



Naming Names: Perceptions of Name-Based HIV Reporting, Partner Notification, and Criminalization of Non-disclosure Among Persons Living With HIV

Robert Klitzman, Sheri Kirshenbaum, Lauren Kittel, Stephen Morin, Shaira Daya, Maddalena Mastrogiacomo, and Mary Jane Rotheram-Borus

Abstract: Policies of name-based HIV reporting, partner notification (PN), and criminalization of non-disclosure of HIV positive status to sexual partners remain controversial. The views of people living with HIV (PLH) are critical to the success of these three initiatives, but have been understudied. Thus, we interviewed 76 PLH about these policies. Themes arose of potential public health benefits (e.g., epidemiological surveillance and notification of possible exposure) and costs (e.g., deterrence of testing); threats to privacy, civil rights and relationships; government mistrust; and beliefs that prevention is an individual, not governmental responsibility. Misperceptions about the intent, content and scope of these policies, and past experiences of discrimination, shaped these attitudes. To enhance development and implementation of HIV prevention strategies, the views of PLH must be taken into account, and education campaigns need to address misperceptions and mistrust. These data shed light on difficulties in developing and implementing policies that may affect sexual behavior, and have critical implications for future research.

Key words: ethics; risk behavior; disclosure

Introduction

In recent years, new HIV-related policy debates and issues have emerged—partly in response to clinical advances resulting from Highly Active Anti-Retroviral Therapy (HAART)—but the views of people living with HIV (PLH) towards these policies, though critical, have not been fully explored. Since the beginning of the HIV epidemic, policy makers have struggled to enact laws and regulations that protect the public from HIV, while

preserving the rights of those infected with the virus. At the core of many of these debates lie questions concerning the appropriate role of the state in shaping private sexual and other behaviors. Ensuing tensions have often led to intense controversy, the nature of which has shifted as both the HIV epidemic and available treatment have advanced. Between 1997-1999, three sets of policies were debated and enacted in some form in most states within the United States (US): (a) name-based HIV case reporting, (b) partner

Correspondence concerning this article should be addressed to Robert Klitzman, HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute, and Center for Bioethics, Columbia University, Unit 29, New York, NY 10032 (NYSPI). E-mail: rlk2@columbia.edu; Sheri Kirshenbaum (NYSPI), E-mail: sk2107@columbia.edu; Lauren Kittel (NYSPI), E-mail: kittel@pi.cpmc.columbia.edu; Stephen Morin, Center for AIDS Prevention Studies, Department of Medicine, University of California, San Francisco, 74 New Montgomery Street, Suite 600, San Francisco, CA 94105. E-mail: smorin@psg.ucsf.edu; Shaira Daya (NYSPI), E-mail: davasha@pi.cpmc.columbia.edu; Maddalena Mastrogiacomo (NYSPI), E-mail: lanev475@yahoo.com; Mary Jane Rotheram-Borus, University of California, Los Angeles, Neuropsychiatric Institute, Center for Community Health, 10920 Wilshire Boulevard, Suite 350, Los Angeles, CA 90024. E-mail: rotheram@ucla.edu

notification (PN) initiatives, and (c) criminalization of non-disclosure of HIV-positive status in sexual situations (Morin, 2000). Treatment advances have shaped these recent policy debates—specifically, as PLH lead healthier, longer lives (CDC, 1998; 2000), they may also be more likely to be sexually active. Hence, new prevention initiatives and public health policies have given increased attention to the role of people living with the virus. In addition, approximately 25% of HIV-infected individuals in the US do not know that they are infected (CDC, 2004). Consequently, the CDC, through the Serostatus Approach to Fighting the HIV Epidemic (SAFE) program, has tried to increase efforts to have these untested individuals voluntarily tested, receive treatments if necessary, and reduce high risk behaviors (Janssen et al., 2001). In general, public policy can critically shape a variety of HIV prevention efforts (Klitzman & Bayer, 2003; Lazzarini & Klitzman, 2002). Yet HIV-related public health policies may be most effective if crafted and implemented with close consideration of the views held by those living with HIV/AIDS, as the cooperation of these men and women is required for policies to be most effective. For example, PN programs depend on index patients with HIV providing as much information as possible about their sexual and needle sharing contacts. Thus, we sought to identify the perceptions of PLH towards these issues.

Background

Name-Based HIV Reporting

Since HIV antibody testing became available in 1985, intense debate has focused on whether HIV infection, as well as an AIDS diagnosis, should be a reportable public health disease (Colfax & Bindman, 1998). The CDC (1999) recommended such a policy and implemented sanctions to encourage states to adopt name-based reporting, similar to that used for other sexually transmitted diseases. Name-based reporting is aimed at epidemiological surveillance. Yet some have argued that such reporting would deter testing and impede the acceptability of early detection, monitoring, and treatment in ways that would far outweigh the public health benefit of maintaining an HIV case

surveillance system (Colfax & Bindman, 1998; Kegeles, Coates, Lo, & Catania, 1989). In New York state, the institution of named reporting and mandatory PN decreased the willingness of pregnant women to undergo prenatal HIV testing and prenatal care (Dolbear, Wojtowycz, & Newell, 2002). Other research suggests that name-based reporting policies may not hamper HIV testing among members of high-risk groups as a whole (Nakashima et al., 1998; Osmond et al., 1999; Schwarcz, Stockman, Delgado, & Scheer, 2004), but contribute to testing delays among some injection drug users (Hecht et al., 2000). In addition, this policy may decrease testing in regions that have the highest HIV-incidence (Aragon & Myers, 1999; Woods, Binson, Morin, & Dilley, 1999). As a result of these controversies, certain advocates have supported non-name-based HIV surveillance instead of name-based reporting (Solomon & Benjamin, 1998). Policies regarding name-based surveillance continue to be topics of controversy. HIV reporting laws differ significantly between states—39 states have adopted name-based reporting and 11 have adopted coded systems. The CDC (2003) has suggested that consistent HIV reporting laws would improve estimates of the epidemic. Hence, as of December 2003, the CDC developed protocols to evaluate surveillance procedures that are being implemented in states such as California, Illinois, and Maryland. However, of note, in the general population, supporters of name reporting have been found to have more negative views of PLH, gays, lesbians and injection drug users (IDU) (Herek, Capitanio, & Widaman, 2003)—biases that PLH may well perceive.

Partner Notification

“Partner notification,” or “contact tracing,” refers to programs that identify sexual or needle sharing partners of an individual infected with a sexually transmitted disease (STD) or HIV, in order to inform these partners of their potential exposure, and urge them to undergo testing, counseling, and, if necessary, treatment. PN programs have been found to detect HIV infected individuals who have not yet been tested, though certain scholars have argued that the number of such individuals is relatively small: .03-.24 per

proband (Macke & Maher, 1999). PN can be initiated by the provider or patient, but has been found to be more effective (i.e., more partners notified) when the provider does the contact, at least among men who have sex with men (MSM) (Landis et al., 1992). Similarly, most STD clinic patients reported willingness to contact partners or provide contact information to providers, but many did not follow-up unless the provider made the referral (Carballo-Diequez et al., 2002). PN programs can be either mandatory or voluntary. Mandated PN has generated substantial negative reactions (ACLU, 1997; Dolbear et al., 2002). For instance, of drug-using PLH, 59% anticipated refusing treatment if PN were required (Rubin, 1991), and 50% feared government interference in an individual's relationships with partners (Rogers, 1996). Similarly, a majority of PLH (80% of whom were MSM) supported health departments offering assistance to those diagnosed with HIV in notifying partners; and would be likely to provide information to health department staff for this purpose, as long as programs were voluntary and confidential (Golden, Hopkins, Morris, Holmes, & Handsfield, 2003). Many STDs are treated in private practices, not in STD clinics (St. Lawrence et al., 2002), yet physicians often do not follow through with PN, and are uncertain about legal requirements for case reporting (St. Lawrence et al., 2002). Hence, perhaps as a result, overall, only a minimum number of people at risk for HIV or certain other STDs are affected by PN programs—17% of cases of gonorrhea, 12% of cases of chlamydia, and less than 1/3 of newly diagnosed cases of HIV (Golden, Hogbed, et al., 2003). Consequently, key debates have arisen concerning the relative emphasis and funding that PN programs should receive. The CDC estimates that 11% of the \$85 million budget for counseling, referral, and testing services in the US is allocated for PN (CDC, 2001; Wasserman & Watson, 2000). Yet some have argued that prevention may represent a better allocation of funding (Morin, 2000).

Criminalization of Non-Disclosure

Criminalization of non-disclosure refers to laws that stipulate that the absence of disclosure of one's HIV positive serostatus to sexual or needle sharing

partners constitutes criminally culpable behavior. The number of states with such policies increased from 26 in 1996, to 31 in 1999 (Morin, 2000). Statutes vary from state to state with regard to prosecution of specific risk behaviors engaged in (i.e., exposure alone versus exposure with resultant infection of others), presence or absence of intent, and the degree of illegality attached (i.e., from misdemeanor to attempted murder). Some states prohibit all sexual activity, while others prohibit only unprotected penetrative acts (Speissegger, Wilson, & Watson, 1999). With the exception of the California statute, these laws do not require acting with intent to infect another person; the behavior alone is sufficient to charge the PLH (Lazzarini & Klitzman, 2002). In addition, laws may exist, but not be much enforced. Criminalization statutes have remained controversial. For example, in December 2003, a former San Francisco health commissioner was charged with "intentionally" infecting sexual partners. However, the court judged him to be innocent due to the plaintiff's failure to meet the legislation's requirement of proof of "intention." The fact that HIV infection occurred was not sufficient in and of itself for prosecution (Van Derbeken, 2003). This judicial decision led to calls for the California legislature to change the current law. Yet the extent to which PLH are aware of these laws, or these statutes may have a deterrent effect on such behavior is not known.

Compared to the perspectives of public health officials, policy makers, scholars, and researchers, PLH may well have a different set of concerns regarding these policies. Yet there are few data on attitudes or perspectives of PLH in this area. During the period of interviewing for this study in 1998-1999, the three states where interviews were conducted had varying policies, as shown in Table 1.

Table 1. Status of HIV related policies by state

	Name-Based HIV Case Reporting	Partner Notification	Criminalization
CA	No law	Implemented	Yes, if with intent
NY	Passed, but not yet implemented	Implemented	No, but have prosecuted
WI	Implemented	Implemented	No, but increased penalty for sex crimes if HIV exposure involved

Methods

Study Context

We conducted in-depth interviews with HIV positive men and women in Los Angeles (LA), Milwaukee (MIL), New York (NY), and San Francisco (SF) between 1998 and 1999 as the initial formative phase of an intervention trial that entered the field in the spring of 2000 and was designed to improve coping skills, reduce transmission risk behaviors, and improve medical adherence and other health-care behaviors. Interviews covered a wide range of areas enabling us to increase our understanding of issues faced by PLH post-HAART. Interview data were used to inform the tailoring of the intervention to study subpopulations, and train staff, regarding issues most relevant to participants.

Participants and Eligibility

A total of 152 in-depth interviews were conducted with 52 MSM, 56 women (WOM), and 44 male IDUs. MSM who were also IDUs were classified IDUs. Individuals were eligible to participate if they were HIV positive, at least 18 years old, able to complete the interview in English, and able to give informed consent. Sixty interviews (20/subgroup) were conducted in New

York (the lead site in this phase of the trial) and 92 at the other sites—approximately 30 interviews (10/subgroup) in each of the other sites. This current manuscript presents data from a subsample (n=76) randomly selected from each subgroup and city.

Procedures

Participants were recruited from HIV primary care clinics and community-based organizations (CBOs) via provider referrals, word-of-mouth, or study announcements at recruitment sites or in newsletters. Those interested in participating contacted study staff, via telephone or in-person, on site. Staff described study objectives and procedures to potential participants and obtained consent for enrollees. Experienced interviewers with master's level social science education received centralized comprehensive training with ongoing supervision. One-on-one interviews lasted 2-3 hours, and used a structured schedule of open-ended questions with follow-up probes as needed. Participants were paid \$25 for completing the interview. All interviews were audiotaped and transcribed. Transcriptions were checked for accuracy across sites through review, and comparison of a subset against the taped interviews.

Assessment Interview

Interviews were broad based and designed to elicit in participants' own terms and words the meanings, norms, interpersonal contexts, daily routines, and other defining features of these individuals' lives (Patton, 1990; Strauss & Corbin, 1990) that could be expected significantly to affect health, sexual and drug use behaviors, psychological and practical adaptation to HIV, and preferences for and participation in a behavioral intervention. Interviews also included questions on attitudes toward, and experiences with, HIV-related policies.

Interviewers were instructed to present the following script to all participants: "I'd like to ask you some questions about some possible government policies about HIV. Have you had any experience with something called HIV partner notification?" If the respondent was unfamiliar with the policy, the

following explanation was provided: "HIV partner notification is a policy in which the government health department tells the sex or drug injection partners of a person with HIV that someone they've been partners with has HIV." If the respondent had experience with the policy, the interviewer asked: "What happened? How did you feel about what happened?" If the respondent had no experience with the policy, the interviewer asked: "How do you feel about this policy?" All respondents were then asked the following: "How do you feel about the government health department keeping a list or registry of the names of people who have HIV? How would there being such a list affect what you do to get services for your health? How do you think this should be handled? Do you think it would change people's behavior? What about it being a crime if an HIV-positive person doesn't fully inform a potential sexual partner about being HIV-positive? How would you feel about that? Do you think this would change people's behavior in any way?" Interviewers were also instructed to probe, as necessary, to ascertain more fully the respondent's awareness, knowledge, attitudes, and experiences concerning these policies. Participants' misperceptions of policies were clarified, though we first tried to grasp participants' understandings of these policy initiatives, and the full nature of any misunderstandings.

Analysis of Qualitative Data

Analyses were informed by grounded theory (Strauss & Corbin, 1990) and were conducted in two phases. In the first phase, investigators reviewed transcripts to identify primary coding categories across the broad range of topics covered, as well as a range of subcodes and themes present within each topic area. Identified coding categories and themes were organized into a formal codebook. A coding team of eight evaluated four transcripts (one from each city, across sub-populations) as a group to establish coding consensus and refine coding schema. Coders had masters or doctorates in social science, or were psychiatrists. New themes that did not fit into the original coding framework were discussed, and modifications were made when deemed appropriate. Thematic categories were refined, merged, or

subdivided, when suggested by associations, overlap, or diversions in the data. Inter-rater discrepancies were discussed until consensus was obtained. This process was repeated until all raters achieved concordance on almost all decisions, after which pairs of evaluators from the larger team coded additional interviews (n = 38) until reaching a clear saturation for major and minor themes and codes.

Based on our analyses of this data set as a whole, several themes emerged concerning individuals' attitudes and experiences with the three above-mentioned HIV-related policies. Hence, the second phase of analyses examined data on the variables we found to be most salient and relevant to these issues within the broader context of participants' lives. We began with the full sample of 152 interviews and randomly selected a subset of 76 interviews for analyses, distributed across subgroup and city to ensure a range of responses. We organized and identified themes into formal coding grids and extracted relevant illustrative quotes from the original transcripts. At least two members of the data analytic team conducted analyses of each interview to ensure coding reliability. Findings report on the patterns of relationships between variables found to be most significant. Our analyses did not indicate the clear presence of other variables (e.g., race, ethnicity, city) that would significantly alter an understanding of the pattern of relationships described here. The themes found and described here also appeared to have face validity.

Sample Description

The randomly selected 76 interviews included 24 MSM, 31 WOM, and 21 IDUs. To characterize the sample, demographic and psychosocial data are presented in Table 2. By study design, most participants were living in New York City, and more men than women were represented in the sample. The majority ranged in age from late 30s to early 40s. The sample varied in terms of racial/ethnic identification, educational background, relationship status, and parenthood. Disability was the primary source of income for participants. Almost all participants reported a lifetime history of drug or alcohol use.

Table 2. Demographic and psychosocial description of sample ($N = 76$)¹

Variable	% Women (n = 31)	% MSM (n = 24)	% IDU (n = 21)	% Total (N = 76)
Age (n = 72) (years): range = 20-59				
Mean (SD)	38.5 (8.3)	39.6 (5.8)	45.8 (6.6)	41.0 (7.7)
Ethnicity (n =66)				
White, non-Latino/a	14.8	40.0	31.6	27.3
Latino/a	11.1	25.0	42.1	24.3
African or Caribbean American	63.0	35.0	26.3	43.9
Other	11.1	0.0	0.0	4.5
Education (n=68)				
Never completed high school or GED	39.2	4.8	21.1	23.5
High school or GED	28.6	47.6	47.3	39.7
Some college	28.6	23.8	31.6	27.9
College or post-college	3.6	23.8	0.0	8.9
Primary Income Source (n=73)				
Own job	20.0	33.3	0.0	19.1
Disability	53.3	50.0	68.4	56.2
Public assistance, non-disability	16.7	12.5	15.8	15.1
Family/friend/partner/spouse support	3.3	0.0	0.0	1.4
Other	6.7	4.2	15.8	8.2
Current Marital Status (n=72)				
Single	35.7	75.0	45.0	51.3
Married/common-law	32.1	4.2	15.0	18.1
Divorced/separated/widowed	32.2	20.8	40.0	30.6
Substance Use				
Lifetime IDU (n=74)	40.0	21.7	100.0	51.4
Past 30 days IDU (n=76)	6.5	4.2	28.6	11.8
Lifetime drug/alcohol use, Including IDU (n=76)	90.3	100.0	100.0	96.1
Children				
Reports having children (n=74)	80.6	26.1	65.0	59.5

Overall, this sample thus reflects key demographic features of PLH in the US.

Results

Content analyses revealed that for each of the public policies examined, respondents' attitudes could be classified as falling into one of three categories—pro, con, or mixed. Within this organizing framework, we

Table 3. Qualitative themes in response to HIV-related policies (*N*=76)

Policy	Pro	Con	Other Themes
HIV Registry	<ul style="list-style-type: none"> • Public health benefits <ul style="list-style-type: none"> - epidemiological surveillance • Positive attitudes secondary to misperceptions about HIV registry 	<ul style="list-style-type: none"> • Fears of threats to privacy, confidentiality and civil rights. <ul style="list-style-type: none"> - fueled by past discrimination • Fears of discrimination <ul style="list-style-type: none"> - loss of benefits/insurance, and employment • Fears of quarantine • Wariness of government • Public health costs <ul style="list-style-type: none"> - deterrence to testing and treatment 	<ul style="list-style-type: none"> • Misperceptions, leading to support of policy <ul style="list-style-type: none"> - Identifying infected partners - More efficient access to health care, govt. assistance, benefits, and services - Govt. already has such a list • Ambivalence
Partner Notification	<ul style="list-style-type: none"> • Public health benefits <ul style="list-style-type: none"> - notification of those potentially exposed - may help to decrease HIV spread - deter unsafe sex • Relief of burden of disclosure • Concerns regarding cooperation • Fears of notified partners learning of their source of exposure 	<ul style="list-style-type: none"> • Privacy concerns • Invasiveness of policy • Unfair burden on infected individuals • Wariness of government • Individual, not government responsibility • Deterrence of testing • Potential harm to relationships • Possible associations between participants' risk behavior and opposition to PN 	<ul style="list-style-type: none"> • Misperceptions <ul style="list-style-type: none"> - Not knowing name of program, but having had experience with it - Confusing PN with criminalization of non-disclosure - Not knowing whether PN involves named reporting • Ambivalence
Criminalization of Non-Disclosure	<ul style="list-style-type: none"> • Public health benefits <ul style="list-style-type: none"> - decrease in transmission - increase disclosure • Support only under certain circumstances 	<ul style="list-style-type: none"> • Individual, not government responsibility • Deterrence of testing • Safer sex more important • Potential for abuse 	<ul style="list-style-type: none"> • Misperceptions <ul style="list-style-type: none"> - Confusion re: "intent" and conjunction with unsafe sex • Ambivalence <ul style="list-style-type: none"> - The degree of appropriate punishment - Relationship between attitudes and one's own risk behaviors

then explored qualitatively respondents' thoughts and feelings about the policies in relation to other aspects of their lives. The data revealed that participants' attitudes arose from a complex interaction of personal experiences as well as perceived implications and misperceptions regarding these policies. Participants' beliefs concerning personal rights and fears of

discrimination and surveillance also played a role in the formation of opinions toward HIV-related policies. Of note, the categorizations of attitudes and themes did not differ substantially among the three subgroups studied (WOM, MSM, and IDUs) or by city. Qualitative themes that arose are described below and summarized in Table 3.

Name Reporting or HIV Registry

Support for HIV Registry

Public health benefits. Some participants supported an HIV registry because of perceived advantages to epidemiological surveillance of the epidemic. As one woman (NY) said, “In some kind of way, we have to keep a statistic or numbers on who’s infected... I ain’t got no problem with it.” Another woman (LA) felt that applying the same policies for other STDs to HIV would help the public to “see HIV as any other disease, which is what it is,”—that is, to decrease stigma.

Positive attitudes secondary to misperceptions about HIV registry. Many of the individuals who held positive attitudes toward HIV name reporting had formulated their opinions based on misunderstandings of the scope or purpose of this policy. For example, perceived benefits included more efficient access to health care, government assistance, and other benefits, based on the misperception that the surveillance registry would be linked to a health care registry. In the words of one woman (NY), “If you’re on this list, then it is definite that you are HIV. So those agencies that have things for HIV positive’s would probably be more available to me because of that list. Being HIV positive is what got me on DAS [Department of AIDS Services] and SSI [Supplement Security Income].” Another woman (LA) said, “If anything, it should help us to get services for our health.”

Similarly, an HIV registry was seen as potentially leading to better coordination of services and support for agencies serving PLH. One male IDU (LA) felt a list was “not that big a deal” and could decrease “the amount of service abuse that’s going on because you can’t bounce from one organization to another. Once you’re in the computer as having services, then if you try to apply somewhere else, [the registry] blocks it. I don’t think it would hinder the services at all, but it might actually save money in the long run.” Respondents believed that such a list could be of assistance to agencies that were seen as “being for us, the poor people” (WOM-LA).

Some individuals felt such a list could help with HIV-prevention. One woman supported the policy,

thinking it would enable her to check a public registry to see if her sexual partners were infected or not. Such a registry was also thought to provide a safeguard to blood banks, enabling them to check the HIV status of donors, in order to protect the blood supply.

Opposition to an HIV Registry

Fears of threats to privacy, confidentiality, and civil rights. With regard to this policy, concerns arose about the loss of confidentiality in contemporary society more broadly, given computers and the Internet. As one MSM (NY) said: “Anybody can get the list nowadays...the janitor, anybody can get access to anything at this point in time.” Another MSM (NY) concurred, feeling computers were “the evil that’s going to be controlling a lot of things. You have to be very careful about that.”

Some viewed privacy as tantamount to one’s very life. Concerning a registry, one woman (MIL) said, “In a way I think it’s wrong because that’s your privacy. *That’s your life!*” One IDU (NY) felt it was a violation of his rights: “One of our amendments to the Constitution is the right to privacy, and that’s kind of breaking our privacy.” Given the growing intrusion of the state in other personal affairs, respondents expressed feelings of deep mistrust of the government and “Big Brother.” Some felt that such a list was inevitable: “They keep a list on everything else; so, what’s new with this?” Another IDU (NY) also viewed the government warily, saying, “I wouldn’t put it past them. It’s none of their damn business.”

Concerns about privacy often arose due to participants’ prior experiences of HIV-related discrimination. A woman (NY) who had felt discrimination from medical providers, and whose family had reacted to her HIV disclosure with fears of casual transmission (e.g., of drinking out of her glass), thought this policy was “violating their rights.” Others wanted control of the information. A woman disclosed her diagnosis as cancer rather than HIV to her 14-year-old daughter who then became angry when learning the truth. The woman (MIL) said, “That’s peoples’ privacy. It’s supposed to be confidential. What if someone gets a hold of it? Don’t tell my kids—that’s my thing.” Of note, at the time of the interview, she still had not told two of

her children. Thus, her experience with her daughter may have reinforced her concerns regarding the need for privacy.

Fears of discrimination. Others expressed concern about specific implications of an HIV registry and particular breaches of confidentiality that could lead to discrimination. Concerns arose about insurers or employers procuring such a list and subsequently making it difficult to obtain or maintain insurance, housing, other benefits, or employment. Fears also arose concerning the potential for the government to decide to use the list for purposes other than those originally agreed upon. One MSM (LA) said, "They're going to start saying, 'well, we're going to send this list around to everybody so they know you've got HIV,' or, 'you can't go in this restaurant.'" Others feared that people could use the list as a weapon to control or malign someone, for example, through "blackmail . . . to harm someone's political career" (MSM-MIL).

Explicit fears arose regarding potential abuse of diagnostic information as "proof" used to hold an individual responsible for infecting others. One woman (NY) said: "I can give it to someone else. Am I going to be held responsible? Are they going to put me in a court of law? Am I going to be accused of giving this disease to someone that maybe I didn't? That's what I have a question about."

Fears of quarantine. Broader themes of discrimination arose, including explicit fears of quarantine. In the words of one woman (LA): "It doesn't sound good. It's like we're the plague or something. It's like they're going to put a sign on my door, 'I'm quarantined. Don't nobody go there. She is a health hazard.' It's a label on me, a sign on me: 'Beware.'" In the words of one MSM (MIL): "I don't see any reason why the government would need a list like that. Part of me says [they're] going to figure out just exactly how we can shift all these people via spaceship to an uninhabited planet or make everybody in Australia move so that we can make our own Devil's Island for those HIV people." In sum, here as elsewhere, future uses of the list, as yet undetermined, caused apprehension.

Wariness of government involvement. Others argued, too, that individuals should be responsible for themselves. In the words of one MSM (NY), "It's not

like you can get HIV just touching somebody...it's not airborne...so that's why I don't believe in that list thing. It's not a public health thing. It's a sexual thing. And as far as I'm concerned, whoever's old enough to have sex is old enough to face up to their own responsibility." Implicit here were issues of what the role of government should be in individuals' lives. He believed individuals acquired the virus not passively, but rather actively, through their sexual or needle sharing behavior, and thus were responsible for the choices they made. Consequently, he saw no place for government regulation. Individuals themselves were responsible for getting infected, and thus for protecting themselves, as well.

Public health costs. Others felt such a list could deter people from getting tested or treated. For example, as one IDU (LA) explained, "It wouldn't affect me because it's already on record that I'm positive. But if they instituted that kind of plan, it would drive a lot of people who are positive underground or deter them from getting the help that they need." Others opposed name reporting, but supported a system of unique identifiers. An MSM (NY) who worked as an AIDS activist felt that name reporting in a particular state would lead people to go to other states to get tested, and that a "witch hunt" could result.

Other Themes

Misperceptions about HIV registry. A number of respondents voiced negative attitudes toward an HIV registry based on misconceptions and confusion about the policy, combined with fears of surveillance. For example, some believed, erroneously, that the government already kept such a list and that they were on it, although their state had in fact not yet adopted the policy: "In a slick way, they have already done that..." said one MSM (NY). Negative attitudes were also based on beliefs about the disclosure of names on an HIV registry. For example, one MSM (LA) believed that a registry would hinder individuals from getting treatment, seemingly based on his assumption that registry information would be given automatically to agencies at which one might seek services. He favored continuation of policies in which patients chose whether to release information to an agency or clinic.

One woman (SF) believed that the government had in fact created the HIV virus, and already kept a list of infected individuals.

Ambivalence about HIV registry. As a result of these conflicting issues and misperceptions, some individuals felt emotionally torn about this policy and held mixed opinions. Conflict often arose from difficulty reconciling wariness with the fact that specific services such as benefits, medical care, and housing subsidies had been gained from other government lists (e.g., for medication, and housing). One IDU (NY) expressed a fear of discrimination but felt the government had a right to possess the information. An MSM (NY) illegal immigrant had mixed feelings, seeing such a list as “disgusting,” and expressing concern about how it could be used for immigration and deportation of illegal aliens. He viewed it as another kind of surveillance, yet at the same time, recognized that he received health care in the US because of his HIV status.

Partner Notification

Support for PN

Public health benefits. Most respondents in general, and women in particular, favored PN as a voluntary service, feeling that people unaware of their exposure to HIV should have this information. Almost one-quarter of respondents had experience with PN programs for HIV or other sexually transmitted infections. The majority of those with this experience favored HIV-related PN programs due to positive experiences and beliefs that such programs could reduce the epidemic. Almost half of those without direct experience with PN programs also held favorable opinions. Generally, those in favor felt that possession of notification information would give individuals the opportunity to make informed choices about testing, seeking education, receiving treatment, if needed, and engaging in subsequent high-risk sexual behavior. In the words of one female (LA) respondent: “It’s better for people to know about the infection than go around infecting others—some people don’t even know that they could have been infected until they hear about the person dying of AIDS.” Many participants seemed to

have desired receiving some notice of potential exposure so that they “might have took [sic] a different precaution to it” (WOM-NY), and were in favor of this policy to prevent others from possibly going through what they had.

Some felt that another benefit of such a policy was that it might deter those notified and possibly infected who may otherwise engage in unsafe sex. One woman (SF) felt it would make individuals responsible for themselves, “Because, [the epidemic] has to stop. That [policy] makes everybody responsible for themselves [sic], you know, and that means...they’re making these people responsible so if they go out and have sex with other people and do it to them on purpose...they’re doing it on purpose, see.” Others agreed, but felt that the policy would not deter everyone. For example, one MSM (SF), in speaking about the policy, said, “it’s cool,” but, “there are people out there who do everybody, and get everybody they can.”

Relief of burden of disclosure. Several respondents with prior experiences with provider-initiated PN programs reported feeling relieved of the burden of having to notify partners themselves. One MSM (MIL), for example, reported that a health worker came to his home: “I was kind of proud in a whacked up sort of way that she was going to contact these people, and that I didn’t have to...the only guilt that came about was the fact that I should have probably told these people before she did.”

Concerns regarding cooperation. Of note, some supported PN, but pointed out potential limitations in that patients may “lie” or not fully cooperate (MSM-SF), and the policy would be difficult to monitor or enforce: “You just don’t give the name” (MSM-NY). Perceived difficulty with the enforcement of cooperation in compiling partner names led some to support the policy, since they felt a potential loophole enabled them to protect their privacy. Others, while supporting PN in principle, articulated concern regarding its general effectiveness, due to this loophole. An MSM (NY) was involved in PN in the 1980s but “didn’t give them everybody[’s name],” saying that his partners already knew.

Fears of notified partners learning of their source of exposure. Another group supported the policy providing it was carried out correctly and, in particular,

“anonymously.” Fears were expressed that domestic violence could result if someone notified through PN could determine who had exposed them.

Opposition to PN

Privacy concerns. Opponents expressed concerns about privacy and civil rights. One IDU (LA) with a long history of incarceration stated: “that they would go to that extreme extent: to start driving over your confidentiality? I feel that it's intrusion into your privacy. And it's very intrusive. It's Big Brother at its worst.” As with an HIV registry, opponents of PN also worried over possible misuse of the confidential information.

Invasiveness of the policy. Some had personal experiences with provider-initiated PN and disliked the process, given the lack of control over one's life that it represented. An IDU (NY) who participated in PN for syphilis, viewed the process negatively, feeling “...continually harassed by the Department of Health. They're more interested in demoralizing people than protecting them.” A woman (MIL) felt “the health department worker was too pushy. It was like what they did with the witch trials and the witch hunts: pretty extreme.” She reported telling the worker that there was no one to contact. Yet the worker kept pressuring her.

Unfair burden on infected individuals. PN was also seen as shifting undo responsibility onto PLH. One MSM (NY) opposed PN as he felt that “some feel that people who are HIV positive are responsible for everything. We are something that threatens.”

Wariness of government. Others expressed general antipathy toward the government. As one MSM (LA) explained, “It looks good on paper, but I don't think it'll fly,” since “everything else the government does gets overrun, bogged down.”

Individual, not government responsibility. Opponents felt that it was an individual's responsibility to protect him or herself, and that the government should not get involved. An IDU (LA), infected by a male partner who had lied about his HIV status (saying he was uninfected) held this view, contending, “He was lying to me. Anyway, that's my fault. The government needs to stay out of this.”

Deterrence of testing. Some opposed mandatory policies because of fears that it could deter people from getting tested. An MSM (MIL) said:

If they state that they're going to force partner notification, people aren't going to go get tested out of the fear that they're going to have to tell who their partners are, and [that their partners will be] notified, and even peer pressure of friends and family finding out that they're HIV-positive—they won't go get tested and will live and reinfect...or infect people even more.

Potential harm to relationships. Even if performed anonymously, such notification might also harm relationships between two people. An MSM (LA) said: “I feel that if you didn't tell that partner, it can be a big blow-up in people's faces or cause a lot of pain and be hectic for another person. It's scary. Someone can really get upset and go after that person.” In short, both psychological as well as physical harm could ensue.

Possible associations between participants' risk behavior and opposition to PN. Potential relationships also arose between attitudes toward PN, disclosure patterns, and sexual risk behavior. Those engaging in sexual risk behavior without disclosure often opposed PN, as did many who did not disclose but engaged in what they perceived to be safer sex. For example, one opponent of PN reported that he does not disclose his serostatus to partners but believes that all the sexual behavior he engages in—including unprotected sex with other HIV positive men—is safe. Another man, who continued to expose dozens of anonymous sexual partners to HIV infection, expressed feeling guilty about his behavior, but still did not support government involvement in such issues.

Ambivalence About PN

As described above with regard to name reporting, the difficulty of reconciling these conflicting arguments about PN led some to feel ambivalent concerning this policy as well. As one MSM (LA), who was a former IV drug user and sex worker said:

It's a double-edged sword. There are advantages and disadvantages. I don't think people should just go out and knowingly give it to people—that

makes you a murderer. God, I don't know, that's a very touch and go question. It could lead up to other invasions of privacy, like being registered. Like in Russia, if you have AIDS, you're in a computer and they know where you are.

Others voiced ambivalence regarding public health benefits. A male IDU (LA) felt PN would prompt some people who were notified to be tested, but may prevent others from doing so because "names on any paperwork" would violate their confidentiality and potentially lead to abuse.

Misperceptions About PN

Several specific misunderstandings and misconceptions about PN arose. When asked if they had ever had experience with PN, several respondents said they had not; yet when the program was explained, they said that they had in fact heard of it and had direct experience with it. One woman (NY) thought PN was a physician informing a patient that he/she was HIV-infected. An IDU (NY) confused PN with criminalization of nondisclosure: "Something like a person like me, if I'm HIV and had sex with somebody and don't tell them nothing: something about give me a felony." An MSM (LA) thought that PN was done in the past for other STDs, but that "they don't do that no more."

Confusion arose over whether PN would involve the reporting of an individual's name, and over how the information collected would be used. One woman (NY), for example, initially was unsure if, "they would name names." When told that name reporting would not be involved, she said, "Well, then that's cool." One of the few women (SF) who expressed opposition to the policy also expressed confusion on this point saying, "if you've got partner notification, then you've got name notification. I don't accept either one of them." As with attitudes toward an HIV registry, past experiences of HIV discrimination colored perceptions. For example, this particular woman reported being notified of her status "crudely and poorly" in the hospital when having a pregnancy test. Of note, participants did not always make clear distinctions between mandatory and voluntary PN programs.

Criminalization of Non-Disclosure of HIV Status

Support for Criminalization

Public health benefits. Based on perceived public health benefits, most participants supported the criminalization of non-disclosure of one's HIV positive status to sexual partners. In fact, many felt this policy could be effective in decreasing HIV transmission by enforcing disclosure and changing sexual behavior. For example, one IDU (LA) said, "I think a lot of the new infections are because the people are not disclosing that they have it." Another participant (MSM-LA) described how the threat of such a law had altered his own actions after he made "a fatal mistake" by not disclosing to a woman who later said that he was trying to kill her and that she could report him to the police. He explained that this legal threat motivated him to alter his behavior with future partners.

Support only under certain circumstances. Others cited specific circumstances under which they would support such a policy. For example, one MSM (NY), who did not disclose to his partners, supported the law only if an individual were infected by force, as in rape. He otherwise felt that in "consensual sex, both parties have to watch out for themselves." Another man supported the policy if an individual had lied about his or her HIV status to a partner, stating, "If they lie, they should be punished."

Opposition to Criminalization

Individual not government responsibility. Others opposed criminalization of non-disclosure, believing that disclosure should be up to the individual—not the legal system. One woman (LA) opposed this policy, arguing that people should be responsible for protecting themselves, even if a partner does not disclose: "You insist upon not using condoms. I don't think that person should be held liable." Some distinguished between ethical and legal culpabilities and felt non-disclosure was morally wrong, "But to make it a crime, I don't know" (MSM-LA).

Deterrence of testing. Opponents of this policy also feared that it could deter people from being tested.

On these grounds, an MSM (MIL) who always disclosed to partners stated: "I think the only behavior that it would change is: people would not go get tested, and the disease would go rampant. I don't believe that it would cause people to have safer sex." Others shared his view and opposed criminalization policies, doubting the potential for deterrence of unsafe sexual behavior.

Safer sex is more important. Others felt that the practice of safer sex obviated the need for disclosure at all. One MSM (LA), for example, who has not disclosed to anyone except his physician, said, "You could have safe sex with a person, and they never have to know if you're HIV or not, as long as you keep insisting on safe sex." Indeed, some thought that since HIV was preventable through safer sex, if individuals became infected, it was their own fault. An MSM (MIL) explained, "I feel no remorse for a person who becomes infected because they didn't know about the other partner." Here again, feelings arose that ultimate responsibility lay with individuals, not government.

Potential for abuse. Another argument against this policy arose from the possibility that such a law could be abused. Specifically, some felt that individuals could lie to incriminate their partners. For example, an IDU (NY) said, "Even if I was doing it with condoms, she can say I was doing it without condoms; and they're going to believe her."

Misperceptions of Criminalization of Non-Disclosure

Confusion arose regarding the meaning of criminalization of nondisclosure. Specifically, participants did not always distinguish among "intended infection," "nondisclosure and unsafe sex," and "nondisclosure" by itself. In the interviews, some voiced fierce opposition to "intended infection," though the policy inquired about was criminalization of nondisclosure—regardless of the kind of sexual behavior engaged in, and of the "intent" of unprotected sex, if it occurred.

Ambivalence About Criminalization

Given the above conflicting arguments, not surprisingly, mixed feelings about criminalization

arose. One woman (LA) said: "It's a crime for a person to go and violate another person's body. That's what happened to me...[But] maybe they didn't know at the time. Would I want that person to sit in jail for life? No, I wouldn't." Here, she implicitly condones transmission if there is a lack of intent, but raises questions about what the appropriate punishment should be.

Tensions at times arose between an individual's attitude about this policy and his or her own behavior. Thus, for example, an IDU (NY) did not feel his partners needed to know his status if he were practicing safe sex (i.e., criminalization of nondisclosure was unnecessary); yet he reported inconsistent condom use, most commonly when mixing sex and drugs. In short, his own behavior contradicted his argument against the policy.

Discussion

Whether participants favored or opposed these three policies, several common themes emerged in their assessments. These themes included appreciation of potential public health benefits, including epidemiological surveillance, deterrence of unsafe sex, and relief of the burdens of disclosure (see Table 3). Against these benefits, individuals voiced fears of threats to confidentiality, privacy, and civil rights (often fueled by experiences of past discrimination), wariness of governmental involvement, and potential public health costs, such as deterrence of testing and treatment. Fears about privacy arose with regard to all three policies, but were most salient in assessments of HIV case reporting, a policy that also raised particular concerns about possible loss of insurance, benefits, or employment. PN specifically raised fears of burdening infected individuals unfairly, potentially harming relationships, and causing domestic violence. Nonetheless, most respondents generally favored PN programs. Concerning criminalization of nondisclosure, questions arose regarding the scope of this policy. Some respondents thought that only particular acts, such as lying about HIV status, should be illegal. Many believed that for HIV-prevention, safer sex was more important than disclosure in and of itself. This last attitude supports evidence (Crepaz & Marks, 2003) that men who both disclosed their HIV status and

discussed issues of safer sex with their sexual partners were more likely to engage in safer sex than were men who disclosed but did not also discuss safer sex. Questions of the details of criminalization policies arose as well, for example as to how much punishment was appropriate. A large proportion of participants supported criminalization policies seemingly as a way to prevent others from being infected as they themselves had been, suggesting a sense of altruism among these groups in regard to this issue. Overall, participants appeared to view more positively policies that they saw as directly helping HIV prevention efforts and individuals at risk, as opposed to policies seen as more distantly helping individuals and more directly aiding the government in its epidemiological pursuits.

Importantly, critical misperceptions frequently arose regarding the definitions, scope, and purpose of each of these policies. These men and women often based their attitudes on mistaken beliefs regarding benefits or drawbacks that might result from these laws. For example, some felt that an HIV registry would provide more efficient access to health care, government assistance, benefits, and other services, while others believed that such a list could be accessed by individuals wanting to know if partners were infected, or that the government already had such a list. This low level of information is consistent with reports that most participants could not correctly identify the HIV reporting policy in their states (Hecht et al., 2000; Schwarcz et al., 2004).

PN in particular appeared to be not well understood. Several respondents initially reported that they had not heard of the term “partner notification,” but when it was described during the interview, they realized they had not only known of the procedure, but had also participated in it. Others confused PN with different procedures such as patient notification of HIV infection by physicians, or HIV name reporting. Participants generally supported informing partners of possible exposure to HIV, yet were also concerned about this process being performed well, recognizing that the program poses profound logistical challenges. These views are consistent with, and help explain, findings of very low utilization of health department-assisted PN programs, even when programs are extensively promoted (Schwarcz, McFarland, Delgado,

Adler, & Withupp, 2001).

Regarding criminalization of non-disclosure of HIV status, respondents were often confused about whether this policy referred to non-disclosure alone or non-disclosure in conjunction with unsafe sex, and whether intent was necessary for prosecution. This policy was designed to be a structural intervention to reduce HIV transmission. Yet if key aspects of a policy are not clear, it may well not have its intended impact.

Misperceptions arose as well about existing legal protections to privacy. For example, one participant’s comment that “one of our amendments to the Constitution is the right to privacy” is in fact incorrect, as the US Constitution does not explicitly refer to privacy. Indeed, this lack of historical protection of privacy has helped prompt efforts such as the Health Insurance Portability and Accountability Act (HIPAA). Recently, privacy has also been increasingly challenged due to widening uses of electronic databases, the Internet, and managed care. Of concern, patients may at times assume that their privacy is more protected than it actually is.

Repeatedly, these men and women had difficulty weighing and evaluating conflicting ethical and public health values involved in these issues. Support for and opposition to these policies were often far from straightforward. Some supported a policy only with certain key caveats regarding, for example, the sensitivity, confidentiality, and anonymity with which these policies would be implemented. Questions emerged about the enforceability and efficacy of these policies. At times, participants recognized shortcomings (e.g., possible misuse of information), but nevertheless supported these policies. Of note, respondents supporting and opposing a particular policy often raised similar concerns, but viewed these points in conflicting ways. For instance, beliefs that a registry could be distributed to agencies from which PLH may seek services led to viewing such a registry both positively, because it would facilitate better access and decrease treatment replication and costs, and negatively, because the list might not be sufficiently controlled and might deter individuals from accessing treatment.

The ambivalence expressed by some participants suggests, too, the degree of difficulty associated with

making these ethical and policy decisions, and the degree to which critical ethical conflicts underlie these debates. For example, it remains unclear how potential public health benefits should be weighed against fears of discrimination; how the government's right to information should be balanced against its potential misuse of that information; and how social gains should be weighed against potential harms to the individual. Other broad ethical questions emerge as well, such as whether responsibility for prevention rests ultimately with individuals or the government—with most respondents here choosing the former. Indeed, one participant felt that even though a partner had lied to him, it was still not the government's role to interfere in this private matter. Many of these individuals wrestled, too, with balancing desires for privacy against recognition that partners, in general, need to be protected from becoming HIV-infected. At times, these PLH felt that their own privacy needs were less important than the protection of others' lives, indicating a degree of altruism regarding these issues that may perhaps have heretofore been underused as a strategy in HIV prevention efforts. The support of many of these PLH for policies of PN and criminalization contrasts with the staunch opposition to these policies voiced by some advocates. Hence, it is possible that certain advocates do not necessarily consistently represent the views of all PLH. This possibility does not diminish the role or importance of such advocates, but raises questions regarding to what extent views of these policies are far more varied and complex than some might assume, and whether and to what degree advocates are responsible for reflecting the views of these groups as a whole. Clearly, in formulating policy, the details, nuances, and range of views of PLH and of people at risk of HIV need to be carefully assessed and maximally taken into account.

A range of factors may help shape these respondents' perspectives. For example, conceivably, those with positive attitudes towards these policies have had fewer experiences of discrimination in the past, and/or are more trusting of government agencies. Such hypotheses could be explored further in the future through quantitative studies. Attitudes towards these policies may be related, too, to one's own risk behaviors. For example, those who engage in risky

behavior may oppose policies that would hold themselves liable. That does not mean these attitudes should be disregarded, but rather that the complicated correlates of the views of some PLH should be recognized.

Of note, profound distrust of government emerged—in part due to past experiences of discrimination as well as historical incidents of maltreatment such as occurred at Tuskegee (Fairchild & Bayer, 1999). Many PLH have faced prior and ongoing discrimination due to their sexual behaviors (e.g., homosexuality, trading sex for drugs or money, and having sex with multiple partners). As a result, these individuals appeared wary of policies that might further stigmatize them. Moreover, in this population, fears of negative consequences of HIV status disclosure or PN, such as domestic violence, are very real. Wariness of the problems of government bureaucracy emerged as well. Given that large numbers of individuals are HIV infected but untested, distrust of government is important as potentially deterring some individuals from testing and accessing treatment. These data support hypotheses by Lazzarini, Bray, and Burris (2002) that strong mistrust of government exists, and may indeed hamper perceptions of the very legitimacy of the law. The current data suggest, too, that these respondents sensed hostile motivations behind these laws, a finding that supports the work of Herek et al. (2003) on continued stigma toward PLH in the US population as a whole. As a result, policy makers need to work to combat these prejudices in the general population. As Burris (2000) described, surveillance by name represents a "larger social struggle for status and power." Indeed, all three of these policies have important "symbolic" value and larger political dimensions. At the same time, these policies have not only "symbolic" value for these respondents, but also very real implications for privacy and civil liberties—potential benefits as well as dangers. Hence, in passing and implementing these laws, policy makers need to demonstrate clear commitment to non-discrimination, and should couple these laws with enhanced protections for privacy, and motivations for at-risk individuals to seek testing, and, if needed, treatment (Burris, 2000).

This study has several potential limitations. The

interviewees were all previously tested and diagnosed with HIV and were receiving services from HIV clinics or CBOs. Consequently, these respondents may not reflect the views of all individuals at risk for HIV. Yet insufficient data is available on the views of PLH concerning these policy issues. Furthermore, the cooperation of these men and women is needed for HIV-prevention policies to be effective. Indeed, these interviews suggest that PN is only as good as the quality and quantity of the data that index patients volunteer to provide about their contacts. Moreover, in general, views toward these policies have been understudied. Importantly, the present sample, though not large enough for certain quantitative analyses, does illustrate the range of variables involved in these attitudes that can be explored further in future research. Another potential limitation is that some participants may have misunderstood aspects of these policies. However, interviewers first elicited participants' comprehension of these policies, rather than immediately correcting misunderstandings, since the investigators thought it was important to ascertain the ways in which participants actually understood these policies at the time. Misperceptions that exist may well be shared by other individuals who have or are at risk of HIV, too. Hence, misunderstandings were corrected, but generally after they were first articulated by participants and explored in the interview.

These findings have several critical implications for future policy and research. Given the complexities and nuances inherent in these issues, policy makers face critical challenges. Clearly, decisions about the appropriate role of the government in regulating public health require broad and careful political consensus. Policy makers, in considering, formulating, and implementing these strategies for HIV prevention need to be exquisitely sensitive to, and address carefully the apprehensions and life contexts explored here. HIV infection occurs disproportionately in disenfranchised populations such as IDUs and African-Americans who often have had limited access to formal support and sometimes education. Policy makers need to approach these statutes in ways that preserve the dignity, and ameliorate the fears of those most affected. Especially since PN and voluntary testing require cooperation by PLH and, in PN, index patients need to be encouraged

to offer names of as many of their contacts as possible, the experiences and perspectives of PLH are vital to consider. Policy makers must demonstrate commitment explicitly to engendering the trust of populations who have or are at high risk of HIV. In the past, the ability of policy makers to appreciate the intricate contexts in which high risk behaviors occur has significantly shaped the success or failure of efforts to create effective HIV-prevention policies (Bayer, 1989). For example, ACT UP helped alter access to drug trials, given that many PLH were willing to risk trying certain drugs, even if these substances had not fully been approved by the FDA. At times, PLH, facing life-threatening illness, differ substantially in their views from many policy makers in ways that remain important to recognize.

This study indicates, too, the necessity of planning for increased public education—targeting and tailoring such efforts to acknowledge these groups' particular concerns and experiences. Such educational efforts can play enormous roles in allaying heightened wariness of government, and reducing confusion as to the intended benefits and potential harms of these programs. Effective public health campaigns should, for example, provide clear rationales for policies. As suggested earlier, an appeal to altruism (e.g., by encouraging individuals to “help stop the HIV epidemic”) may also potentially aid acceptance of these policies. Informational and educational efforts could be organized through CBOs, many of which already have established and trusted positions within communities, and are involved in treatment and education with individuals at risk for, or already infected with HIV. Though one might argue that increased public education may discourage some individuals from seeking testing, since these individuals' names will be reported if they test positive, this concern about name reporting has not been found to be a reason for untested individuals to avoid HIV testing (Hecht et al., 2000).

As suggested above, the current study raises several critical questions in need of further research. For example, do criminalization laws in fact deter unsafe sex, and if so, to what extent, and among whom? The threat of the law did in fact alter the behavior of some of these respondents. Future research can clarify,

too, how these competing views and perspectives can or should be weighed, and elucidate the extent and contribution of various factors and contexts that may affect approaches to these policies. Future research can examine these issues quantitatively among larger samples as well.

These data also shed light on the difficulties involved in designing and implementing policies that affect sexual behaviors. Key ethical questions emerge as to the appropriate role of the government—its potential “invasiveness”—and the most appropriate way to balance social benefits and threats to individual privacy. Misunderstandings and misperceptions arise in part because taboos, often unspoken, enshroud sexuality and sexual behavior. These taboos may be affected by laws, and can also in turn influence enactment, enforcement, and public education concerning legislation. These data shed light, too, on challenges to the development of policy that stem in part from the inherently intimate nature of most sexual behavior. Questions emerge, for example, of determining whether intent is present, and is conscious or not. As a result, too, of the multifaceted and largely private nature of sexuality, policies can also have a variety of unintended effects (e.g., domestic violence, and harm to relationships) that may not be readily visible outside of a relationship, and hence may be difficult to assess. These data can thus help illuminate how the intricacies of sexuality and social policy intersect in the complex lived experiences of men and women.

This research has crucial implications internationally as well, particularly in the resource-poor, or developing world, where the HIV pandemic is spreading at an even faster rate than in the US, and where effective and appropriate prevention policies are desperately needed. Yet in these countries, serious challenges emerge in incorporating and integrating HIV prevention programs from the US, given differing cultural, social, historical and political contexts and norms. Further work needs to determine the views and approaches of PLH in other cultures, too, toward prospective HIV prevention policies. The current data, suggesting ranges of misperceptions, concerns, and issues, can potentially help inform such efforts.

In sum, to be effective, policy makers need to be

keenly aware of the attitudes and values of individuals who have been or will be affected by these laws; the nuances and misperceptions involved regarding these policies; and the social and cultural contexts within which these initiatives will be implemented. This research suggests a continuing need to assess and take into account as much as possible the perspectives of PLH in order to develop and implement the most effective and appropriate public policy both in the US and abroad to help stymie the HIV pandemic. ♦

Acknowledgments

This research was funded by National Institute of Mental Health grants U10-MH57636, U10-MH57631, U10-MH57616, and U10-MH57615; and NIMH center grants P30-MH058107 (Mary Jane Rotheram-Borus, Ph.D., PI), P30-MH57226 (Jeffrey A. Kelly, Ph.D., PI), P30-MH43520 (Anke A. Ehrhardt, Ph.D., PI), and P30-MH062246 (Thomas J. Coates, Ph.D., PI).

The authors thank those at NIMH: Ellen Stover, Ph.D., and Willo Pequegnat, Ph.D., for their technical assistance in developing the study and Christopher M. Gordon, Ph.D., and Dianne Rausch, Ph.D., for their support of this research. Gratitude is also given to Susan Tross, Ph.D., and Gary Dowsett, Ph.D., for methodological guidance; to Brian Dodge, Ph.D., for reading previous versions of this manuscript; to the Columbia University Center for Bioethics, including Ruth Fischbach, Ph.D., Joyce Plaza, M.A., Scott Reiners, and Frank Griggs; to the assessors in each city who conducted the interviews; to our clinic and community based organization collaborators; to all other support staff involved in the project; and to the men and women who participated in the interviews.

This study was conducted by the NIMH Healthy Living Trial Group. Research Steering Committee (site principal investigators and NIMH staff collaborator): Margaret A. Chesney, Ph.D.¹, Anke A. Ehrhardt, Ph.D.²,

-
1. University of California, San Francisco
 2. New York State Psychiatric Institute/Columbia University, New York
 3. Medical College of Wisconsin, Milwaukee
 4. National Institutes of Mental Health, Bethesda, Maryland
 5. University of California, Los Angeles

Jeffrey A. Kelly, Ph.D.³, Willo Pequegnat, Ph.D.⁴, Mary Jane Rotheram-Borus, Ph.D.⁵ Collaborating Scientists, Co-Principal Investigators, and Investigators: Eric G. Benotsch, Ph.D.³, Michael J. Brondino, Ph.D.³, Sheryl L. Catz, Ph.D.³, Edwin D. Charlebois, Ph.D., M.P.H.¹, Don C. DesJarlais, Ph.D.⁶, Naihua Duan, Ph.D.⁵, Theresa M. Exner, Ph.D.², Rise B. Goldstein, Ph.D., M.P.H.⁵, Cheryl Gore-Felton, Ph.D.³, A. Elizabeth Hirky, Ph.D.², Mallory O. Johnson, Ph.D.¹, Robert M. Kertzner, M.D.², Sheri B. Kirshenbaum, Ph.D.², Lauren E. Kittel, Psy.D.², Robert Klitzman, M.D.², Martha Lee, Ph.D.⁵, Bruce Levin, Ph.D.², Marguerita Lightfoot, Ph.D.⁵, Stephen F. Morin, Ph.D.¹, Steven D. Pinkerton, Ph.D.³, Robert H. Remien, Ph.D.², Fen Rhodes, Ph.D.⁵, Susan Tross, Ph.D.², Lance S. Weinhardt, Ph.D.³, Robert Weiss, Ph.D.⁵, Hannah Wolfe, Ph.D.⁷, Rachel Wolfe, Ph.D.⁷, Lennie Wong, Ph.D.⁵ Data Management and Analytic Support: Philip Batterham, M.A.⁵, W. Scott Comulada, M.S.⁵, Tyson Rogers, M.A.⁵, Yu Zhao, M.S.⁵ Site Project Coordinators: Kristin Hackl, M.S.W.³, Daniel Hong, M.A.⁵, Karen Huchting, B.A.⁵, Joanne D. Mickalian, M.A.¹, Margaret Peterson, M.S.W.³ NIMH: Christopher M. Gordon, Ph.D.⁴, Dianne Rausch, Ph.D.⁴, Ellen Stover, Ph.D.⁴

References

- American Civil Liberties Union (ACLU). (1997, October). HIV surveillance and name reporting: A public health case for protecting civil liberties. *An American Civil Liberties Union Report*. Retrieved June 14, 2002, from <http://www.aclu.org/Privacy/Privacy.cfm?ID=14512&c=27>
- Aragon, R. & Myers, J. (1999). HIV testing after implementation of name-based reporting. *JAMA*, *281*(15), 1377-378.
- Bayer, R. (1989). *Private acts, social consequences: AIDS and the politics of public health*. New York: The Free Press.
- Burris, S. (2000). Surveillance, social risk, and symbolism: Framing the analysis for research and policy. *Journal of Acquired Immune Deficiency Syndromes*, *25*(Suppl 2), 120-127.
- Carballo-Dieiguez, A., Remien, R.H., Benson, D.A., Dolezal, C., Decena, C.U., & Blank, S. (2002). *Intention to notify sexual partners about potential HIV exposure among New York City STD clinics' clients*. Unpublished manuscript.
- Centers for Disease Control (CDC). (1998). Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. *Morbidity and Mortality Weekly Report*, *47*(RR5), 42-82.
- CDC. (1999). Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *Morbidity and Mortality Weekly Report*, *48*(RR13), 1-28.
- CDC. (2000). HIV/AIDS Surveillance Report: US HIV and AIDS cases reported through June 2000. *Department of Health and Human Services Report*, *12*(2), 5-10.
- CDC. (2001). Revised guidelines for HIV counseling, testing referral. *Morbidity and Mortality Weekly Report*, *50*, 1-58.
- CDC. (2003). HIV/AIDS update: A glance at the HIV epidemic (a surveillance). Retrieved December 30, 2003, from <http://www.cdc.gov/nchstp/od/news/At-a-Glance.pdf>
- CDC. (2004). Implementation of named HIV reporting—New York City, 2001. *Morbidity and Mortality Weekly Report*, *52*(51), 1248-1252.
- Colfax, G.N., & Bindman, A.B. (1998). Health benefits and risks of reporting HIV infected individuals by name. *American Journal of Public Health*, *88*(6), 876-879.
- Crepaz, N., & Marks, G. (2003). Serostatus disclosure, sexual communication and safer sex in HIV-positive men. *AIDS Care*, *15*(3), 379-87.
- Dolbear, G., Wojtowycz, M., & Newell, L. (2002). Named reporting and mandatory partner notification in New York state: The effect on consent for perinatal HIV testing. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, *79*, 238-244.
- Fairchild, A., & Bayer, R. (1999). Uses and abuses of Tuskegee. *Science*, *24*, 910-913.
- Golden, M., Hogbed, M., Hansfield, H., St. Lawrence., J., Potterat, J., & Holmes, K. (2003). Partner

6. Beth Israel Medical Center, New York

7. St. Luke's-Roosevelt Medical Center, New York

- notification for HIV and STD in the United States: Low coverage for gonorrhea, chlamydial infection, and HIV. *Sexually Transmitted Diseases*, 30, 490-496.
- Golden, M., Hopkins, S., Morris, M., Holmes, K., & Handsfield, H.H. (2003). Support among persons infected with HIV for routine health department contact for HIV partner notification. *Journal of Acquired Immune Deficiency Syndromes*, 32, 196-202.
- Hecht, F.M., Chesney, M.A., Lehman, J.S., Osmond, D., Vranizan, D.K., Colman, S., Keane, D., Reingold, A., Bindman, A.B., & MESH Study Group. (2000). Does HIV reporting by name deter testing? *AIDS*, 14, 1801-1808.
- Herek, G., Capitano, J., & Widaman, K. (2003). Stigma, social risk, and health policy: Public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychology*, 22, 533-540.
- Janssen, R., Holtgrave, D., Valdiserri, R., Shepherd, M., Gayle, H., & De Cock, K. (2001). The serostatus approach to fighting the HIV epidemic: Prevention strategies for infected individuals. *American Journal of Public Health*, 91, 1019-1024.
- Kegeles, S.M., Coates, T.J., Lo, B., & Catania, J. (1989). Mandatory reporting of HIV testing would deter men from being tested. *JAMA*, 261, 1275-1276.
- Klitzman, R., & Bayer, R. (2003). *Mortal secrets: Truth and lies in the age of AIDS*. Baltimore: Johns Hopkins University Press.
- Landis, S., Schoenbach, V., Weber, D., Mittal, M., Krishan, B., Lewis, K., & Koch, G. (1992). Results of randomized trial of partner notification in cases of HIV infection in North Carolina. *New England Journal of Medicine*, 326(2), 101-106.
- Lazzarini, Z., Bray, S., & Burris, S. (2002). Evaluating the impact of criminal laws on HIV risk behavior. *Journal of Law, Medicine & Ethics*, 30(2), 239-253.
- Lazzarini, Z., & Klitzman, R. (2002). HIV and the law: Integrating law, policy, and social epidemiology. *Journal of Law, Medicine & Ethics*, 30(4), 533-47.
- Macke, B., & Maher, J. (1999). Partner notification in the United States: An evidence based review. *American Journal of Preventative Medicine*, 17(3), 230-242.
- Morin, S.F. (2000). Early detection of HIV: Assessing the legislative context. *Journal of Acquired Immune Deficiency Syndromes*, 25(Suppl. 2), 144-150.
- Nakashima, A.K., Horsley, R., Frey, R.L., Sweeney, P.A., Weber, J.T., & Fleming, P.L. (1998). Effect of HIV reporting by name on use of HIV testing in publicly funded counseling and testing programs. *JAMA*, 280(16), 1421-1426.
- Osmond, D.H., Bindman, A.B., Vranizan, K., Lehman, J.S., Frederick, M., Keane, D., & Reingold, A. (1999). Name-based surveillance and public health interventions for persons with HIV infection. *Annals of Internal Medicine*, 131(10), 775-779.
- Patton, M.Q. (1990). Humanistic psychology and humanistic research. Special issue: Human inquiry & the person-centered approach. *Person-Centered Review*, 5, 191-202.
- Rogers, S.M. (1996, July). *Partner notification with HIV-infected drug users: Results of formative research*. Paper presented at the International AIDS Conference, Vancouver, Canada.
- Rubin, S.M. (1991, July). *Partner notification may deter HIV positive drug users from treatment*. Paper presented at the International AIDS Conference, Amsterdam, Netherlands.
- Schwarcz, S., McFarland, W., Delgado, V., Adler, B., & Withupp, D. (2001). Partner notification for persons recently infected with HIV: Experience in San Francisco. *Journal of Acquired Immunity Deficiency Syndrome*, 28, 403-404.
- Schwarcz, S., Stockman, J., Delgado, V., & Scheer, S. (2004). Does name-based HIV reporting deter high-risk persons from HIV testing? Results from San Francisco. *Journal of Acquired Immune Deficiency Syndrome*, 35(1), 93-96.
- Solomon, L., & Benjamin, G. (1998). National HIV case reporting. *New England Journal of Medicine*, 338, 626-627.
- Speissegger, L., Wilson, S., & Watson, A. (1999). *Criminal transmission and exposure*. Retrieved June 14, 2002, from <http://stateserv.hpts.org>. Now at <http://www.ncsl.org>
- St. Lawrence, J., Montano, D., Kaprzyk, D., Phillips, W., Armstrong, K., & Leichter, J. (2002). STD

- screening, testing, case reporting and clinical and partner notification practices: A national survey of US physicians. *American Journal of Public Health*, 92, 1784-1788.
- Strauss, A., & Corbin, J.M. (1990). *Basics of qualitative research: Grounded theory, procedures and techniques*. Newbury Park, CA: Sage Publications.
- Van Derbeken, J. (2003, December 10). HIV transmission case tossed out. Man didn't intentionally infect, judge finds. *San Francisco Chronicle*. Retrieved May 26, 2004, from <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2003/12/10/BAGL53JSM61.DTL>
- Wasserman, S., & Watson, A. (2000). *Partner notification programs*. Retrieved June 14, 2002, from <http://www.stateserv.hpts.org>. Now at <http://www.ncsl.org>
- Woods, W., Binson, D., Morin, S., & Dilley, J.W. (1999). HIV testing after implementation of name-based reporting. *JAMA*, 281(15), 1377-1378.