



Published in final edited form as:

Int J STD AIDS. 2009 September ; 20(9): 613–618. doi:10.1258/ijjsa.2008.008417.

HIV sero-positive status disclosure to prospective sex partners and criminal laws that require it: Perspectives of persons living with HIV

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When you think about [HIV infection] first off, because it's a sexually transmitted disease you would think it was similar to gonorrhea or syphilis ...if you caught gonorrhea or syphilis you went to your local health department. You got a cure. You did not get arrested.

Introduction

A substantial number of persons living with HIV engage in sex with partners who are unaware of their HIV-positive serostatus.^{1,2,3,4,5} Some of these individuals will eventually disclose to these partners. Others will not. Some may not have sexual contact with the partner again. Others will continue a sexual relationship but will never disclose. Still other persons living with HIV choose to forgo sex entirely rather than risk disclosing their HIV-positive serostatus to potential sex partners.

The decision to disclose one's HIV-positive sero-status to prospective sexual partners is difficult for some. Barriers to disclosure include fear of rejection, fear of a partner reacting with anger or even violence, and fear of losing control over very private, potentially-damaging information.^{6,7,8,9,10}

Seropositive status disclosure allows couples to make informed choices and together reduce the possibility of HIV transmission.¹¹ Twenty-four U.S. states currently have HIV-specific laws that require persons who are living with HIV to disclose their positive serostatus to prospective sex partners.^{12,13} Commentary about the laws has been plentiful and often critical.^{13,14,15,16} At the crux of much of the criticism about the laws is the concern that the coercive and punitive nature of the criminal law undermines public health efforts to control the spread of HIV. Specifically, the concern is that HIV disclosure laws may deter persons who have HIV or are at risk for HIV infection from accessing public services designed to diagnose and treat persons who are HIV-infected and to prevent further transmission.^{12,13,17}

Critics suggest that HIV disclosure laws may provide a disincentive for HIV-positive persons to disclose their HIV positive serostatus to others lest their sexual behavior come under the scrutiny of the law.^{12,16} Other concerns are that the laws, by singling out persons living with HIV, may increase HIV-related stigma or reinforce prejudicial attitudes towards persons living with HIV by suggesting that HIV-positive persons are a threat to the health and safety of others.^{17,18} Since the success of public health efforts to prevent further spread of HIV depends on the voluntary cooperation of persons who are at risk for the virus or who are already infected,¹⁹ concerns that HIV disclosure laws may serve as a disincentive to cooperate in these efforts are quite serious.

Although scholars in law and public health have questioned whether the criminalization of HIV exposure may in some ways hamper efforts to combat HIV infection, few studies have empirically investigated the topic,^{18,20,21} and only one prior study has addressed the topic through discussion with persons living with HIV.¹⁸ In conjunction with a larger quantitative study on HIV disclosure laws, we conducted focus group discussions about Michigan's HIV disclosure law with 31 HIV-positive persons living in Michigan. Our objective was to better understand the law from the perspective of the persons whose behavior it regulates and upon whom the success of HIV prevention efforts largely depends. We sought to explore common concerns about the potential negative effects of HIV disclosure laws on persons living with HIV in order to identify potential barriers to positive health behavior and quality of life.

Methods

Sample

As part of a larger study on criminal HIV disclosure laws, 31 HIV-positive Michigan residents agreed to take part in focus group discussions on criminal HIV disclosure laws. The participants were recruited through flyers posted at an annual, statewide retreat for persons living with HIV hosted by the Michigan Department of Community Health and at a local AIDS service organization (ASO) HIV-positive residents of Michigan who had participated previously in our quantitative study of Michigan's HIV disclosure law were eligible to participate in one of the focus group discussions. All persons who expressed interest in the focus groups were invited to participate. Facilitators reviewed consent forms with participants prior to beginning the discussion. Because the only record that would identify individuals as participants in the study would be a signed consent form, a waiver of documentation of consent was requested and granted by the internal review board overseeing the project. (For further information on participant recruitment in the larger study see Galletly, DiFranceisco, & Pinkerton, in press.²¹)

The focus groups were mixed with respect to the gender, race, and sexual orientation of participants. Approximately half of the participants were African American, two-thirds were male, and half identified themselves as men who have sex with men. One focus group comprised 12 members, another had 13, and the final group had 6 members. Participants were assured that their identities would be kept confidential. Identifying information such as participant name, address, or date of birth were neither recorded nor requested. The study protocol was approved by the Medical College of Wisconsin IRB.

Data collection

The focus group discussions were conducted in the Spring of 2007 in private meeting rooms at the retreat center and at a participating ASO. Each 90 minute focus group discussion began with a review of the state's criminal HIV disclosure law. The study interview guide then elicited participant feedback on various aspects of HIV sero-positive status disclosure and Michigan's criminal disclosure law. All discussions were audiotaped. Focus group members were given a gift card to one of two retail chains with stores statewide to compensate them for their participation.

Data analysis

Focus group discussions were transcribed verbatim, de-identified, and uploaded into ATLAS.ti 5.2 qualitative data analysis software.²² After transcription, the original audiotapes were destroyed. An iterative approach was used to guide data analysis. Preliminary codes were identified during the development of the discussion facilitator's guide and refined throughout the coding process. Emergent themes were also identified and refined during the coding process. Two independent raters applied the final coding system. Discrepancies between raters were discussed until consensus was reached.

Michigan's HIV disclosure law

Michigan has a particularly onerous HIV disclosure law. Enacted in 1988, the law requires HIV-positive serostatus disclosure prior to "sexual penetration" which is defined as anal, vaginal, and oral sex and "any other intrusion, however slight, of any part of a person's body or of any object into the genital or anal openings of another person's body".²³ There are no affirmative defenses in the law such as a provision for condom use which would decriminalize otherwise proscribed behavior. Violation of the law is a felony with a penalty of one or more years in prison.²⁴

Results

Several main themes emerged during the focus group discussions. The themes most often addressed included 1) perceived responsibility to prevent infection, 2) concern about unwanted secondary disclosure of HIV-positive status, 3) fear of being falsely accused of violating Michigan's HIV disclosure law, and 4) perceived vulnerability of HIV-positive persons within the US legal system. The following discussion outlines each of these themes.

Responsibility to prevent infection

Presumably, the goal of Michigan's HIV disclosure law is to prevent uninformed sex partners from becoming infected with HIV. Focus group members unanimously endorsed this goal and most went one step further--they believed that they had a moral obligation to protect all sexual partners (whether informed or uninformed) from contracting HIV. As one man said:

You're not only infecting that person, you're infecting that person and their future [partners]...so it's on your conscience that you have to use protection.

A female member of another focus group summarized the prevention ethic from her perspective. Even if an at-risk person requests unsafe sex,

...the [HIV] positive person should take the responsibility and say ‘Baby you be wearing a condom.’

A member of the third group was even more adamant. When asked how she would respond if an informed, at-risk partner wanted to have unsafe sex she said,

Don’t let the door hit you in the watchamacallit on your way out...

Most participants also believed that there was some duty to disclose one’s HIV-positive serostatus to prospective partners. As one man said, “There are certain things that people have that should be disclosed. It [HIV-positive status] should be disclosed.” A man in another group framed HIV-positive serostatus disclosure as a moral imperative:

You have a moral responsibility to let somebody know your situation so it won’t happen to them.

Note that this participant does not seem to distinguish between sero-positive status disclosure (letting “somebody know your situation”) and HIV transmission prevention efforts (making sure that “it won’t happen to them”). The participant may assume that once the infected partner has disclosed, the at-risk individual will take steps to avoid HIV transmission.

Although most participants agreed that HIV-positive persons have a duty to disclose their positive status to prospective sex partners, this duty was sometimes qualified by consideration of transmission risk to the partner. Noting that the Michigan law requires disclosure prior to activities that pose little risk to partners, a male participant said,

...even if it’s something as simple as me giving oral sex to somebody else I have to disclose... Well I do that anyway. I don’t need to be forced. But what you’re doing is you’re limiting what sexual activity’s gonna happen to me on occasions where it wouldn’t even matter. I’m at no risk to this person. By giving them oral sex there’s no need for me to disclose this to them...

This participant linked the duty to disclose with the risk of transmission. If the risk of the partner becoming infected with HIV is negligible, disclosure may not be necessary. Note however that this participant makes it a point to assert that he would disclose regardless of the law. He appears to resent the implication that he would not disclose unless required to do so.

Several participants acknowledged that while positive serostatus disclosure is a moral objective, behavior sometimes falls short of that standard in sexual situations. As one man explained,

...it’s a give and take situation. You have people that’s maliciously out here doing it and then you have these people that don’t feel comfortable revealing their status but at the same time knows the responsibility of having safer sex and not to infect their partners and all of that. That part of it is not being said. It [HIV-positive status

disclosure] is very hard for a person infected with HIV—people do it, some people can reveal their status. But it's hard for the average individual...

The participant drew a distinction between people who do not disclose and are attempting to expose others and people who do not disclose but practice safer sex. He suggested that while disclosure is preferable, nondisclosure when combined with safer sex may be an acceptable alternative. Again, however, nondisclosure with unsafe sex is unacceptable.

Perceived Negative Impact of Michigan's HIV Disclosure Law

As the quotes above illustrate, focus group participants were morally aligned with the purported purpose of Michigan's HIV disclosure law in that everyone believed that HIV-positive persons have a duty to protect others from HIV infection, and many endorsed serostatus disclosure to prospective partners as a personal and social norm. Importantly, however, participants objected to what they perceived as the negative impact of the law on persons living with HIV, including the possibility of unwanted secondary disclosure and being falsely accused of violating Michigan's disclosure law.

A central theme in the discussions was participants' perceived vulnerability to unwanted secondary disclosure by a prospective partner to whom they disclosed in compliance with the law. One man described his conundrum as follows:

You don't want your status known, right? So you tell the person you're gonna have sex with [that you have HIV]. They don't want to do it then, right? ...but then they tell everybody else 'He's got HIV.' You say 'Damn, I didn't want everybody to know. I was just trying to tell her because I wanted to have some sex and now she went and exposed my status...'

When participants discussed concerns about unwanted secondary disclosure they often imagined that the discloser would be someone who declined to have sex after the other's sero-positive status disclosure and then shared their private information with others. To many participants, the prospect of rejection was doubly uninviting--rejection could be emotionally difficult and could result in unwanted secondary disclosure.

Participants perceived the consequences of unwanted secondary disclosure as very serious. One man said,

...It's so easy to lose everything you've got because you disclose your information and then it goes like a domino ...and then what you gonna do? Can't get a job, can't get a girlfriend, can't do nothing.

Another man agreed:

Unless they totally understand the situation and are totally educated on the problem, both totally educated on the do's and don'ts of this problem, they'll say 'no' [to sexual activity] and then they'll go... 'He's got AIDS over here.' Then you gotta leave the state.

Participant concern about losing control over who is aware of their private health information was pervasive. From their perspective, one incident of unwanted secondary disclosure could lead to a catastrophic, nearly universal, breach of confidentiality.

Another, related theme in the focus groups was participants' perceived vulnerability to being falsely accused of violating Michigan's HIV disclosure law. Sexual activity and sero-positive status disclosure typically occur in private. There are often only two witnesses to the events--the HIV-positive person and the ostensibly HIV-negative partner--and there is likely to be little evidence with which to prove that the HIV-positive person indeed disclosed. Participants feared that the HIV disclosure law might be exploited by unscrupulous persons who would falsely accuse them of failing to disclose. A woman who was told about the law soon after being diagnosed with HIV recalled:

So when I became HIV-positive honestly after you figure it was a deadly disease as it was deemed to be and then you hear about this law the first thing--if you have sex with somebody even if you don't like them or however it goes they could just say 'Hey well that person gave me HIV.' And that was one of the things that stuck out in my head...

This participant recalls that one of the first things she noticed about the law was that it made HIV-positive persons vulnerable to false accusation. A male participant interrupted her to agree:

I started to hear about lawsuits, people accusing people falsely--threatening. And that made me look at the law and see what was really in there.

This participant reported becoming aware of lawsuits, or the threat of lawsuits, based on unfounded allegations that a person living with HIV failed to disclose his or her positive serostatus to a sex partner. From his perspective, Michigan's law (and fear of criminal penalty) provided leverage with which to exploit persons living with HIV.

Often participants' concerns about being falsely accused of violating the law centered around one or the other of two potential scenarios. In the first, the HIV-positive person discloses his or her status to a prospective sex partner who consents to engage in sexual activity but later becomes angry--perhaps after a bitter breakup--and accuses the infected person of not disclosing. As one female participant said,

"Yeah they're mad at you, [want to] get back at you, to spite you, things like that."

In the second scenario, the individual who falsely accuses the HIV-positive person of not disclosing may have little or no relationship with them. In this case a person finds out about the HIV-positive person's status by happenstance--perhaps after a prospective partner breaches the other's confidence--and then seizes an opportunity to profit at the HIV-positive person's expense by "suing" for nondisclosure. As one man described this scenario:

...you tell them [a prospective sex partner] your medical status and they say 'no' [to sexual activity] and then they tell everybody, then that messes up your confidentiality and then someone just... will say 'Hey I can get some money because everybody in the neighborhood know this so I'm gonna go to the prosecutor's office...'

Although this participant appears to misunderstand the distinction between criminal prosecutions, which rarely net monetary damages, and civil actions, which could net damages, his perception of vulnerability to legal action is clear.

Participants also considered the possibility that another HIV-positive person might falsely accuse them. In this scenario, the accusation would not only be that they did not disclose to the person, but that they also infected him or her. Again the motive could be spite:

You could make somebody angry just because you didn't sleep with them. They say 'Well you know what? He infected me.'

Or the motive could be profit:

...I feel like people will accuse you of things, they probably had [HIV] before you did and they'll go around and say you gave it to them just so they can get some money.

For a variety of reasons these "suits" would be unlikely to succeed, and it would be even less likely that the claimant would receive monetary damages if the suit were successful. Most participants from this generally low-income sample would be what is described as "judgment proof"--their lack of assets and income would make recovering a monetary judgment doubtful. Still, discussion about the possibility of someone falsely accusing them to gain profit emerged as a dominant theme in the focus groups.

Perceived Legal Vulnerability

Underlying participants' concern about being falsely accused of not disclosing their positive sero-status to others was their belief that they could not defend themselves against such accusations. Participants had little faith that if they were falsely accused of violating Michigan's HIV disclosure law, they would be treated fairly within the legal system. Participants were concerned that negative attitudes toward persons living with HIV might bias police and judges against them, making these authorities more likely to believe they had committed a crime. As a female participant explained, "There's a stigma that goes along with it [being HIV-positive] that's associated with criminal activity..." A male participant added, "[HIV infection is] associated with drug addiction. They think all people with HIV is a dope shooter."

Several participants perceived an animus toward persons living with HIV in the legal system--one that went beyond biased attitudes to include frank discrimination. One woman explained,

They [judges] believe in that stigma. They don't love us at all. They would love to see us locked up, and when the police arrest you they gonna call you all kind a nasty names...I believe the judges will definitely try to hang you.

Another woman concurred,

...they the ones who get you...and I would be scared to death if I let a judge I'm in front of know that I'm HIV positive.

A man shared much the same sentiment about police:

It doesn't matter who you run into, it's kinda what they think, if they're not educated [about HIV]. They have power to destroy your life anyway. They're gonna do it if they want to.

HIV disclosure laws are unusual in that the nature of the crime broadcasts to others that a person accused is infected with HIV. Participants feared being identified as HIV-positive in a criminal justice proceeding, making the prospect of being falsely accused of not disclosing to a prospective sex partner seem particularly perilous.

Inequitable Distribution of Burdens

Although participants believed that they had a moral duty to prevent sex partners from becoming infected with HIV, when it came to a law mandating sero-status disclosure, they wanted both sexual partners to be held accountable for HIV prevention. Participants objected to the law because they felt that the law distributed the burdens associated with HIV prevention inequitably. To participants' way of thinking, the law holds HIV-positive persons responsible for protecting the health of the at-risk partner who is required to do nothing. As one man said,

...where is the law of a person taking the responsibility for opening themselves up for sexual contact with another human being?...You're asking the law to protect you [the HIV-negative person] more than you protect yourself, okay?

From participants' perspectives, it seemed unfair that Michigan's HIV disclosure law requires HIV-positive persons to disclose without requiring anything of the ostensibly at-risk partner. The law appears to disregard the at-risk partner's abdication of personal responsibility when they did not insist on using condoms or initiate a conversation about HIV.

Compounding this sense of inequity is that fact that HIV-positive persons also must bear the burden of the disease. One participant wondered:

...who takes responsibility for the person who's negative? Where do they come in? I don't understand that. Why aren't they taking responsibility for their own self? It comes back to us who haven't had the touch, who've been destroyed financially, emotionally, physically, mentally, and those things are things that we crave that we've deprived ourself of.

This participant noted that HIV-positive persons not only bear the burden of the disease, they are also assigned the burden of prevention. Of particular irony is the fact that the law assigns responsibility for HIV prevention to the party most likely to be sexually deprived.

A related theme that emerged during the discussions was the sense that, while the law went to great lengths to protect the health interests of HIV-negative persons, the law did nothing to protect HIV-positive persons from the risks they incur when they conform to the mandate of the law and disclose--risks such as unwanted secondary disclosure and being falsely accused of not disclosing. Participants felt as if the law disregarded their interests:

Male Participant #1: There is no law that really protects us...

Male Participant #2: ...anybody in this room could say that I [infected them].

Male Participant #1: But yet we're supposed to take responsibility for someone else.

Male Participant #2: ...to protect those people, that's right.

Participants had much the same concern with regard to their risk of unwanted secondary disclosure:

If they gonna enforce the law about us having sex with people, they ought to enforce the law about if you tell somebody... like they said, we tell somebody and they say 'no [to engaging in sexual activity]' like he said, they gonna go tell everybody 'look he got AIDS.'

To participants, if the law requires people living with HIV to disclose sensitive information, the law should also protect them against unwanted secondary disclosure.

Ultimately, participants' accounting of the burdens and risks created by Michigan's HIV disclosure law led them to conclude that the state valued their interests less than the interests of those who did not have HIV. As one participant recounts,

It was explained to me that the reason that [they enacted the disclosure law] was because those that were not infected had the right to be protected from those who were infected.

This statement not only suggests that HIV-positive persons are dangerous to others (i.e. people need to be protected from HIV-positive persons), it suggests that the rights of those infected are subordinate to the rights of those who are (ostensibly) HIV-negative.

Discussion

Several interesting findings emerged from the focus group discussions. First, HIV-positive participants agreed with the ostensible purpose of Michigan's HIV disclosure law. Participants felt strongly that they had a duty to protect sex partners from infection. Many also felt that they had a duty to disclose their positive sero-status to sex partners, or in the absence of disclosure, to engage in only very low- to negligible-risk activities.

Second, participants felt vulnerable to HIV-related hostility and discrimination, especially in the criminal justice and court systems. Having HIV-infection was something that participants saw as a potential social and legal liability. Despite the ostensibly improved social climate for persons living with HIV in the US,²⁵ participants were reluctant to be widely identified as HIV-positive.

Third, participants felt that Michigan's HIV disclosure law inequitably distributed the burden of transmission prevention in sexual interactions (i.e. the HIV-negative partners are not assigned a role in protecting themselves) while overlooking the potential negative impact of the law on persons living with HIV. To participants, the law seems to imply that the interests of those who know they are infected are subordinate to those who are or believe they are uninfected.

Discussion of Michigan's HIV disclosure law seemed to heighten participants' perceptions of the social and legal vulnerability associated with having HIV. HIV-positive persons in Michigan are required to risk disclosure of their seropositive status even before engaging in very low- and even no-risk sexual activities, thus increasing the likelihood of rejection and unwanted secondary disclosure. Should a sexual/romantic liaison ensue, the prospect of a disgruntled partner falsely accusing the HIV-positive person of violating Michigan's HIV disclosure law loomed large. Participants also feared being exploited by persons who discovered their positive-serostatus by chance and might try to capitalize on their vulnerable position by falsely accusing them of violating the law. These fears of false accusation heightened participants' sense of the importance of keeping their positive serostatus confidential, yet being charged with violating the disclosure law would ensure that their positive serostatus would be known to justice officials who were perceived as biased against persons living with HIV.

It is also important to note, however, that some of the concerns brought up by participants are based at least in part on misunderstandings about the nature of proceedings in criminal and civil law. For example, several participants were concerned that, were they accused of violating Michigan's disclosure law, they could not prove they had disclosed to the partner. However under the Michigan statute, nondisclosure is an element of the crime; the prosecutor must prove that the HIV-positive person did not disclose, not vice versa. Other participants were concerned that they could be falsely accused of violating the disclosure law by someone seeking a monetary award. They did not seem to be aware that even if they were to have resources to attach in a suit, Michigan, like most states, bans suits for damages for infliction of emotional distress by "exposure" to HIV absent actual physical injury such as a viral transmission.²⁶ Many participants also seemed unaware of Michigan's HIV-specific confidentiality law,²⁷ which includes provisions addressing breach of confidentiality by a social contact.

Normative theories of legal compliance emphasize the importance of the law being seen as a respected institution by those whose behavior it attempts to regulate.²⁸ Perceptions of fairness and justice may determine more about an individual's satisfaction with a legal experience than the outcome of that experience.²⁸ Many persons living with HIV occupy marginal positions in society. The legal system may not be seen (and likely is not seen) as a positive social force for many persons living with HIV. As such, it is not surprising that participants support the law's HIV transmission prevention objective and yet object to law itself. When participants consider Michigan's HIV disclosure law, they see the potential the law creates to exacerbate their already socially and legally vulnerable positions in society.

As mentioned above, scholars have expressed serious concerns about applying criminal laws to address undisclosed exposure to HIV.^{13,14,15,16,17} HIV disclosure laws have the potential to exacerbate HIV-related stigma and discrimination and could complicate the already difficult decision to disclose to prospective sex partners. Findings from Dodds & Keogh's 2006 focus group discussions on the criminalization of HIV transmission in England and Wales¹⁸ suggest that these concerns are well-founded, and findings in the present study confirm these results. HIV-positive participants in both studies objected to the implication that HIV-positive persons should bear the sole burden of transmission prevention and

instead advocated for shared responsibility between partners. Participants in both studies also expressed concern about prosecutions based on less than truthful testimony or reliable evidence, and in both, concerns about discrimination in the judicial system were also expressed.

Additional research is needed to explore the impact of criminal HIV disclosure laws on the safer sex and disclosure behaviors of persons living with HIV. Key questions include whether HIV-positive persons living in states that have enacted HIV disclosure laws are more likely to disclose their sero-positive status to prospective sex partners than persons living in states without such laws. Comparisons of perceived HIV-related stigma and discrimination and comfort with seropositive status disclosure between HIV-positive persons living in states with and without HIV disclosure laws would also be instructive. Finally, little is known about the impact of disclosure laws on HIV-negative members of at-risk populations. Research should be conducted to determine whether awareness of a state's HIV disclosure law confers a false sense of protection and an abdication of responsibility for safer sex behavior among HIV-negative persons.

Acknowledgments

This research was supported by grants R21-MH073495 and P30-MH52776 from the National Institute of Mental Health. The authors thank Scott Burris, Mark Peterson, Steve Pinkerton, and Ralph Resenhoelt for their assistance.

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