

Stigma, Social Risk, and Health Policy: Public Attitudes Toward HIV Surveillance Policies and the Social Construction of Illness

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Abstract

This study examined how illness-related stigma can be symbolically expressed through public attitudes toward health policies. Data from a 1999 national telephone survey with a probability sample of English-speaking US adults (N = 1,335) were used to assess how support for HIV surveillance policies is related to AIDS stigma and negative attitudes toward groups disproportionately affected by the epidemic. Anonymous reporting of HIV results to the government was supported by a margin of approximately 2-to-1, but name-based reporting was opposed 3-to-1. Compared to other respondents, supporters of name-based surveillance expressed significantly more negative feelings toward people with AIDS, gay men, lesbians, and injecting drug users. More than one third of all respondents reported that concerns about AIDS stigma would affect their own decision to be tested for HIV in the future. Implications for understanding the social construction of illness and for implementing effective HIV surveillance programs are discussed.

In his account of 19th century cholera epidemics

in the United States, historian Charles Rosenberg (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 the course of socially constructing an illness, symptoms are identified and the disease is named. Theories of origin, transmission, prevention, and cure are formulated, promulgated, criticized, and revised. Responsibility and blame often are assigned. Those who contract the disease come to be regarded as victims or patients, guilty or innocent, dangerous or benign, heroic or pitiable (Herek, 1990).

Public health policy is created and implemented within this context, and efforts to track, treat, and prevent a disease are part of the latter’s social construction. The social nature of illness is particularly evident with a stigmatized disease such as AIDS. Since the earliest days of the epidemic, people with AIDS (PWAs) and those suspected of being infected with HIV have been subjected to social ostracism, discrimination, and even violence (Gostin & Webber, 1998; Herek & Glunt, 1988; Herek, Mitnick, et al., 1998; Kegeles, Coates, Christopher, & Lazarus, 1989; Zierler et al., 2000). These reactions are rooted not only in fears of HIV transmission but also in the use of AIDS as a vehicle for expressing disapproval of the communities it disproportionately affects, especially gay people and injecting drug users, or IDUs (Capitanio & Herek, 1999; Herek, 2000; Herek & Capitanio, 1999a; Pryor, Reeder, & Landau, 1999).

When a disease is stigmatized, public health policy can help to protect those who are ill from popular prejudice or it can promote discrimination against them. Examples of both

uses of policy can be found in the history of the AIDS epidemic in the United States. Antigay and conservative political groups have often advocated policies that would seriously compromise the human rights of PWAs and members of at-risk minority groups under the guise of protecting public health. During the 1980s, for example, California voters were asked four times to enact sweeping AIDS policies that would have subjected PWAs to various public health restrictions. These initiatives included provisions to eliminate anonymous HIV testing, repeal legislation prohibiting employment discrimination on the basis of HIV status, and quarantine PWAs (Dannemeyer, 1989; Herek & Glunt, 1993; Krieger & Lashof, 1988). By contrast, the public health profession has recognized that fears of AIDS stigma and its attendant discrimination could deter people at risk for HIV from being tested, obtaining treatment, and seeking assistance with risk reduction (Chesney & Smith, 1999). Reflecting this concern, early AIDS-related public health policies in the United States included extraordinary protections for the privacy and confidentiality of PWAs and people at risk for HIV (Bayer, 1991).

At the end of the twentieth century, however, many public health officials began to advocate changes in AIDS-related policies, especially in the area of HIV surveillance. AIDS has long been a reportable disease but, until relatively recently, asymptomatic HIV infection was not reported in most states. Historically, there were many reasons for this policy, including that HIV infection was often detected only when AIDS symptoms appeared, effective treatments were not available, and public health workers feared that mandatory reporting of the names of the infected would discourage high-risk individuals from being tested for HIV and thereby hamper prevention efforts (Bayer, 1999). During the 1990s, however, as treatment advances widened the time gap between initial infection and the appearance of symptoms, health officials recognized a need for monitoring new HIV infections in order to track the epidemic, allocate resources, and plan for the future. This need,

coupled with beliefs that AIDS stigma had diminished and that anonymous reporting systems had only limited effectiveness, eventually led many influential public health authorities to support mandatory name-based reporting of new HIV infections (Gostin, Ward, & Baker, 1997; see generally Beckerman & Gelman, 2000; Centers for Disease Control and Prevention, 1999; Steinbrook, 1997). Opponents to such policies argued that fears of prejudice and discrimination still played a significant role in personal decisions to seek HIV testing and treatment, and that mandatory names reporting would deter many people from being tested (Aragón & Myers, 1999; Katz, 1998; "Privacy in H.I.V. reporting," 1997; Rotello, 1997; Woods, Binson, Morin, & Dilley, 1999).

Burris (2000) attempted to reframe this debate by introducing the construct of *social risk*, which he defined as "the danger that an individual will be socially or economically penalized should he or she become identified with an expensive, disfavored, or feared medical condition" (p. S122). Social risk comprises both the objective threat of harm and the subjective perception of risk for harm. Burris (2000) noted that perceived risk often has little to do with objective probabilities of actual harm, but may play an important role in shaping responses to public health policies. This idea is consistent with Scambler's (1989) hidden distress model, which posits that shame and fear of discrimination (which he termed *felt stigma*) motivate individuals with a stigmatized condition to attempt to pass as members of the nonstigmatized majority. Successful passing reduces their likelihood of experiencing actual discrimination (*enacted stigma*) but significantly disrupts their lives and often increases their psychological distress.

The constructs of social risk and felt stigma both highlight the important role played by the social climate in defining the behavioral options available to individuals with a stigmatized illness. Social risk and felt stigma are heightened to the extent that stigma is perceived to be widespread. The more strongly that specific illness-related policies are promoted by perpetrators of stigma,

the greater the potential for members of the stigmatized group to react to those policies in terms of felt stigma.

Public health authorities who began to advocate named reporting in the late 1990s clearly were not attempting to promote stigma, nor is it reasonable to believe that they had any malicious intent in promulgating new surveillance policies. Indeed, named reporting has many potential public health benefits (Gostin et al., 1997) and the objective risks associated with it are probably small (Burris, 2000). However, to the extent that a policy such as named reporting is linked with AIDS-related stigma in public perceptions, its adoption may heighten perceived risk among HIV-infected people and those at risk for infection. Debates about health policies such as HIV surveillance procedures, therefore, should be understood in the context of the ongoing social construction of AIDS as an illness. If a policy such as named reporting becomes widely perceived as an instrument of stigma, its adoption may increase the social risk experienced by people with HIV despite the best efforts of public health officials to reduce the likelihood of enacted stigma.

In the present paper, we use survey data from a national probability sample to examine public perceptions of AIDS stigma, attitudes toward HIV surveillance policies, and relationships between the two. We hypothesize that: (a) the continuing existence of AIDS stigma is widely recognized among the US public, (b) concerns about stigma potentially affect decisions to be tested for HIV, and (c) public support for named reporting is strongest among those who are the most likely to stigmatize people with HIV and members of other groups symbolically linked to the epidemic, such as gay men, lesbians, and IDUs. To the extent that the data support these hypotheses, much of the perceived social risk associated with name-based HIV surveillance can be understood as reflecting an accurate assessment of the realities of AIDS-related stigma.

Method

Data were collected in a national telephone

survey conducted between September 1998 and May 1999 by the Survey Research Center at the University of California at Berkeley, using their computer-assisted telephone interviewing system.

Sample

The sampling frame was the population of adults (≥ 18 years) residing in households with telephones in the 48 contiguous states. Within households, respondents were randomly selected from among the English-speaking adult residents. Data were collected simultaneously from two samples, both drawn with a list-assisted random-digit dialing (RDD) procedure (Casady & Lepkowski, 1993). One sample consisted of 666 respondents who had participated in a 1997 survey on AIDS stigma and consented to be recontacted for a follow-up interview.¹ The completion rate for follow-up interviews was 78%. The second sample consisted of 669 new respondents and had a response rate of 58% using AAPOR Response Rate Formula 2 (American Association for Public Opinion Research, 1998). The two samples did not differ in terms of gender (56% female for the combined samples), race and ethnicity (82% non-Hispanic White), education level (Median = some college or post-secondary education without a degree), or annual household income (Median = \$40-50,000).² In preliminary analyses, the two samples were compared on items relevant to the present paper. Response distributions did not differ between the samples except for one item (noted below). Consequently, data from the samples were combined for the analyses reported here. More information about the sample and data collection procedures is reported elsewhere (Herek, 2002; Herek, Capitanio, & Widaman,

¹ For more details about the 1997 survey, see Capitanio & Herek, 1999; Herek & Capitanio 1999a, 1999b; Herek et al., 2002)

² By comparison, the US adult population was approximately 52% female and 72% non-Hispanic White, with a median educational level of some college (no degree) and a median 1999 household income of approximately \$42,000 (U.S. Census Bureau, 2002). Thus, the sample somewhat overrepresented women and non-Hispanic Whites.

2002).

Measures

Perceptions of HIV Stigma

Respondents were asked how much people with AIDS have been unfairly persecuted over the years – whether they have faced “a great deal” of unfair persecution, “some,” “a little bit,” or “no unfair persecution at all.” Next, they were asked whether people with AIDS *now* face a great deal of unfair persecution, some, a little bit, or no unfair persecution at all.

Social Risk and HIV Testing

Respondents were asked whether they had ever been tested for HIV and, if so, their most recent test year and result. The next question was “If you were going to be tested in the future for some reason, how concerned would you be that you might be treated differently or discriminated against if your test result were to come out positive for the AIDS virus – very concerned, somewhat concerned, a little concerned, or not at all concerned?” They were then asked how much their level of concern (very concerned, etc.) would affect their decision to be tested.³

Attitudes Toward HIV Surveillance Procedures

To assess the effect of type of surveillance policy (named versus anonymous) on support for HIV case reporting, we embedded a split-ballot experiment within the survey (see Sniderman & Grob, 1996, for discussion of the advantages of utilizing experimental design in surveys). Respondents were randomly assigned to answer one of three versions of a question about HIV case reporting.⁴ Version 1 asked whether respondents would “favor or oppose a law that required doctors to report the names and

³ The questions about future HIV testing were designated only for respondents who did not report having already tested positive for HIV. Because no respondents had tested positive, all of them were asked the follow-up questions.

⁴ A randomization check showed that respondents in the three experimental conditions did not differ significantly on gender, race, age, educational level, marital status, geographic residence, employment status, religiosity, and political party.

addresses of anyone who tests positive for the AIDS virus to the federal government.” Version 2 measured attitudes toward a “law that required doctors to report statistical information, but not names, about anyone who tests positive for the AIDS virus to the federal government.” Version 3 was similar to Version 2, but added the proviso that “strict measures” would be taken “to preserve the privacy of those who test positive.”⁵ Framed in traditional experimental terminology, the different item wordings each constituted a treatment condition (i.e., named reporting, anonymous reporting, anonymous reporting with explicit mention of privacy safeguards) whose effects were measured by the response outcome (support or nonsupport for HIV case reporting). Because assignment to conditions was random, we can attribute differences in response patterns to the experimental manipulation (i.e., the type of testing policy described in the question).

Attitudes Toward PWAs and Other Stigmatized Groups

Attitudes toward “people with AIDS,” “men who are homosexual,” “women who are lesbian or homosexual,” and “people who inject illegal drugs” were measured with 101-point feeling thermometers (e.g., Herek & Capitano, 1999b). Higher ratings indicate warmer, more favorable feelings toward the target whereas lower ratings reveal colder, more negative feelings.

Results

Perceptions of AIDS Stigma

The vast majority of the sample believed that people with HIV have been and continue to be targets of persecution (Table 1): 86% believed that PWAs faced “some” or “a great deal” of unfair persecution in the past, and 77% believed that such persecution continued in 1999. Most respondents (59%) gave the same response to both questions (e.g., “a great deal”). Of those whose responses to the two items differed, most (36% of the sample) perceived less stigma in the present. Their modal response pattern (evidenced

⁵ The items are available on the Internet (<http://www.AIDSstigma.net>) or from the first author.

by 23% of the sample) was that PWAs faced “a great deal” of persecution in the past and “some” persecution in the present. Only 6% perceived more stigma in the present than the past.

Insert Table 1 about here

Social Risk and HIV Testing

Slightly more than half of the sample (52%) reported having been tested for HIV. Most had been tested once (33% of those tested) or twice (21%); 12% had been tested 10 times or more. About half of those tested (51%) reported that their most recent test was in the previous 2 years, whereas 11% had not been tested since 1991. No respondents reported a positive test result. As shown in Table 1, most respondents would be “very concerned” (39%), “somewhat concerned” (29%), or “a little concerned” (15%) about being stigmatized if they were to test positive in the future.⁶ Table 1 also shows that such concerns would affect the actual decisions of less than half of the respondents who felt them. Of those reporting any concern about being stigmatized, 56% said it would have no effect on their decision to be tested. The remainder reported that their concerns would affect their decision “a great deal” (13%), “some” (19%), or “a little” (12%). In the total sample, 37% of all respondents indicated that their decision to be tested for HIV would be affected to some extent by concerns about stigma.

Insert Table 2 about here

Attitudes Toward HIV Surveillance

⁶ This was the only item for which significant differences were observed between subsamples. Respondents in the follow-up sample were significantly less likely than those in the new RDD sample to be “very concerned” at the prospect of stigma if they tested positive for HIV (35% vs. 44%, respectively) and more likely to report that they would not be concerned at all (18% vs. 13%, $\chi^2 [3, n = 1318] = 11.99, p < .01$).

As shown in Table 2, attitudes toward surveillance strategies were significantly affected by whether seropositive individuals’ names would be reported (Version 1 of the question) or not (Versions 2 and 3). Only about one fourth of respondents who were asked about name-based reporting supported it. By contrast, those who were asked about anonymous reporting supported it by margins of roughly 2-to-1. The difference between support for named reporting (Version 1) and anonymous reporting (Versions 2 and 3) was highly reliable, as indicated by the wide gaps (more than 30 percentage points) between 95% confidence intervals (CIs) shown in Table 2. Support for the various types of HIV surveillance did not differ significantly by whether respondents had themselves been tested for HIV.

Although most respondents believed that people with AIDS faced persecution, this belief was significantly less likely to be expressed by supporters of name-based reporting than by supporters of anonymous reporting: 72.5% of those who favored name-based reporting perceived that PWAs faced “some” or “a great deal” of persecution in the past, versus 85.3% of those who supported anonymous reporting and 87.3% of those who supported anonymous reporting with strong privacy protections, $\chi^2 (2, N = 711) = 12.72, p < .01$. The proportions perceiving that PWAs currently faced persecution were, respectively, 59.8% versus 78.6% and 75.8%, $\chi^2 (2, N = 712) = 14.95, p < .001$. Among those opposed to reporting, no significant differences were observed across experimental conditions for the proportions perceiving that PWAs were persecuted in the past (range = 87.4% to 91.9%) or currently (range = 81.1% to 84.2%).

Correlates of Support for Name-Based Reporting

Figures 1-4 show thermometer means for respondents opposing and supporting each surveillance policy, with 95% confidence intervals depicted by error bars.⁷ Differences

⁷ These analyses excluded 92 respondents believed it was “very likely” that they were HIV-positive; described themselves as lesbian, gay, or bisexual, or

between groups are significant ($p < .05$) when CIs do not overlap. Although the magnitude of thermometer scores varied across targets, a consistent pattern emerged: Supporters of name-based reporting gave significantly lower ratings (more negative attitudes) for all targets than did opponents of name-based reporting. Indeed, for PWAs (Figure 1), gay men (Figure 2), and lesbians (Figure 3), supporters of name-based reporting gave significantly lower ratings than all other respondents. The point-estimate of their ratings of IDUs was also the lowest (Figure 4), but the CIs overlapped with three of the five other respondent groups. Across the other five response groups (i.e., excluding supporters of named reporting), thermometer scores did not differ significantly for any of the targets, as indicated by the overlapping CIs.

Insert Figures 1-4 about here

Discussion

The findings help to illuminate the social milieu in which U.S. adults perceived public health policy and made decisions about getting tested for HIV at the end of the 20th century. Clearly, AIDS was widely regarded as a stigmatized disease although about one third of the public believed that the level of stigma was lower than in the past. More than three fourths of respondents believed that PWAs continued to experience more than incidental persecution. Given this perception, it is not surprising that most would be concerned about being stigmatized if they themselves were to test positive for HIV in the future. For more than one third, such concern would affect their decision to be tested.

The public's concerns about stigma provide a context for interpreting their attitudes toward HIV surveillance policies. Clear majorities of respondents supported anonymous case reporting

declined to report their sexual orientation; or reported having ever injected illegal drugs or declined to answer the injecting drugs question. These exclusions of target group members left an effective sample of $n = 1243$.

but opposed name-based reporting, which suggests that widespread opposition to name-based reporting reflected concerns about privacy and stigma rather than opposition to reporting per se. Support for anonymous testing was somewhat lower when the question stipulated that privacy would be protected than when such protections were not mentioned, although the difference in responses to the two items was not statistically significant. We suspect that the mere fact that the Version 3 question mentioned privacy raised respondents' concerns about this issue and made them somewhat more reluctant to endorse even anonymous reporting.

Compared to other respondents, supporters of name-based reporting perceived AIDS stigma to be less extensive and they expressed more negative attitudes toward PWAs and other groups associated with HIV in popular perceptions (gay men, lesbians, IDUs). Only attitudes toward IDUs overlapped between supporters of name-based surveillance and other respondents, which may reflect the generally negative ratings that all respondents gave to IDUs. These patterns reveal a clear association between support for name-based reporting and AIDS-related stigma, and are consistent with the interpretation that the former was a proxy for the latter.

The link between AIDS stigma and support for name-based reporting highlights a potential impediment to effective implementation of a national name-based surveillance policy. Such a policy may evoke anxiety and encounter resistance to the extent that it is perceived as insensitive to – or even fostering – preexisting AIDS stigma. The accurate perception that people who stigmatize PWAs also support name-based reporting may have created widespread suspicion about such reporting through a kind of guilt by association. Such concerns are especially likely in communities with a strong collective memory for the previously mentioned ballot initiatives and other past attempts to enforce AIDS-related stigma through health policy. They are probably strongest in communities with members whose behavior places them at higher risk for HIV infection than was typical of

respondents in the present sample, such as the gay male community (Woods, Binson, et al., 1999; Woods, Dilley, et al., 1999). Even if many individuals in those communities are unaware of the surveillance policies in effect in their home state (as is probably the case for most people; Hecht et al., 2000), community norms may foster a heightened sense of social risk in response to policies that are perceived to be linked to stigma.

The survey findings highlight the ways in which the stigma associated with a disease or the groups affected by it can influence public attitudes toward health policy. Historical examples abound of stigma interfering with effective collective response to diseases ranging from cholera to syphilis (Brandt, 1987; Rosenberg, 1987). In all of these cases, the social construction of the illness incorporated moral judgments about the circumstances in which it was contracted as well as preexisting hostility toward the groups perceived to be most affected by it. Such constructions can contribute substantially to the social risk and felt stigma associated with a disease and, consequently, influence the behavior of individuals at risk for contracting it.

The data reported here were collected in 1999, at the height of a national debate about named reporting policies. Because of the passage of time since the survey was completed, we have described the present findings in historical terms. However, the issue of HIV surveillance policies remains controversial. Whereas a majority of states have implemented a named reporting policy, California, the nation's most populous state, has not. Instead, reflecting concerns about the impact of stigma on testing, California and several other states use anonymous identifiers to report new HIV infections (Heredia, 2002). Moreover, given the substantial differences we found between attitudes toward named reporting versus anonymous reporting, as well as the strong association between support for named reporting and negative attitudes toward PWAs and other groups, it seems unlikely that attitudes toward surveillance policies have reversed themselves since the survey was completed.

Public health officials have acknowledged the

need for safeguarding confidentiality in HIV surveillance (Centers for Disease Control and Prevention, 1999). The present study underscores the importance of working actively to allay public concerns about stigma and possible suspicions about HIV reporting policies. To be effective, surveillance policies should not only include stringent confidentiality safeguards but should also make the public aware of those safeguards and of public health professionals' ongoing commitment to eradicating AIDS stigma and discrimination. This commitment could be demonstrated by initiation of explicit antistigma campaigns related to HIV at the national, state, and local levels.

In addition, the public health establishment's credibility with key groups affected by the epidemic (whose cooperation is vital to the success of HIV surveillance programs) would be enhanced by taking strong, well-publicized stands against the ongoing stigmatization of those groups. Given the strong linkage in the United States between AIDS stigma and negative attitudes toward gay and bisexual men (e.g., Herek & Capitanio, 1999a), it may be especially important for the public health community to initiate and promote programs to combat sexual prejudice and discrimination against gay, lesbian, and bisexual people.

In the early years of the AIDS epidemic, health workers and researchers were able to enlist support from affected groups, in part because of their willingness to distance themselves from government policies that were hostile and discriminatory toward those groups. As the epidemic continues, successful collaborations between affected communities and public health professionals will continue to depend on the latter's willingness to publicly oppose laws, policies, and individuals that are perceived as perpetuating stigma.

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Table 1

Distributions of Responses to Questions About Perceptions and Concerns Related to HIV Stigma

Item	%
PWAs unfairly persecuted in past?	
A great deal	44.1
Some	41.6
A little bit	9.8
No unfair persecution at all	3.1
PWAs persecuted now?	
A great deal	21.9
Some	55.3
A little bit	17.4
No unfair persecution at all	4.3
How concerned about stigma if tested positive?	
Very concerned	38.7
Somewhat concerned	29.2
A little concerned	15.4
Not at all concerned	15.4
Effect of concern on decision to be tested?*	
A great deal	13.1
Some	19.0
A little	12.1
No effect	55.8

* Asked only of those who reported any concern about being stigmatized if they were to test positive.

Note. Table reports unweighted percentage of sample giving each response. Percentages do not sum to 100% because of “Don’t know” responses and refusals.

Table 2

Support for Different Policies for Reporting Information About HIV-Positive Individuals

Item Version	% Support	Confidence Interval (95%)
Names reporting (<i>n</i> = 417)	24.7	20.6 - 28.8
Statistical information only (<i>n</i> = 478)	71.5	67.5 - 75.5
Statistical information with privacy safeguards (<i>n</i> = 423)	64.1	59.5 - 68.7

Note. Table excludes 17 refusals and “Don’t know” responses, which were distributed nearly equally across the three item versions. Table reports unweighted data.

Figure Captions

Figure 1. Mean Feeling Thermometer Ratings of People With AIDS (PWAs) by Supporters and Opponents of Three Types of HIV Surveillance.

Note to Figure 1. 95% confidence intervals are depicted by error bars.

Figure 2. Mean Feeling Thermometer Ratings of Gay Men by Supporters and Opponents of Three Types of HIV Surveillance.

Note to Figure 2. 95% confidence intervals are depicted by error bars.

Figure 3. Mean Feeling Thermometer Ratings of Lesbians by Supporters and Opponents of Three Types of HIV Surveillance.

Note to Figure 3. 95% confidence intervals are depicted by error bars.

Figure 4. Mean Feeling Thermometer Ratings of Injecting Drug Users (IDUs) by Supporters and Opponents of Three Types of HIV Surveillance.

Note to Figure 4. 95% confidence intervals are depicted by error bars.







