HIV disclosure as practice and public policy

Barry D. Adam
University of Windsor

Follow this and additional works at: https://scholar.uwindsor.ca/socanthpub

Part of the Sociology Commons

Recommended Citation
https://scholar.uwindsor.ca/socanthpub/7

This Article is brought to you for free and open access by the Department of Sociology, Anthropology and Criminology at Scholarship at UWindsor. It has been accepted for inclusion in Sociology, Anthropology, and Criminology Publications by an authorized administrator of Scholarship at UWindsor. For more information, please contact scholarship@uwindsor.ca.
November 2014

HIV disclosure as practice and public policy
HIV disclosure as practice and public policy

Barry D. Adam\textsuperscript{ab}, Patrice Corriveau\textsuperscript{c}, Richard Elliott\textsuperscript{d}, Jason Globerman\textsuperscript{b}, Ken English\textsuperscript{e} & Sean Rourke\textsuperscript{fb}

\textsuperscript{a} Department of Sociology, Anthropology and Criminology, University of Windsor, Windsor, Canada
\textsuperscript{b} Ontario HIV Treatment Network, Toronto, Canada
\textsuperscript{c} Department of Criminology, University of Ottawa, Ottawa, Canada
\textsuperscript{d} Canadian HIV/AIDS Legal Network, Toronto, Canada
\textsuperscript{e} AIDS Bureau, Ontario Ministry of Health and Long Term Care, Toronto, Canada
\textsuperscript{f} Department of Psychiatry, University of Toronto, Toronto, Canada

Published online: 14 Nov 2014.

To cite this article: Barry D. Adam, Patrice Corriveau, Richard Elliott, Jason Globerman, Ken English & Sean Rourke (2014): HIV disclosure as practice and public policy, Critical Public Health, DOI: 10.1080/09581596.2014.980395

To link to this article: http://dx.doi.org/10.1080/09581596.2014.980395

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the “Content”) contained in the publications on our platform. Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Versions of published Taylor & Francis and Routledge Open articles and Taylor & Francis and Routledge Open Select articles posted to institutional or subject repositories or any other third-party website are without warranty from Taylor & Francis of any kind, either expressed or implied, including, but not limited to, warranties of merchantability, fitness for a particular purpose, or non-infringement. Any opinions and views expressed in this article are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor & Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages,
and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Terms & Conditions of access and use can be found at http://www.tandfonline.com/page/terms-and-conditions

It is essential that you check the license status of any given Open and Open Select article to confirm conditions of access and use.
HIV disclosure as practice and public policy

Barry D. Adam\textsuperscript{a,b,*}, Patrice Corriveau\textsuperscript{c}, Richard Elliott\textsuperscript{d}, Jason Globerman\textsuperscript{b}, Ken English\textsuperscript{e} and Sean Rourke\textsuperscript{f,b}

\textsuperscript{a}Department of Sociology, Anthropology and Criminology, University of Windsor, Windsor, Canada; \textsuperscript{b}Ontario HIV Treatment Network, Toronto, Canada; \textsuperscript{c}Department of Criminology, University of Ottawa, Ottawa, Canada; \textsuperscript{d}Canadian HIV/AIDS Legal Network, Toronto, Canada; \textsuperscript{e}AIDS Bureau, Ontario Ministry of Health and Long Term Care, Toronto, Canada; \textsuperscript{f}Department of Psychiatry, University of Toronto, Toronto, Canada

(Received 18 September 2013; accepted 11 October 2014)

Responses to the largest surveys of HIV-positive people in Ontario show that most either disclose to or do not have partners who are HIV-negative or of unknown status. Non-disclosure strategies and assumptions are reported by relatively small sets of people with some variation according to employment status, sexual orientation, gender, ethnicity, and having had a casual partner. Interviews with 122 people living with HIV show that disclosure is an undertaking fraught with emotional pitfalls complicated by personal histories of having misread cues or having felt deceived leading up to their own seroconversion, then having to negotiate a stigmatized status with new people. In gay communities, constructions of the self as individual actors in a marketplace of risk co-exist with the sexual etiquette developed throughout the AIDS era of care of the self and other through safer sex. Among heterosexual populations, notions of responsibility show some divergence by gender. The findings of this study suggest that the heightened pressure of criminal sanction on decision-making about disclosure in personal interactions does not address difficulties in HIV transmission and is unlikely to result in enhanced prevention.

Keywords: criminalization; disclosure; HIV

The objective of this study is to characterize the prevalence and correlates of sero-status disclosure among a sample of HIV-positive individuals in Ontario and to look behind the numbers to their own characterizations of expectations and responsibility to disclose. The results of this inquiry point to a disjuncture between the practicalities of disclosure in everyday life and the somewhat abstracted vision of the rational actor envisioned in court decisions requiring near universal disclosure in sexual interactions. It is a disjuncture that reveals how enforcement of the rational actor model of human behavior may run at cross-purposes to effective HIV prevention.

In recent years, the question of disclosure of HIV status to prospective sexual partners has risen in prominence in Canada, largely as a result of court decisions and media attention given to those decisions. While AIDS service organizations have long relied on the promotion of a safer sex ethic that cautions everyone to take responsibility for HIV prevention through protected sex, the demand for disclosure of sero-status has tended to shift responsibility for HIV prevention more toward HIV-positive people to

\*Corresponding author. Email: adam@uwindsor.ca

© 2014 The Author(s). Published by Taylor & Francis.

This is an Open Access article. Non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly attributed, cited, and is not altered, transformed, or built upon in any way, is permitted. The moral rights of the named author(s) have been asserted.
warn prospective partners in advance of a sexual interaction. This shift has become especially acute in Canada, where in the 2000s, a rising number of high-profile prosecutions of HIV-positive people for not disclosing or exposing partners to potential HIV infection has brought the question of disclosure into the public sphere (Mykhalovskiy & Betteridge, 2012). In 1998, the Supreme Court of Canada established in R. v. Cuerrier that HIV-positive people must disclose their sero-status in situations of ‘significant risk of serious bodily harm’ (Elliott, 1999; Symington, 2009). In 2012, the same court specified a very restrictive standard by ruling, at least in the case of vaginal sex, that HIV-positive people are relieved of the obligation to disclose under the criminal law only when they use a condom and have a ‘low viral load’ (Canadian HIV/AIDS Legal Network, 2012). It is in this changing social and legal context that this study set out to investigate the views of HIV-positive people on their own expectations and practices regarding disclosure in everyday life.

A growing research literature on the criminalization of HIV has pointed out a range of negative consequences, most notably arbitrary and differential enforcement, heightened stigmatization of HIV-positive people, lack of deterrent effect, and potential discouragement of HIV testing (Galletly, Lazzarini, Sanders, & Pinkerton, 2014; Galletly & Pinkerton, 2006; Lazzarini, Bray, & Burris, 2002; O’Byrne, Bryan, & Roy, 2013). In addition, studies of disclosure practices have found that the pressure of criminalization may not increase actual disclosure in practice nor increase safer sex practice (O’Byrne, 2011; Simoni & Pantalone, 2004). While some may disclose more, others become less open about their HIV status (Dodds, Bourne, & Weait, 2009, pp. 141–142), rely on indirect disclosure or ‘subtle cues or inferences’, make presumptions about sexualized settings like bathhouses, or read consent to unprotected sex as evidence of sero-positivity (Adam, Husbands, Murray, & Maxwell, 2008; Bourne, Dodds, Keogh, Weatherburn, & Hammond, 2009; Serovich, Oliver, Smith, & Mason, 2005). The findings of this study suggest that the heightened pressure of criminal sanction on decision-making about disclosure in personal interactions does not address difficulties in HIV transmission and is unlikely to result in enhanced prevention.

Methods

The findings reported here draw on answers to questions added to the two major cohort studies of HIV-positive people in Ontario, the Ontario HIV Treatment Network Cohort Study (OCS) (http://www.ohtncohortstudy.ca/) (N = 959) and the Positive Spaces, Healthy Places cohort study (PSHP) (http://www.pshp.ca/) (N = 442) plus in-depth qualitative interviews with 122 OCS participants. Drawing from all three data sources allows for broad representation of people living with HIV in accord with the epidemiology of HIV prevalence in Ontario as measured by risk group, age, gender, sexual orientation, and ethno-cultural origin. Of the 122 interviews, 8 were conducted in French in Ottawa, the rest being in English in Toronto (N = 93) and Ottawa (N = 21) where 83% of HIV-positive people in Ontario live. Ten interviews were with people who had some kind of direct experience with the criminal justice system either as complainants, defendants (including some who were convicted of charges related to non-disclosure or exposure to HIV), or former sex partners contacted by police for testimony in HIV-related trials.

The cohort surveys asked study participants about their expectations of casual sexual partners to disclose to them and then of their own disclosure practices with partners. As well, they were asked about their own reasons for disclosing or not disclosing. The pattern of response was then analyzed for variation by a range of demographic categories:
age, ethnicity, language of interview, income, education, sexual orientation, gender, as well as having had a casual sexual partner in the previous three months.

A subset of OCS study participants, broadly representative of the demographics of HIV prevalence in Ontario, were then invited to be interviewed to gain further insight into perceptions of disclosure expectations and responsibilities. Questions asked about recent sexual interactions and the circumstances leading to (non)disclosure, as well as a subsequent specific question, There is a lot of debate about people’s responsibility to disclose their HIV status. Do you think there are circumstances when someone with HIV should be charged with a crime, and perhaps sent to prison, for (a) having oral sex without a condom without telling?, (b) for having unprotected vaginal or anal sex without telling sexual partners he or she has HIV beforehand?, (c) for having unprotected sex with an undetectable viral load? Interviews were transcribed and examined for common themes using constant comparative analysis with NVivo software.

The study proposal was reviewed in accord with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans by research ethics boards at the University of Windsor and the University of Ottawa. A community advisory committee with representatives from HIV-positive people, AIDS service, and legal organizations plus the provincial ministry of health assisted the development of the research project. An honorarium of $30 was provided to interview participants in recognition of time and travel expenses.

Table 1. Demographic characteristics of study participants.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>OHTN Cohort Study</th>
<th>PSHP Cohort Study</th>
<th>Qualitative interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>772 (80.7%)</td>
<td>323 (74.1%)</td>
<td>102 (74.1%)</td>
</tr>
<tr>
<td>Female</td>
<td>185 (19.3%)</td>
<td>107 (24.5%)</td>
<td>19 (25.9%)</td>
</tr>
<tr>
<td>Transwoman</td>
<td>4 (&lt;.01%)</td>
<td>6 (1.4%)</td>
<td>1 (.8%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–29</td>
<td>42 (4.4%)</td>
<td>6 (1.4%)</td>
<td>2 (1.6%)</td>
</tr>
<tr>
<td>30–39</td>
<td>113 (11.8%)</td>
<td>67 (16.0%)</td>
<td>17 (13.9%)</td>
</tr>
<tr>
<td>40–49</td>
<td>369 (38.5%)</td>
<td>195 (46.7%)</td>
<td>52 (42.6%)</td>
</tr>
<tr>
<td>50–59</td>
<td>315 (32.8%)</td>
<td>117 (28.0%)</td>
<td>36 (29.5%)</td>
</tr>
<tr>
<td>60+</td>
<td>120 (12.5%)</td>
<td>33 (7.9%)</td>
<td>15 (12.3%)</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay/homosexual</td>
<td>542 (56.9%)</td>
<td>222 (52.4%)</td>
<td>79 (64.8%)</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>334 (35.1%)</td>
<td>172 (40.6%)</td>
<td>36 (29.5%)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>76 (8.0%)</td>
<td>26 (6.1%)</td>
<td>7 (5.7%)</td>
</tr>
<tr>
<td>Ethno-racial identification</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>621 (64.8%)</td>
<td>322 (72.9%)</td>
<td>83 (68.0%)</td>
</tr>
<tr>
<td>African/Caribbean</td>
<td>206 (21.5%)</td>
<td>56 (12.7%)</td>
<td>24 (19.7%)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>36 (3.8%)</td>
<td>56 (12.7%)</td>
<td>10 (8.2%)</td>
</tr>
<tr>
<td>Asian, Latin American, Middle Eastern</td>
<td>96 (10.0%)</td>
<td>8 (1.8%)</td>
<td>10 (8.2%)</td>
</tr>
<tr>
<td>no response</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$20,000 per year</td>
<td>407 (43.3%)</td>
<td>299 (70.0%)</td>
<td>62 (52.8%)</td>
</tr>
<tr>
<td>$20,000–39,999</td>
<td>214 (22.8%)</td>
<td>87 (20.4%)</td>
<td>31 (25.4%)</td>
</tr>
<tr>
<td>$40,000-</td>
<td>319 (33.9%)</td>
<td>41 (9.6%)</td>
<td>29 (23.8%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>304 (31.7%)</td>
<td>189 (43.0%)</td>
<td>42 (35.0%)</td>
</tr>
<tr>
<td>Trade/college/some university</td>
<td>371 (38.7%)</td>
<td>180 (41.0%)</td>
<td>39 (32.5%)</td>
</tr>
<tr>
<td>University or post-graduate degree</td>
<td>284 (29.6%)</td>
<td>71 (16.1%)</td>
<td>39 (32.5%)</td>
</tr>
</tbody>
</table>
Demographic characteristics

Overall, study participants from the three data sources have the following demographic characteristics shown in Table 1.

Expectations regarding disclosure by partners

Questions added to the two large cohort studies show the expectations of people living with HIV regarding their disclosure to sexual partners and partners’ disclosure to them (Table 2).

Generally the expectation that casual partners will disclose is not high. Since OCS study participants could check off more than one rationale regarding the decision to disclose, the pattern of multiple responses was also examined. The most frequent overlap of responses was 15 of those who indicated it was not necessary to tell a partner because they had protected sex, also checked off that they tell some partners that they were HIV-positive but not others.

Statistical analysis (Pearson $\chi^2$) of the PSHP data reveals some variation in attitudes and practices in different populations. Overall 18.3% do not expect a sexual partner to disclose HIV status but this varies by sexual orientation with gay men having less expectation (26.7%), followed by bisexual men (23.1%), heterosexual men (10.0%), and finally heterosexual women having the greatest expectation that sexual partners will disclose (5.1%) ($p = .015$). The OCS data show a similar pattern but with even higher

Table 2. Disclosure practices and expectations.

<table>
<thead>
<tr>
<th>I expect a casual sexual partner to tell me if he or she</th>
<th>PSHP $(n = 438)$</th>
<th>OCS $(n = 959)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is HIV-negative</td>
<td>112 (26%)</td>
<td>191 (20%)</td>
</tr>
<tr>
<td>Is HIV-positive</td>
<td>215 (49%)</td>
<td>390 (41%)</td>
</tr>
<tr>
<td>Is unaware of their HIV status</td>
<td>85 (19%)</td>
<td>189 (20%)</td>
</tr>
<tr>
<td>I do not expect my casual sex partner to tell me about their HIV status</td>
<td>79 (18%)</td>
<td>278 (29%)</td>
</tr>
<tr>
<td>I do not have a casual sex partner</td>
<td>237 (54%)</td>
<td>361 (38%)</td>
</tr>
</tbody>
</table>

Concerning HIV-negative partners and partners whose HIV status I did not know, with whom I had anal or vaginal sex in the last six months (please check all that apply):

<table>
<thead>
<tr>
<th>PSHP</th>
<th>OCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I told of all my partners that I am HIV-positive</td>
<td>196 (45%)</td>
</tr>
<tr>
<td>I did not tell any of my partners that I am HIV-positive</td>
<td>24 (5%)</td>
</tr>
<tr>
<td>I told some of my partners that I am HIV-positive and did not tell others</td>
<td>38 (9%)</td>
</tr>
<tr>
<td>I dropped hints that I could be HIV-positive</td>
<td>20 (5%)</td>
</tr>
<tr>
<td>I didn’t feel it was necessary to tell my partner(s) because we had protected sex</td>
<td>41 (9%)</td>
</tr>
<tr>
<td>I didn’t feel it was necessary to tell my partner(s) because they should presume everyone is positive</td>
<td>20 (5%)</td>
</tr>
<tr>
<td>I didn’t feel it was necessary to tell my partner(s) because they were willing to have unprotected sex</td>
<td>20 (5%)</td>
</tr>
<tr>
<td>I didn’t feel it was necessary to tell my partner(s) because it is their responsibility to use a condom if they want to</td>
<td>14 (3%)</td>
</tr>
<tr>
<td>I was afraid to tell my partner(s) I was HIV-positive</td>
<td>17 (4%)</td>
</tr>
<tr>
<td>I did not have an HIV-negative partner or partner(s) whose HIV status I did not know</td>
<td>26 (6%)</td>
</tr>
</tbody>
</table>
numbers of gay men not expecting disclosure: gay men (40.2%), bisexual men (27.6%), heterosexual men (11.5%), and heterosexual women (10.7%). This same variation is evident by ethnicity where a greater proportion of African, Caribbean, and Aboriginal populations are female or heterosexual when compared to white study participants. The expectation that sexual partners will not disclose is 20.3% among white people, 11.1% among African and Caribbean people, and 8.9% among Aboriginal people ($p = .048$). For the OCS, the comparable numbers are 33.3% among white people, 17.0% among African and Caribbean people, and 25.0% among Aboriginal people ($p < .01$).

With HIV-negative partners and partners of unknown HIV status, 44.7% of PSHP respondents told all partners that they are HIV-positive, while 32.4% had no partners of this type (48% of OCS respondents report no partners who were HIV-negative or of unknown status). Between 1 and 9% report alternative strategies to disclosure, including not telling any partners, telling some partners, and dropping hints about HIV status. Others feel it is unnecessary to tell because they had protected sex, because partners should presume everyone is positive, because a partner was willing to have unprotected sex, or because it is a partner’s responsibility to use a condom if he or she wants to. Between 3 and 6% report being afraid to disclose they have HIV. Unemployed respondents in the PSHP cohort are more likely not to disclose (10.3%, $p = .008$), to drop hints (8.5%, $p = .016$), to feel disclosure is unnecessary with protected sex (15.4%, $p = .009$), and to be afraid to disclose (21.4%, $p = .003$). Gay and bisexual men are a little more likely to disclose to only some partners (bisexual 19.2%, gay 11.3%, $p = .020$), to drop hints (gay 7.2%, $p = .047$), and to feel disclosure is unnecessary with protected sex (12.0%, $p = .031$). Compared to those without casual partners, respondents with casual partners are more likely to tell only some partners (13.9%, $p < .0001$), feel it is unnecessary to disclose with protected sex (16.4%, $p < .0001$), feel it is unnecessary to disclose because a partner should presume everyone is positive (8.0%, $p = .002$), because a partner is willing to have unprotected sex (5.5%, $p = .013$), or because it is a partner’s responsibility to use a condom (7.5%, $p < .0001$). This finding is comparable to a recent study in British Columbia that found lower rates of disclosure among those reporting sex with a stranger (Hirsch Allen et al., 2014).

Most HIV-positive people in this survey, then, either disclose to, or do not have, partners who are HIV-negative or of unknown status. Non-disclosure strategies and assumptions are reported by relatively small sets of people with some variation according to employment status, sexual orientation, gender, ethnicity, and having had a casual partner.

### The multiple rationalities of disclosure

How these disclosure strategies work in everyday life is revealed in interviews where context and conflicting dynamics create situations that prove difficult to navigate. Several people articulate the double bind created by the obligation to disclose and fear of rejection, leading to emotionally fraught choices in deciding to disclose. One interviewee, who was prosecuted for non-disclosure, reflects on the tension inherent in disclosure decisions.

I went through a depression because now I was totally alone. I stopped eating, wasn’t taking no medication. I felt that I failed. I came to Canada and failed and now I’m dying too. I don’t remember how many women, but a number of women for many years and I didn’t tell them … Well after I found out I was positive, it was hard for me to disclose. I felt if I
told anybody that I would be judged and nobody would want to be close to me again. It might have been selfish. In fact it was. It took me a long time to realize it was. It took me a couple years of program to realize that was a very selfish move … I told her I was scared. I didn’t want to lose her. I was afraid I was going to lose her and I didn’t want to tell her. I didn’t know how to answer. I wasn’t trying to lie to her. I didn’t know what to tell her and I didn’t want to because I was afraid if I told her, you’ll walk away, you’ll never see me again and I would lose and I wasn’t trying to get you sick like me or trying to get you infected or anything. (041, African/Caribbean, heterosexual, male, 40s)

Others experience disclosure as an obligation that runs against a tacit norm of silence around HIV questions:

A few times I have disclosed or they’ve asked me flat out, ‘Are you positive or negative?’ and I will tell them but often it’s not discussed. Guys don’t want to talk about it, whether they’re positive or negative. It kind of kills the romance or the sort of kind of hotness of the potential for getting together. (013, white, gay, male, 50s)

As far as I can see, from people I’ve talked to, I’d say 99.9% of the people never tell anyone they’re positive, unless they’re asked. (011, white, gay, male, 50s)

The result is a tendency to engage in a tacit dance of assumptions and intuitions, along with reading of context, in order to assess the viability of disclosure in personal interactions.

The last time was in a bathhouse situation. It was a guy that I recognized from online. At least his profile says that he’s positive. He recognized me as well. So there was already a bit of a connection. Although we didn’t exchange words in the situation, we both kind of knew where we were coming from. We ended up having unprotected sex. (006, African/Caribbean, gay, male, 40s)

Considerable effort may go into testing the waters to determine how understanding the other person may be. Disclosure may at first take the form of partial or indirect strategies. One study participant describes the disclosure process as one of feeling ‘under siege’ in a context where disclosure may elicit a stigmatizing reaction.

The whole night I talked about Fashion Cares, HIV, ACT [AIDS Committee of Toronto], me doing outreach. (I: Like you did as much as possible without saying it to infer that you were?) It might sound like beating around the bush but I really did kind of like … I mean do I have to fucking write it on my forehead for real? (054, white, gay, male, 50s)

I don’t always tell. I probably told more before but now, I’m very wary because I don’t know … Sometimes when I’m chatting to somebody I’ll kind of drop some hints and if they don’t seem to pick it up, then I’ll just walk away because I’ll say, well I don’t think this person is positive, so you know what, I’m just going to leave it … People who are HIV that I’ve had discussions with, also feel under siege and maybe less likely to bring up some things or just to look for totally anonymous sex where not even your name is asked. (078, white, gay, male, 40s)

For some, reading the situation, especially in a gay context where men are presumed to be largely in the know about HIV issues, can lead to the inference that the other may also be an HIV-positive man who is cautious about disclosing.

If someone wants to do something unprotected, that’s a big signal. It’s someone’s telling you (pause) by action, not verbally, that they are HIV. (022, white, gay, male, 40s)
From a gay’s perspective, we know generally, you know, when I don’t ask or they don’t ask, it’s a given we’re both HIV and we’re going to have probably unprotected sex … If he says, I’ll only play wrapped, then I will respect that and play wrapped. (069, white, gay, male, 40s)

Sometime tacit assumptions can lead to misunderstanding or to the perception of outright deception reported by some individuals as the circumstance that led to their own exposure to HIV:

I asked him if he had ever been tested and ... like the phrasing I would have used was, ‘Are you clean?’ And then I went and got all my tests done and then he was like, ‘Yeah, I did that too’. What the fuck, you didn’t do it, do you know what I mean? and he didn’t. (I: So you were using condoms and then you had this discussion. You went and got tested, not with him though?) Yeah. (I: So then you just come back and you say, I’m good?) Yeah, I’m good, now you want to ... because I was trying to go through all the like motions of like now we’re going to be in this monogamous relationship. (073, white, queer, female, 20s)

I went in for standard blood work because it’s required by our insurance company and they said, ‘Well you’re HIV-positive,’ and I said that’s impossible because I’ve only been playing around with two people and one is my partner of four years and the other one is a friend of ours. The friend of ours had it and he knew. I found out he knew he had it and he’s telling everybody he doesn’t. (018, white, gay, male, 40s)

Those interviewed for this study, then, point toward a number of circumstances and factors that make routine disclosure a complex and emotionally difficult accomplishment. Perhaps most fundamental is the difficulty of setting oneself up for rejection in the process of seeking affection and support. Some perceive that they are required to rupture a norm of silence or at least feel obliged to ease prospective partners into the realization that they may be positive. Disclosure is an undertaking fraught with emotional pitfalls complicated by personal histories of having misread cues or having felt deceived leading up to their own sero-conversion, then having to negotiate a stigmatized status with new people.

Whenever I tell somebody, the person run away so this creates a very huge problem for me. (023, Latin American, heterosexual, male, 50s)

I was raised a certain way and I got infected at the age of 18. I’m 33. 15 years I’ve had to deal with this, 15 years of being dumped because I disclosed or guys don’t want to be with me or ... you know, it hurts, it damn well hurts and I know it does. (055, white, gay, male, 30s)

**Poz on poz sex**

Some seek to resolve disclosure problems by pursuing other HIV-positive people for sexual or romantic connection. At the same time, a good many express reluctance to have unprotected sex even with other HIV-positive people (Adam, Husbands, Murray, & Maxwell, 2005).

My strain might be totally different than your strain and while I may pick up your strain and it may not cause me any further ill effects, it may produce a rather nasty new strain that I’m capable of passing on or vice versa. Or it may have a hell of an impact on my drug regimen. (002, white, gay, male, 60s)
I won’t infect him with my HIV and I certainly don’t want to get infected with his HIV … If I have to go on his medication at some point, I don’t want to be immune to it … It pisses me off when they know they’re HIV-positive and they’re out there infecting person after person after person and they know it. Well that’s just yes, that should be stopped. (015, white, gay, male, 40s)

If I have sex with somebody who is positive, I don’t want she’s kind of virus, strain, to have it. That’s what the doctor told me always. So I believe in that. (030, African/Caribbean, heterosexual, male, 30s)

Others believe that when having sex with a partner who is also HIV-positive, safer sex is less of a concern or experience a sense of relief at no longer having to feel like ‘a pariah.’

I got mixed up and had a bit of a crystal meth problem and through that, I met … there’s a whole community of guys who … were just on disability, never worked, didn’t seem to want to work again. Some guys did have jobs. They were positive. They knew we were positive. They were all into partying and doing drugs and having unprotected sex. I think part of it for me was just for so many years I had drummed into my head, ‘You’ve got to have safe sex,’ and then suddenly to me the whole group of people who … you don’t feel like you’re a pariah or everybody was just fine with it [unprotected sex]. (020, white, gay, male, 40s)

I will admit to being fairly flexible or accommodating of the other person’s wishes to go barrier free. It’s probably reflective of the fact that condoms aren’t a terrible amount of fun and I’m guilty I guess of being all too happy to go along with it. (042, white, gay, male, 30s)

Online I’ve already posted, so most of the time they’ve read it and sometimes they haven’t. But generally I clarify like ‘by the way, I’m positive’. If the [HIV-positive] person is open to not using condoms, that’s their choice and I’m not going to fight them on that. (089, Asian, gay, male, 20s)

The pressure to disclose, then, produces a disparate array of effects in everyday interaction: heightened fear of rejection that makes disclosure even harder to accomplish, indirect or partial disclosure, readings of tacit signs and assumptions about partners’ serostatuses, and avoidance of the need to disclose by pursuing other HIV-positive partners.

**Constructions of responsibility**

Many study participants reflect on the meaning of responsibility in HIV exposure or transmission. For many, their sense of responsibility is consistent with a larger societal ‘rhetoric of individualism, personal responsibility, consenting adults, and contractual interaction’, a ‘moral reasoning widely propagated by government and business today that constructs everyone as a self-interested individual who must take responsibility for himself in a marketplace of risks’ (Adam, 2005).

I’m an adult, they’re an adult. You take responsibility for yourself and if you give me something, it’s my own fault for having sex with you and not finding out. (011, white, gay, male, 50s)

When people have sex, they should always protect themselves. You’re responsible for yourself and that’s why I don’t understand why they’re being charged. It’s your fault too. That’s how I feel. (017, Aboriginal, gay, male, 40s)
You have to take some responsibility for your life some place. We can’t have a nanny state where everything is just perfect … You’re not mentally incapable and you’re not being raped and you’re not being forced in to this; nobody is bending your arm. You’re having sex because you want to have sex so why are you not taking care of yourself? (021, white, gay, male, 50s)

Many of the men interviewed articulated a strong sense of individual obligation where responsibility should not be conceived as exclusively or primarily a problem falling to HIV-positive people and that all have a responsibility for their own health.

It’s a personal choice that you choose. We’re all adults. You have to live by the consequences of our decisions right. That’s the way I look at it. (024, African/Caribbean, gay, male, 40s)

I don’t think the onus should be on the person who’s positive necessarily or the person who knows that they’re positive. It should be everybody’s responsibility to protect themselves. We’ve all heard about HIV. Grow up and take some responsibility. (054, white, gay, male, 50s)

You know what decisions you take … You have to be responsible yourself for your own decisions. I’m not there to impose my thoughts on anybody … He shouldn’t go to prison for that. It’s for the other person to force, the other person to say, ‘Put on a condom.’ (F14, white, gay, male, 30s) translated from French.

It is noteworthy that male voices are strongly represented in these constructions of the self as an autonomous male actor responsible for protecting himself against HIV. In many ways, then, dominant discourses circulating in neoliberal societies provide moral precepts and rationales for individualized constructions of responsibility that preclude a need for disclosure, notions consistent with longstanding messaging on safe sex from AIDS service organizations to treat all prospective sex partners as potentially HIV-positive.

**Collective or interpersonal responsibility**

Others express a sense of responsibility embedded in collective or interpersonal loyalties rather than individualism.

I have no shame whatsoever. I am very open about it and it’s the first thing I tell anybody. If they ask me, fine, or I’ll mention it. I mention the fact I’m gay, I mention the fact I’m HIV-positive. The positive person is the responsible one 100% and the other person maybe 50 or 70% for the negative person for their responsibility too. (016, white, gay, male, 60s)

What shocked me was the fact that somebody would have sex with another person without letting him or her know that they’re HIV and that there’s a possibility of transmission. I just find that very disturbing … I have a lover that I’ve been with for 46 years and we still have sex. He is not HIV and he does not have Hep C. We do it in such a way that there is no transmission or whatever of fluids, even though my counts in HIV have been undetectable for the last 8 or 10 years and now the Hep C is down to supposedly zero. The fear of passing something on unknowingly or knowingly has become part of my life. (001, white, gay, male, 60s)

A tension between individualized and collective notions of responsibility circulates through a number of the narratives, reflecting the lineaments of moral reasoning in the
larger society (Rangel & Adam, 2014). Constructions of the self as individual actors in a marketplace of risk co-exist with the ‘sexual etiquette’ developed in gay communities throughout the AIDS era of care of the self and other through safer sex (Weeks, 1995). In casual sexual encounters, where partners may not be well known, marketplace presuppositions come to the fore in a sexual field (Green, 2014) characterized by brevity and anonymity. Combined with the difficulties of disclosure, individualized notions of responsibility may gain the upper hand.

Conclusion

As court cases have acquired extensive media attention over the last decade, that coverage in turn has influenced the general public, risk populations, and HIV-positive people. The result has been a feedback loop, accelerating through the 2000s, where criminal prosecutions for failure to disclose HIV status have generated publicity that has implicitly instructed the public on how to respond to HIV. One participant in this study testifies that

my ex was charged and he was found guilty … (I: Charged by you?) No … it was really like the police that put it in my head to charge which was kind of like weird and fucked up. They’re like … I would have never really thought that. (073, white, queer, female, 20s)

When official agencies like the police and public health ‘put it in my mind’ to prosecute, then criminalization rises to the status of a primary response to HIV transmission rather than a recourse of last resort.

At the same time, increasing reliance on the criminal justice system to enforce a principle of near universal disclosure of HIV-positive status, even when transmission is unlikely, presses HIV-positive people into an untenable double bind: they must place themselves into the risky position of heightening the possibility of rejection, stigmatization, and prosecution. Double binds constitute a shaky foundation for consistent practice and for effective public policy. As interviews with people living with HIV show, the exigencies of everyday personal interactions make routine disclosure far from easy. Examination of everyday disclosure decisions shows a range of incommensurable rationalities that shape these decisions such as personal ethics and morality, ethical precepts circulating in the larger society, the fear of rejection, degree of intimacy between partners, and capacity for self-assertion, as factors in disclosure dynamics. This in turn leads to ways in which notions of responsibility figure in the reflections of people living with HIV. The gap between these everyday practices and situations on the one hand and the rational deterrence presumptions of criminal justice proceedings on the other point towards ways in which the criminalization of HIV may work at cross-purposes to effective HIV prevention. Perhaps paradoxically, the elevation of disclosure as a strategy of HIV prevention by the courts and media coverage shifts perceptions and negotiations of HIV management in ways that may actually undermine effective HIV prevention by making disclosure feel more risky for HIV-positive people when it becomes an act subject to legal scrutiny. As well it may create a generalized expectation that HIV-positive people will always disclose, and therefore condom use is unnecessary because non-disclosure comes to signify HIV-negative status. Obscured by criminalization trends is the fact that protected sex, especially in a situation where treatment has succeeded in attaining an undetectable viral load in the HIV-positive partner, continues to be a much more reliable method of avoiding HIV (as well as several other sexually
transmitted infections) than disclosure. The elevation of disclosure to a primary strategy for HIV prevention, then, exerts increasing pressure on a double bind that cannot be relied on to result in decreased HIV risk and may divert attention from or undermine safe sex practice.

Acknowledgments

This study was made possible with the assistance of: Tsegaye Bekele, Sandra Gardner, and Lucia Light; advisory committee members Murray Jose, Rick Kennedy, Frank McGee, Eric Mykhalovskiy, Fanta Ongoiba, Ryan Peck, John Plater, Michael Sobota, and James Watson; and support by a grant from the Ontario HIV Treatment Network. The OHTN Cohort Study Team consists of Jean B. Rourke, Ann Burchell, Sandra Gardner, Sergio Rueda, Ahmed Bayoumi, Jeffrey Cohen, Curtis Cooper, Don Kilby, Mona Loutfy, Fred Crouzet, Anita Rachlis, Nicole Mittmann, Janet Raboud, Irving Salit, Edward Ralph, Roger Sandre, Marek Smieja, and Wendy Wobeser. The Positive Spaces Healthy Places Cohort Study Team consists of Jean B Rourke, Ruthann Tucker, Saara Greene, Amrita Ahluwalia, Jean Bacon, Anne Bowlby, Steve Byers, James Dunn, Dale Guenter, Steven Hwang, Jay Koonstra, Frank McGee, LaVerne Monette, Lea Narciso, and Michael Sobota.

References


