Telling It Like It Is:
Disclosure of HIV Status
Peter Keogh

Much research emphasizes that for gay men, knowledge of one’s own and one’s partners HIV status is important in determining whether or not a condom is used for anal intercourse. That is, men are more likely to engage in unprotected anal intercourse with partners whom they know or believe to be the same HIV serostatus as themselves.¹,²,³

However, recent research on the sexual behavior of gay men diagnosed with HIV shows that this group engages in significantly more unprotected anal intercourse with both regular, casual, and anonymous sexual partners than do men who believe or know themselves to be uninfected.⁴ Thus, it is important to understand the roles that both knowledge of a partner’s HIV status and disclosure of one’s own play in influencing the sexual decision making of people with HIV.

Historically, however, most social scientific discourses on gay men with HIV attempted to explain sexual risk behavior in terms of factors within the individual rather than the interrelational contexts within which gay men live. Thus research has concentrated on psychological well-being, sexual dysfunction or psychosexual morbidity, or the effects of treatments on sex.⁵

More recently social science research has begun to investigate the relational, social, and cultural factors in sexual decision making.¹,⁶,⁷ This article is based on British research in this area, highlighting the role of disclosure in determining the nature of sexual encounters.

Using the voices of the men who took part in the research to illustrate points, this article demonstrates how concerns about disclosure of a seropositive HIV status to sexual partners generates considerable anxiety among those who disclose, especially among those who have been recently diagnosed. It also shows how such difficulties lead to the creation of more fluid notions of disclosure. Most importantly, this article raises questions regarding what constitutes disclosure and knowledge and emphasizes that disclosure is a relational as opposed to individual activity.⁸

Researchers observed 90 men participating in 10 groups. The mean age of the sample was 31 years (with a range of 21 years old to 54 years old). Seventy-eight men were White European, eight were White non-European. Two men were African Caribbean and one each was African and Asian. The mean number of years since an HIV diagnosis was two-and-a-half (with a range from three months to nine years). Eight men had an AIDS diagnosis.⁸

The Anxiety of Telling

Many men reported a new anxiety towards sex in the period following diagnosis. Along with concerns about responsibility for the safety of a sexual encounter—that is, concerns about infecting sexual partners—disclosure was at the center of this anxiety. Difficulties in disclosing HIV status to potential partners arose because men experienced their partners’ reactions as problematic. First, they feared sexual rejection. Many men had experienced this rejection—although the anticipation of it was perceived as more damaging than actual rejection.

Then, after all that chatting up and effort, having to anticipate the worst automatically, that this one might just be the one who will throw a real wobbly . . . to prepare yourself for that every time you
So here's a confession: I have trouble talking about sex. I'm fine talking about condom use and anal receptive sex and vaginal intercourse and can even comfortably apply the vernacular. I guess what I mean is that I'm fine talking about other people's sex. But talking to a partner of mine about sex is another matter, and I am more than a little bit surprised that I am willing to admit in this editorial.

I know that other people—people I know—have similar inhibitions. This fact helps me muster the courage to continue writing, but I don't think it helps much else.

I must admit that there were times earlier in the epidemic when, wondering in the moment of sex about the serostatus of a partner, my restraint stopped me from asking this most pertinent question. If I was being safe, it should not have mattered, right? Right. But somehow, I think it strange that I could be so tight-lipped about such a fundamental topic.

I haven't forgotten all the political and civil rights arguments to maintain the secrecy of serostatus: everything from discrimination to viral apartheid loomed and continue to loom. Still, it must say something about the nature of our relationships and ourselves—irrespective of these real dangers—that some of us have trouble telling it like it is and others of us have trouble hearing these truths.

I have sex. I used to really enjoy cruising, you know, the chase, but this just wears you down.

Even when potential partners responded positively to a disclosure, this response was not always welcome: for example, disclosure might lead to an inordinate interest from sexual partners in the study participant's HIV disease. Respondents reported having to field inquiries about their general state of health and whether their friends had died. This was experienced as an invasion of privacy or as simply distressing, particularly during an encounter that was supposed to be enjoyable and sexual. One man said: "You spend the whole evening talking about being sick and people dying. They don't seem to want to know anything about you, just your HIV. It's really rather depressing, like you're a freak or something."

However, if a man did not disclose his HIV status to sexual partners, he felt that he had to take complete responsibility for the safety of the sexual encounter. The greatest fear in this context was accidentally infecting a partner, either through a faulty or broken condom or through oral sex (men were particularly worried about ejaculating in the mouth of their partners or the infectivity of their pre-ejaculate). For example, one man asked: "What if the condom breaks and you don't notice? What do you tell him after if you haven't told him you're HIV [seropositive] already? There's no way to tell him then."

Respondents also worried about the effects of alcohol or drugs on their own or their partners' ability to make judgments. In addition, they feared recriminations from sexual partners who might subsequently find out that they were HIV positive—even if the encounter had been safe. In limited social networks of gay men, this possibility is very real.

My history is that a lot of people I sleep with are friends of friends. They're people I know. I mean a lot of my gay friends have become friends of mine usually after we've had sex and so that if I don't tell them and they discover from somebody else, then, you know, that becomes a barrier, so I need to tell people, but I'm scared.

Finally, respondents were worried that if a casual sexual encounter resulted in a friendship or relationship, which many desired, it would be jeopardized when they subsequently disclosed their HIV status. This feeling of responsibility and secrecy was experienced by many as a barrier to intimacy and made sexual encounters stressful.

I'd like to think that I'll fall in love again, and you think, now, where does that happen? It happens between the sheets or over break-
Perceptions of a partner’s attitudes and HIV status will be important in determining how a person discloses his or her HIV status.

Within long-term relationships, full disclosure was generally the norm. This may have been because both partners had tested seropositive or may it may have happened at the outset or shortly after the start of a relationship. However, as noted above, difficulties with disclosure were often an inhibiting factor in starting a relationship.

In casual encounters disclosure and knowledge of HIV status was sometimes established through conversation before the sexual encounter, but, more often, was established on the second or third encounter. In this case, both partners were diagnosed with HIV and arranged to engage in unprotected anal intercourse. As one respondent put it: “One of us usually suggests it after we’ve had sex the first time that the next time we should do it unsafely. It’s never a long discussion, it’s a quick thing really. But the first time, it’s always safe, because you have to agree first.”

While the importance of disclosure is clear, the definition is often not. For example, some men would disclose or assess their partner’s likely HIV status in more subtle ways, often dropping clues regarding their HIV status and basing their action on available evidence. Thus, they might use common understandings to indicate HIV status, rather than overtly disclose. Two examples demonstrate this approach:

I like to sit and listen to how they are talking, sometimes they give themselves away by general chit-chat, you know, you can tell.

I didn’t have to tell him, I knew by the person he was and the things we were talking about [acquaintances in common, being unemployed and on state benefits] that he was positive and I assumed he knew it about me.

Respondents also used inferential reasoning in anonymous sexual encounters. In some cases, assumptions of a partner’s likely HIV status was based on how he looked or on his behavior. For example, sometimes assumptions were based merely upon the fact that a partner was willing to engage in unprotected anal intercourse. One respondent talks of encounters in a backroom: “Everyone knows I’ve got it [HIV]. . . . How I look at it is if someone wants me to screw them in the back room, they must be HIV [positive] otherwise they are bloody stupid.”

Informed Sexual Practice

Although the necessity to disclose can generate anxiety and conflict, it is also used to inform sexual practice, mainly with regard to unprotected anal intercourse. Most interesting in this respect is the question of what can reasonably be considered disclosure of one’s own, or knowledge of one’s partner’s HIV status for gay men diagnosed with HIV.

The bald statement of fact “I’m HIV positive” not only gives a partner the chance to reject outright, but in many ways, is simply inappropriate. Within casual sexual encounters, it involves the exchange of what might be considered private information with relative strangers. In more romantic situations, disclosure may break the mood, and in anonymous situations, verbal interaction may contravene social rules.

The problem of disclosure is dealt with through the development of more subtle methods of communication based on conversation or behavior (for example, discussion or knowledge of HIV treat-
Clearinghouse: Disclosure

References


It's Saturday morning. I'm flipping through my local gay and lesbian weekly newsletter, half awake, and I run into a two-page ad jumping out of the text. It talks about recent findings from the AIDS conference in Geneva: an HIV-negative man has been infected with a drug resistant strain of HIV. People who are HIV-positive are at risk for being reinfected with new, drug resistant strains, and on and on.

My heart is beating faster. See, my boyfriend David is HIV-positive, and I'm not. He's just told me a couple weeks ago that he's been fucking and getting fucked with another guy with HIV, and they're not using condoms. He knows it's risky but he says he's "been good all these years" and feels he "deserves it."

In addition, David's been having sex with another guy, Matt, who is HIV-negative, and he's been letting Matt fuck him without a condom. He says it's Matt's decision, and that Matt is not too worried. He says also that Matt has been fucking his HIV-positive ex-lover for many years without a condom and has remained negative.

It's His Decision

I was a bit dazed. I said, "How could you do this when you know Matt's putting himself at risk?" "It's Matt's decision," David responded. "Yeah, but you're there, too. You are part of the decision."

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"Yeah, but you’re there, too. You are part of the decision."
It's important to know that all of this is taking place in the context of our attempts to resolve other issues in our relationship. We are taking six weeks off from each other, except for letters, to figure out where we want to go. I had been composing lots of different (and long) letters examining all the aspects of our relationship and what I want and where I think we should be heading. But then I woke up in the middle of the night terrified about him having sex without a condom with someone with HIV. Everything else going on with us sort of paled.

Just Stop It!

So I wrote him a short, strong letter telling him to stop it. I told him if he didn't stop, I was going to call every friend he has and tell them to call him and make him stop. This isn't about us as a couple, it's about me caring for him and wanting him to stay healthy.

Well, predictably, the letter didn't go over too well. He said he was touched by my concern and angry at being told what to do. He acknowledged the risk but said he didn't regret his actions. He said he will have to decide what to do on his own.

He's not someone who likes to be backed into a corner—which is just what my letter did. After reading his response, I felt bad; I had handled it poorly. I know how I could have phrased that letter so he would have felt like he had space, felt my concern, and been more likely to say, “You’re right, I need to think more about what I am doing here.”

But I just couldn't imagine writing a balanced, dispassionate letter when my lover is putting himself at risk like that. What I really wanted to say was, “Are you crazy!? Stop it now!”

I say this is just about me caring about him, but it is about us as a couple too. I want to know my partner cares about his health. And I want a partner who considers the relationship when making what could be life-and-death decisions.

There is, of course, another issue to all of this. David is having what seems to be the most intimate kind of sex you can have, and he's doing it with someone other than me. He says “he really wants that” with me, but knows he can't have it; we both agree on that. It makes me sad. I guess I'd like that with him too. Frankly, I have been so immersed in safer sex education for so many years I have refused to even let that part of my desire surface.

Saturday Morning

So, the question for me this Saturday morning is, do I mail him this AIDS Foundation ad? It may have new information he doesn't know (I hadn't heard about the case they referred to). It may piss him off and make him even more resistant to my concerns. But I decide not to send it. He gets POZ and BETA and all those other publications about living with HIV. I hope this information will get to him soon. I don't think I am the best messenger right now.

What I want him to know is that I love him and that I want us to be together for a long, long time. I know he feels the same about me. I want him to keep all of that in mind when he's making decisions about what kind of sex he's going to have. I can't force him to do anything, but I can keep reminding him that we have a really sweet future to live together—maybe that's a message that really will sink in.
Determinants of Disclosure
Disclosure of HIV-positive status to partners. Archives of Internal Medicine. 1998; 158: 253-257. (Brown University; Boston University School of Medicine and Public Health; and Boston Medical Center.)

Recently infected people with one sexual partner are 3.2 times more likely to disclose their HIV status than people with multiple partners, according to a study of determinants of disclosure among 203 urban hospital patients.

Researchers recruited patients who had received primary care for HIV for the first time from the HIV clinics at Boston City Hospital and Rhode Island Hospital. Sixty-nine percent of the patients were male, 46 percent were Black, 27 percent were White, and 23 percent were Latino. Forty-one percent reported that their primary risk activity was injection drug use, 39 percent became infected through heterosexual sex, and 20 percent were homosexual or bisexual men; 64 percent reported having sexual partners during the prior six months. The mean age of the sample was 36.

Sixty percent of the study's participants had disclosed their HIV infection to all of their sexual partners. Of the 99 subjects who were married or in primary relationships, only 12 percent had not disclosed their serostatus to that person. The most commonly cited reasons for failing to inform primary partners were beliefs among subjects that doing so would be too stressful, that it would cause partners to leave, that they needed to deal with their own emotions regarding HIV first, or that their partner could not handle the emotional impact of the disclosure.

Notably, participants with high levels of spousal support were 2.8 times more likely to disclose their serostatus than those without spousal support. Yet, participants reporting low levels of support from friends were 2.7 times more likely to disclose than others.

White and Latino participants were 3.1 times more likely to disclose their serostatus than Black participants. Women were 2.4 times more likely to disclose than men. Twenty-one percent of participants with one sex partner had not disclosed their serostatus to that person, and 58 percent of those with two or more partners had not disclosed their status to all of them.

HIV-Infected Women and Fears of Disclosure

A preliminary study of 50 seropositive women found that 76 percent experienced acceptance, support, and understanding upon disclosure of their HIV status to partners, family members, or friends. While 62 percent of the women feared rejection, discrimination, and violence prior to disclosure, only 22 percent experienced negative outcomes such as these.

At an urban clinic in Baltimore, researchers interviewed women between the ages of 16 and 45 about disclosure experiences. Eighty-six percent of the subjects were African American, 66 percent were unemployed, and 88 percent were unmarried. Fifty percent of the women said they had been infected through heterosexual transmission, and 56 percent reported previous or current injection drug use.

The researchers recorded and transcribed responses to six open-ended questions, and then developed categories for classifying statements. At the time of the interview, 98 percent of the participants had disclosed their HIV status to at least one person; 82 percent had disclosed to more than one person. Twenty-two percent of the women experienced rejection, abandonment, or shame upon disclosing their HIV status. Two women reported violence as a result of disclosure.

Disclosure as a Coping Mechanism
Holt R, Court P, Vedhara K, et al. The role of disclosure in coping with HIV infection. AIDS Care. 1998; 10(1): 49-60. (The University, Newcastle upon Tyne; Bristol Royal Infirmary; North Yorkshire Health Authority; and Newcastle General Hospital.)

Disclosure of HIV infection can be both a source of stress and a primary coping mechanism, according to a British study of disclosure to friends, family, and sexual partners. Subjects who had recently been diagnosed with HIV tended to delay disclosure in order to come to terms with the news of their infection. However, disclo-
Researchers recruited gay or bisexual men from HIV treatment centers, hospital clinics, and commercial establishments frequented by gay men. Ninety-eight percent of participants were White, and 73 percent reported being in a primary sexual relationship. Seventy-three percent reported regular alcohol consumption; 60 percent used recreational drugs weekly and 79 percent of these used marijuana. Fifty percent were asymptomatic, 33 percent were symptomatic, and 18 percent had an AIDS diagnosis. Ages ranged from 20 years old to 53 years old.

During private interviews, all 40 participants reported that disclosure of HIV infection had been a major source of stress. Although some men sought support from other HIV-infected people immediately after receiving their antibody test results, the majority delayed disclosure to partners, family, and friends. In a few cases, men disclosed simultaneously both their sexuality and their HIV status to their families. Others anticipated negative responses from families and decided not to disclose. Most men with symptomatic HIV disease or AIDS disclosed only to their families and close friends. Some felt that poor health and subsequent changes in their physical appearances left them no choice but to disclose.

The Responsibility to Disclose

A comprehensive review of the discourse on sexual responsibility found that public opinion has shifted from widespread support of the belief that people are responsible to protect themselves through their own condom use to the currently popular belief that HIV-infected people should protect their sexual partners by disclosing their HIV status. Early in the epidemic, there were three objections to the idea that HIV-infected people have a duty to disclose their serostatus. First, because people may misrepresent their serostatus, many people would fail to protect themselves with partners they believe to be uninfected. According to this argument, if everyone protected themselves by using condoms, there would be no false sense of security and no need to disclose HIV status.

Second, because people who consent to unprotected sex knowingly place themselves at risk, an HIV-infected person should have no obligation to disclose his or her serostatus; becoming infected in this way was analogous to a self-inflicted injury. Proponents of the “self-protection” model also feared that a moral duty to protect partners would lead to criminalization of unsafe sex.

Finally, the responsibility to disclose was seen as a violation of the right to privacy, and further, commentators feared that forced disclosure would cause division, single out infected people, and create an atmosphere of “viral apartheid.”

By the early 1990s, the self-protection model was seen as inadequate, particularly for women, many of whom could not impose condom use on their male partners, and for young gay men. The self-protection model also did not address psychological issues that may inhibit safer sex practices, such as denial about a partner’s risks and relapse into unsafe sex. In addition, the possibility of condom misuse and breakage increased the perceived importance of disclosure. In response to these concerns, safer sex in conjunction with self-disclosure became widely accepted.
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