer caregivers and advocates. In the early years of the epidemic, secondary stigma was perhaps less visible and researchers appropriately focused their work on people with HIV. Now, however, recognition of the courtesy stigma associated with AIDS creates a challenge for researchers. They must broaden their inquiry to define the structural and functional properties of relations between primary and secondary targets of AIDS stigma that provide the channels through which stigmatization spreads from the former to the latter. Such spread is most likely a form of social transmission, involving processes of social inference about the relations between primary and secondary targets, judgments of interpersonal similarity between the two kinds of targets, and

imputations of the motives and characterological attributes of secondary targets that lead them to voluntarily associate themselves with the primary targets of AIDS stigma.

Because the links between the mechanisms of primary and secondary AIDS stigma raise basic questions about social relations and cognitions, they represent a particularly inviting challenge to researchers in the social and behavioral sciences. In addition, the phenomena associated with courtesy stigma also provide opportunities for researchers to examine the processes by which the targets of such stigma can and do cope with their stigmatization, including processes of distancing or detachment from the primary targets of stigma (with attendant consequences for increasing the isolation of PWHIVs) as well as processes of challenging the beliefs of the perpetrators of courtesy stigmatization.

Professional and volunteer caregivers' experiences with courtesy stigma may increase their stress associated with providing services to persons living with HIV, and may lead to demoralization, burnout, withdrawal, and early termination of service. Accordingly, the remediation of courtesy stigma among HIV service providers may not only ensure that such caregivers continue to serve, but also may make their work ultimately more satisfying to themselves and to the recipients of their services.

Research on Perpetrators of AIDS Stigma

To date, most empirical research on AIDS stigma has focused on perpetrators. In such research, stigma typically has been operationalized in terms of hostile attitudes and negative affect toward persons perceived to have AIDS or HIV; negative stereotypical beliefs about them; verbal and behavioral expressions (and intended expressions) of these attitudes, emotions, and beliefs; overt rejection of PWHIVs and avoidance of contact with them; and unfair, discriminatory, and hostile behavior toward them.

The scientific literature contains reports on large-scale surveys with probability samples that included questions about AIDS stigma, as well as reports of laboratory studies on the psychological processes underlying AIDS stigma. Both sources

of data have important limitations, however. Most large-scale surveys have been sponsored by commercial news organizations, and have tended to reflect breaking news stories rather than substantive questions about key sociological and psychological variables. The number of questions about AIDS in national surveys has dropped substantially since the early 1990s as the epidemic has faded from national consciousness as a breaking news story. Laboratory studies, for the most part, have been conducted only with small convenience samples, which severely limits the generalizability of their findings. Moreover, the results of laboratory studies have yet to be translated into useful interventions for reducing stigma among perpetrators and potential perpetrators.

Population surveys and laboratory experimentation that overcome these limitations are important components of an AIDS stigma research agenda. Descriptive studies and intervention research on perpetrators should both be encouraged. In addition to documenting the prevalence of stigma in the population and identifying intergroup variation (e.g., differences among ethnic and racial groups), further descriptive research is needed to identify the social psychological processes that underlie AIDS stigma. Such research should focus both on social variables (e.g., the effects of interpersonal contact with PWHIVs, the role of social reference groups in shaping individual attitudes) and psychological variables (e.g., the cognitive organization of attitudes toward PWHIVs). Of specific interest is the time course of psychological reactions to PWHIVs. Research concerning other forms of prejudice (e.g. racial prejudice) suggests that people may have immediate negative reactions to stigmatized individuals, often followed by more thoughtful or reflective responses. Research is needed to integrate the study of AIDS stigma with these contemporary approaches to understanding the social cognitive processes involved in prejudice.

Empirical research should also consider the interaction between AIDS stigma and the other forms of social stigma and prejudice with which it is often coupled, including the stigma associated with homosexuality, drug use, race,

and poverty. Such research should also consider the relationship between AIDS stigma and concern for one's personal well-being. The often-documented relationship between stigmatizing attitudes and overestimation of the risks of HIV transmission through casual social contact suggests that an exaggerated sense of personal vulnerability is linked to AIDS stigma. Whether there is a causal relationship between these variables — and, if so, its direction — is an appropriate topic for empirical study.

Another focus for research in this area is the relationship between stigma and notions of responsibility, blame, and controllability. Stigma is generally more likely to be directed at undesirable conditions that are perceived to have been acquired through voluntary behavior. This pattern raises the question of how AIDS educational messages can communicate the importance of taking responsibility for one's own safety from HIV (e.g., through practicing safer sex) without also communicating the idea that people with HIV are blameworthy for their condition and, therefore, deserving of stigma. How can expressions of stigma best be discouraged even when the perpetrator perceives HIV-infection to be the responsibility of the target of stigma?

A primary goal of descriptive studies should be to provide insights into AIDS stigma that will facilitate the development of interventions to effectively combat it. The finding that direct interpersonal contact with PWHIVs is often associated with lower levels of stigma, for example, suggests the possibility that fostering such contact experiences might help to reduce stigma among some uninfected individuals.

Stigma interventions inevitably will have to deal with the symbolic aspects of AIDS stigma as well as its instrumental components. Because many stigmatizers perceive AIDS as a threat not only to their physical well being but also to their important values and social identities, their reactions to PWHIVs are strongly affective, are tied to other prejudices, and often involve multiple and conflicting emotional experiences. Reducing AIDS stigma, therefore, necessarily involves addressing the specific threat that a stigmatizer experiences. Interventions may be

effective with some individuals only if they also attack other forms of stigma (e.g., antigay attitudes). Because some stigmatizers will be highly resistant to direct attitude change attempts, additional strategies may be needed to change attitudes indirectly by first changing behaviors, for example, through enforcement of nondiscrimination laws and policies.

CONCLUSION

We urge all AIDS researchers to seriously consider whether direct study of stigma is appropriate for their research question and, if so, to explicitly examine the effects of stigma in their studies of the psychosocial aspects of AIDS and HIV infection. We believe that empirical research will be most effective in meeting this goal when it is interdisciplinary and employs a variety of quantitative and qualitative methodologies.

As the nature of the epidemic evolves, so too will the manifestations and nature of AIDS stigma change. Although much AIDS stigma in the United States has focused on gay men and male homosexual behavior, this pattern may change as the epidemic is increasingly perceived to be a problem of the poor, homeless, and disenfranchised. Symbolic AIDS stigma may come to serve primarily to express antipathy toward the homeless, for example, or toward members of racial and ethnic minority groups.

New advances in treating HIV infection are likely to affect the stigma experienced by PWHIVs. Recent reports of the effectiveness of combination drug therapies may have already caused public perceptions of AIDS to begin to shift from fatal disease to chronic illness. Such a change may reduce the extent of stigma, especially instrumental stigma. At the same time, improved treatments may create new situations in which stigma arises. For example, PWHIVs who attempt to return to the work force after a long period of disability may find that their previous status as a disabled person becomes a source of stigma that interferes with their opportunities for employment.

Empirical research on AIDS stigma will fill important gaps in current knowledge and provide critical information for the design of strategies for overcoming the effects of stigma. More

generally, it has the potential for providing a better general understanding of how the many types of stigma function on both a psychological and societal level. Thus, one legacy of the AIDS epidemic will be to help society not only in coping with the stigma of AIDS, but to better prepare for the stigma associated with communicable diseases in the future.

We recognize that the research program proposed here will take considerable time to complete. In the short term, therefore, we urge researchers, health care professionals, policy makers, and political leaders to make a strong commitment immediately to work to stop the epidemic of stigma. As long as stigma remains widespread and poorly understood, it will threaten the well-being of people with HIV, their loved ones, and caregivers, and will prevent society from effectively eradicating the scourge of HIV.

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