

AIDS Stigma and HIV-Related Beliefs in the United States: Results from a National Telephone Survey

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AIDS-related stigma historically has interfered with effective societal response to the epidemic, and has imposed hardships on people living with HIV, their loved ones, caregivers, and communities. In the United States, concerns about such stigma and its effects on AIDS prevention and treatment led to the institution of public policies specially designed to protect the privacy and confidentiality of PWAs and people at risk for HIV.

Recent debates about public health policy have raised the question of whether these extraordinary measures are still needed, or whether AIDS should now be treated in the same way as other communicable diseases. Proponents of the latter perspective have argued for the institution of measures such as mandatory contact tracing and reporting of the names of persons with HIV to the federal government. Underlying these proposals has been the assumption that AIDS stigma has sufficiently abated so that fear of prejudice and discrimination no longer plays a significant role in personal decisions to seek HIV testing, counseling, and treatment. Empirical data concerning the accuracy of this assumption have been lacking, however.

The present study assessed the prevalence of AIDS stigma in the USA in 1997, and compared current levels with those assessed in a 1990-91 survey.

Method

List-assisted random digit dialing (RDD) was used to generate a probability sample of telephone numbers, representing private households in the 48 contiguous states. Telephone interviews were conducted with 1712 English-speaking adults, with each respondent randomly selected from among the members of her or his household. The analyses reported here were conducted with respondents who self-identified as heterosexual and who did not report that they had tested positive for HIV. The margin of error due to sampling is approximately plus-or-minus two percentage points.

Prevalence of stigma. Questions were asked about multiple factors related to AIDS stigma. These included affective reactions to PWAs, beliefs about PWAs and HIV transmission through casual contact, levels of comfort with PWAs, intentions to avoid PWAs, attitudes toward AIDS policies, and other AIDS-related attitudes and beliefs.

Groups associated with AIDS. We also asked respondents about the first group or type of person that came to mind when they heard the word *AIDS*.

Symbolic stigma. Finally, a substitution experiment was performed to assess the extent to which AIDS-related stigma reflects symbolic expressions of disapproval for particular social groups and behaviors. In the experiment, we compared public reactions to a hypothetical PWA depending on the PWA's race, gender and sexual orientation, and source of infection.

Each respondent was posed a description of a hypothetical person with AIDS. We randomly varied the PWA's *race* (Black or White), *sex and sexual orientation* (heterosexual woman, heterosexual man, bisexual man, homosexual man) and *route of infection with HIV* (receiving a blood transfusion approximately 15 years earlier, having sex with one partner over the past 15 years, having sex with multiple partners over the past 15 years, sharing needles for drugs over the past 15 years). Combining these three variables yielded 32 different descriptions of the hypothetical PWA. Each respondent received one description, and was asked to report his or her beliefs about the PWA's responsibility for being infected, feelings toward the PWA, and willingness to help the PWA.

Key Findings

Prevalence of Stigma

- The majority of the US public — 77% — believed that people with AIDS are unfairly persecuted in our society.
- The proportion of the population supporting extreme coercive policies against PWAs has declined since 1991. In the 1997 survey, 17% supported quarantine for PWAs and 19% supported public disclosure of the names of PWAs. In a 1991 survey, these policies were supported by, respectively, 36% and 30% of the US public.
- The vast majority of the public supported mandatory HIV testing for immigrants (77%), people considered to be at high risk for AIDS (74%), and pregnant women (84%).
- Compared to 1991, fewer people said that they would avoid a PWA in various hypothetical situations. 10% would have their child avoid another schoolchild with AIDS (compared to 16% in 1991), 12% would avoid a coworker with AIDS (compared to 20% in 1991), and 33% would avoid shopping at a neighborhood grocery store whose owner has AIDS (compared to 47% in 1991).
- However, many of those who would not actively avoid a PWA in these situations would nevertheless feel uncomfortable about being around the person with AIDS: 27% of respondents would feel uncomfortable about having their own child interact with the school child with AIDS, 25% would feel uncomfortable working in the same office as the coworker with AIDS, and 30% would feel uncomfortable about shopping in the store whose owner has AIDS.
- The proportion of the public that believes casual social contact might spread HIV has increased somewhat since 1991. 55% believed that it was possible to contract AIDS from using the same drinking glass as a PWA (compared to 48% in 1991), 41% believed that AIDS might be

contracted from a public toilet (compared to 34% in 1991), and 54% believed that AIDS might be transmitted through a cough or sneeze (compared to 45% in 1991). Most of the shift in beliefs since 1991 has occurred as a result of fewer people believing that AIDS *definitely cannot be transmitted* through these routes, and more believing that these routes are merely *somewhat unlikely* to spread AIDS. The proportion believing that these forms of casual contact are *somewhat likely* or *very likely* to transmit AIDS has remained fairly stable.

- Consistent with widespread inaccurate beliefs about casual contact, 27% of respondents reported that they would be less likely to wear a sweater that had been worn one time by a PWA than if it had been worn once by another person — even if the sweater had been cleaned and sealed in a new package so that it looked like it was new. 28% of respondents said that they would feel uncomfortable drinking out of a glass in a restaurant if a PWA had used the same glass a few days earlier, even if it had been washed and sterilized.
- Compared to 1991, more respondents agreed that people who got AIDS through sex or drug use have gotten what they deserve (29%, compared to 20% in 1991). When the issues of blame and responsibility were posed in less negative terms, 55% of respondents agreed that most people with AIDS are responsible for having their illness. 51% agreed that it's their own fault if people get AIDS these days. 26% agreed that most people with AIDS don't care if they infect other people with the AIDS virus.

Groups Associated with AIDS

When asked “When you hear the word *AIDS*, what groups or type of people first comes to your mind,” more than half indicated that they thought first about gay or bisexual men (41%) or gay/bisexual men and injecting drug users (10%). Another 10% thought first of drug users. The remainder thought first of hemophiliacs and the recipients of blood products (2%), other types of individuals and groups (15%), or reported that no group came to mind when they heard the word *AIDS*.

Symbolic Stigma

In the United States, much of the stigma associated with AIDS has resulted from the fact that AIDS has had a disproportionate impact on disliked segments of society, especially gay men and injecting drug users. Our experiment indicated that PWAs are judged more harshly depending on how they contracted HIV and whether or not they are heterosexual.

- PWAs who were infected through sharing needles or through sex with multiple partners were evaluated more negatively than PWAs who were infected through sex with one partner. PWAs who were infected through a blood transfusion were evaluated the most positively.
- When a PWA was described as having contracted AIDS through sex (whether with one partner or many), the PWA was judged differently depending on his or her sexual orientation. Gay and bisexual men were judged more harshly than heterosexual men and women, even controlling for their source of infection. Women respondents tended to evaluate bisexual men the most

negatively, whereas male respondents tended to evaluate gay men the most negatively.

- Somewhat surprisingly, Whites did not judge Black and White PWAs differently. However, Black respondents tended to evaluate Black PWAs *more* harshly than White PWAs, and this pattern was more pronounced among Black women respondents than among Black men respondents.

Conclusions

Although its manifestations have changed in some respects during the 1990s, AIDS stigma persists in the United States. Support for blatantly stigmatizing policies has decreased, but support remains high for mandatory testing of specific groups. A significant minority of the public expresses discomfort at the prospect of personal contact with PWAs. AIDS continues to be a strongly symbolic issue, with much of the US public associating AIDS with gay and bisexual men. Moreover, stigma is more strongly expressed against gay or bisexual men who contracted HIV sexually, compared to heterosexual PWAs.

The understanding that HIV cannot be transmitted through casual social contact appears to be eroding, possibly because public health campaigns in the United States have not reinforced this belief in recent years. Although modest, this trend is a cause for concern because people who overestimate the risks of casual contact are significantly more likely to stigmatize people with AIDS.

The survey results raise concerns that advocates of mandatory names reporting and contact tracing may be underestimating the continuing importance of AIDS stigma in the United States. Indeed, the data indicate that most of the US public believes that stigma is widespread, that is, that PWAs are unfairly persecuted by society. Even if it is inaccurate, this perception may well affect personal decisionmaking about being tested or treated for HIV. Thus, public health officials and policy makers would be well-advised to seriously consider the potential effects of AIDS stigma — both the reality of stigma and the perception that it is widespread — on new policies for tracking the epidemic.

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