

It's not just what you say: Relationships of HIV disclosure and risk reduction among MSM in the post-HAART era

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Abstract

In the post-HAART era, critical questions arise as to what factors affect disclosure decisions and how these decisions are associated with factors such as high-risk behaviors and partner variables. We interviewed 1,828 HIV-positive men who have sex with men (MSM), of whom 46% disclosed to all partners. Among men with casual partners, 41.8% disclosed to all of these partners and 21.5% to none. Disclosure was associated with relationship type, perceived partner HIV status and sexual behaviors. Overall, 36.5% of respondents had unprotected anal sex (UAS) with partners of negative/unknown HIV status. Of those with only casual partners, 80.4% had > 1 act of UAS and 58% of these did not disclose to all partners. This 58% were more likely to self-identify as gay (versus bisexual), be aware of their status for < 5 years and have more partners. Being on HAART, viral load and number of symptoms were not associated with disclosure. This study—the largest conducted to date of disclosure among MSM and one of the few conducted post-HAART—indicates that almost 1/5th reported UAS with casual partners without disclosure, highlighting a public health challenge. Disclosure needs to be addressed in the context of relationship type, partner status and broader risk-reduction strategies.

Introduction

A substantial number of people living with HIV (PLWH) do not disclose to sexual partners (Perry et al., 1990; Stempel et al., 1995), yet questions remain concerning factors that affect these decisions and whether and how these decisions are related to HIV transmission, particularly in the post-HAART era. Several studies have attempted to describe the relationship between HIV disclosure and sexual risk behavior. Disclosure of HIV infection may motivate partners to protect themselves. Yet, protection may occur regardless of disclosure, or lack thereof, and some patient advocates have suggested that encouragement of disclosure places an undue responsibility on infected individuals who are already stigmatized (Chambers, 1994). Qualitative data suggest that disclosure is complex, occurring in the context of risk-reduction strategies (Klitzman & Bayer, 2003) and that factors such as perceived status of partner, type of sexual activity and viral load may be involved in disclosure decisions.

Non-disclosure may occur due to fears of rejection, feelings of shame, desires to maintain secrecy, feelings that safer sex obviates the need for disclosure (Klitzman, 1999; Klitzman & Bayer, 2003; Simoni et al., 1995), fatalism, perceived community norms against disclosure (Sheon & Crosby, 2004) and feelings that individuals are responsible to protect themselves, not their partners (Wolitski et al., 2003). In contrast, disclosure may occur due to a sense of responsibility to partners and concerns for a partner's health (Klitzman & Bayer, 2003; Wolitski et al., 2003) and—with a main partner—need for support. From an ethics and human rights perspectives, questions arise of whether partners have a right to know if their partner is infected in order to be able to make a fully informed decision about what sexual behavior to engage in. These issues can be complicated by local laws regarding knowingly transmitting HIV and by complex gender role norms (Klitzman & Bayer, 2003; Klitzman et al., 2004b). PLWH may selectively disclose if the anticipated rewards

outweigh the perceived costs (Derlega et al., 1993) but it remains unclear how individuals determine and weigh such complex costs and rewards and vary in such assessments (Klitzman & Bayer, 2003; Klitzman et al., 2004a).

Past quantitative research findings have presented a mixed picture. Increased disclosure may be associated with reduced sexual risk behavior among men and women, regardless of sexual orientation (Kalichman & Nachimson, 1999). However, among a sample of MSM, disclosure was not related to whether safer sex occurred or not, questioning the assumption made in post-test counseling that disclosure may decrease unsafe sex (Marks & Crepaz, 2001).

Past quantitative studies have also found that particular factors are associated with either disclosure or unsafe sex. Non-disclosure, regardless of the type of sexual behavior engaged in, has been found to increase as the number of partner's increases (Marks et al., 1991) and to be associated with psychological distress (Kalichman & Nachimson, 1999). Unsafe sex, regardless of whether disclosure occurred or not, has also been found to be more common with partners who are perceived to be HIV-infected (versus of negative or unknown HIV status) (Marks et al., 1994). Among young gay men, unsafe sex has been found to be more common with main than with casual partners and to be more likely with HIV-positive partners. Disclosure occurred more when partners were perceived to be HIV-positive as well (Lightfoot et al., 2005). In a sample of 219 HIV-positive Latino MSM, of whom 91% were born outside the US, Poppen et al. (2005) found that seroconcordance, main partner relationship and disclosure were all interrelated and associated with UAS with their most recent partner. Questions thus arise about how these factors might be related among casual partners and non-Latino MSM. None of these prior studies of disclosure have assessed all of these variables together among MSM of varying ethnic and racial backgrounds: specifically, the relationships of disclosure to unsafe sex, relationship type and perceived partners' status, examining all three of these variables.

Moreover, many studies of disclosure among MSM occurred before the advent and widespread use of HAART, which may alter the relationships between unsafe sex, disclosure and other variables. Disease progression itself is not necessarily related to disclosure to sexual partners (Mansergh et al., 1995; Perry et al., 1994; Serovich, 2001), yet HAART may be changing attitudes and patterns of risky behavior. Approximately 20% of HIV-infected men and women believe that protease inhibitors reduce risks and needs for safe sex (Kravcik et al., 1998). Among MSM, those who have reduced concern about HIV

due to HAART are more likely to engage in high-risk behavior (Ostrow et al., 2002). Perceptions that HAART lowered risk have been found among not all MSM, but only those who practiced high-risk behavior (Remien et al., 2005).

Hence, in a larger sample of MSM, we decided to explore these issues to clarify and assess several of these complex variables. These issues can be important in designing and implementing public health efforts to decrease the further spread of the epidemic.

Methods

Procedures

Individuals who are HIV-positive in four US cities (San Francisco, Los Angeles, New York City and Milwaukee) were screened between 7/2000 and 1/2002 for recruitment into a randomized, controlled clinical trial of an individually administered cognitive-behavioral intervention. Recruitment and screening of potential intervention study participants were undertaken in medical clinics and community agencies serving HIV-positive clients. The current data consists of the baseline assessment.

The screening and assessment procedures have been reported elsewhere (Johnson et al., 2003; Weinhardt et al., 2004). In brief, participants were required to be at least 18 years old, provide written informed consent and written medical documentation of their HIV-positive serostatus. Potential participants were excluded if they showed severe neuropsychological impairment or psychosis as assessed by senior project personnel in collaboration with the clinical supervisor at the involved institution. Overall, 3,818 women and men were screened using a comprehensive assessment instrument. This paper focuses on data from 1,828 men reporting a homosexual or bisexual orientation.

Assessment interviews were conducted in private settings in research offices, community-based organizations and clinics in the four cities. Procedures involved a combination of Audio Computer Assisted Self-Interviewing (ACASI) and Computer Assisted Personal Interviewing (CAPI) using Questionnaire Development System (QDS) version 2.0 by Nova Research Company. This approach has been proposed as an effective method of decreasing social desirability and thereby enhancing the veracity of self-reports of sensitive behaviors and attitudes (Gribble et al., 1999; Turner et al., 1998). To accommodate lower literacy respondents, we aimed for low reading levels in assessment selection wherever possible and all items were read aloud, either by the interviewer for CAPI administration or by a recorded voice for ACASI assessment of sexual

behavior. Assessments were conducted in Spanish for participants who preferred this language. The interview was conducted over 2–4 hours with regular breaks allowed to minimize respondent fatigue. Participants were compensated \$50 for completing the baseline interview. Those needing childcare were also eligible for \$10 to defray those costs.

Measures

Measures included demographic/background factors, the Sexual Risk Behavior Assessment Schedule (Meyer-Bahlburg et al., 1991) over the past three months, health status (self-reported viral load, HIV-related symptoms), substance use and disclosure questions. For each sex partner, men were asked to indicate the partner’s most recent HIV test result (positive, negative, not tested, unknown) and whether that partner was aware of the participant’s HIV status (i.e. disclosure had occurred).

Results

Of the total baseline sample ($N=3,818$), 1,828 (47.9%) were men who reported sex with other men. Among these 1,828 men, 35.8% were black, 37.7% were white, 18.1% were Latino and 10.7% were ‘other’ ethnicity. Sixty-two percent had education beyond high school (HS), 24.7% reported a general equivalency diploma or HS diploma and 13.3% less than a HS education; 35.5% were currently employed, 39.5% had served jail time and 69.5% reported having health insurance. In the previous year, 31.1% reported being homeless or living in a shelter, 10.4% reported injecting drugs; 79.8% reported a homosexual orientation, 18.4% identified as bisexual and 1.8% as ‘other’ sexual orientation. On average, men had been living with HIV for 8.81 years (range 0–24), 76.7% were on HAART and 59% reported an undetectable viral load.

In the prior three months, 80.6% ($N=1,473$) were sexually active, with a median number of three sex partners, (range: 1–300). Of sexually active men, 408 (27.7%) had a main partner only, 329 (22.3%) had both main and casual partners and 736 (50%) had casual partners only. Across partnership type, 50.3% reported HIV concordant (HIV-positive) partner(s) only.

Overall, 46% of men disclosed to all partners, with the remaining men disclosing to some or none. Among the 742 men with a main partner, this partner was reported to be HIV-positive by 58.5%, HIV-negative by 29.3% and unknown/untested by 12.2%. Most men (87.7%) with a main partner disclosed their HIV status to him; however, as shown in Table I, disclosure varied with knowledge of partner status. While over 93% of men who knew their main partner’s serostatus reported disclosure to that partner, only 42.2% of those with a main partner of unknown/untested status disclosed. Yet most non-disclosure occurred in the context of safer sex. Among the 154 men practicing UAS with their main partner, all but five engaged in UAS with a seroconcordant partner who knew their status.

Table II summarizes sexual risk behavior overall in this sample. Of these, 63.5% could be classified as no/low risk: (19.5% were abstinent, 22.7% had protected anal sex only, 14.5% had oral sex only and 6.9% had UAS with HIV-positive main partners only). Of the sample, (36.5%) were high risk, having UAS with serodiscordant or unknown main or casual partners.

Among men with casual partners (see Table III), 41.8% disclosed to all, 36.7% to some and 21.5% to no partners. Of casual partners, 37.5% were believed to be HIV-positive, with the remaining two-thirds of partners perceived to be either HIV-negative or of unknown status. Disclosure in casual partnerships also varied significantly by perceived partner status, with greater disclosure when all partners were believed to be HIV-positive.

Of those with casual partners, 65.2% engaged in at least one act of UAS (see Table IV). Of these men,

Table I. Disclosure among men with main partners by partner status.

Status of main partner	Practicing safe and unsafe sex ¹						Practicing UAS ²					
	Total		Disclosed		Did not disclose		Total		Disclosed		Did not disclose	
	N	%	N	%	N	%	N	%	N	%	N	%
HIV-positive	431	58.5	403	93.5	28	6.5	150	97.4	149	98.7	1	33.3
HIV-negative	216	19.3	205	94.9	11	5.1	1	0.7	1	0.7	0	0
Unknown, not tested	90	12.2	38	42.2	52	57.8	3	1.9	1	0.7	2	66.7
Total	737	100	646	87.7	91	12.3	154	400	151	98.1	3	1.9

¹Chi-square = 195.77; $p < 0.000$.

²Chi-square = 67.09; $p < 0.000$.

Table II. Sexual risk behavior ($N = 1824$).

	<i>N</i>	%
No or low risk		
Abstinent	355	19.5
Protected anal sex only	414	22.7
Oral sex only	264	14.5
Unprotected anal sex, concordant partner	126	6.9
Total	1,159	63.5
High risk		
Unprotected anal sex with serodiscordant, untested or unknown status partner	665	36.5

Note: A total of 1,870 men reported a homosexual or bisexual orientation but 42 had missing data pertinent to these analyses.

fewer than half informed all partners of their status. Partners were most likely to be informed about HIV status when the partner's status was assumed to be HIV-positive. Among men with multiple casual partners, 63.4% who believed their partners were all HIV-positive disclosed to all partners, versus 29.3% of those who had partners with a perceived negative or unknown status. About 10% of men with casual partners practiced UAS only with main partners, the majority of whom (91.8%) were seroconcordant and disclosed to.

The riskiest group of men appears to be those engaging in UAS with casual partners. Among these men practicing UAS with casual partners, backward logistic regression was used to identify the most parsimonious set of variables associated with disclosure (Table V). Variables entered into the equation included background characteristics (age, race, education, sexual orientation), number of years since learning HIV status, health status (if on HAART, if undetectable viral load and number of HIV-related symptoms), substance use (i.e. if recreational drug use in the prior three months and if daily or more alcohol use), use of HIV support services and sexual partnership variables (number of sexual partners and if all partners were HIV concordant). Odds of disclosing status to all partners were lower among men who had a self-reported homosexual (versus bisexual) orientation, awareness of their HIV serostatus for <5 years and more partners. Men who reported that all partners were seroconcordant had over 4.5 times greater odds of disclosing to all

casual partners. When controlling for site, the same three variables emerged as having the strongest associations with disclosure among men with casual partners engaging in UAS. Being on HAART, undetectable viral load and number of HIV-related symptoms were not associated with disclosure among these men.

Conclusions

These data raise several critical public health concerns that have key implications for interventions aimed at HIV prevention. Overall, these data confirm several findings from prior qualitative research (Klitzman & Bayer, 2003) that indicated that, given competing sexual desires and ethical concerns, HIV-infected MSM engage in a range of sexual strategies involving disclosure specifically: abstaining from sexual behavior; disclosing and practicing safe sex; not disclosing but practicing safe sex; disclosing but practicing unsafe sex; or neither disclosing nor practicing safe sex. In the present study, we found similar patterns and were able to quantify the proportions that fit each of these categories, including the proportion that falls into this last 'riskiest' category. In the present sample, two-thirds of participants used risk-reduction strategies. But public health concerns remain, given that one-third of HIV-positive MSM practiced high-risk sex (UAS with partners of unknown/untested status) and most MSM practicing UAS with casual partners did not disclose their serostatus. Hence, individuals in these groups need to be targeted for prevention efforts.

For years, many advocates have argued in favor of the so-called 'code of the condom'—that as long as sexual partners used condoms, disclosure was unnecessary (Chambers, 1994).

If all MSM—infected and uninfected—protected themselves, disclosure would not be needed, because no HIV transmission would occur. Indeed, in our qualitative research (Klitzman & Bayer, 2003), many HIV-infected men reported that they 'do not tell, but practice safe sex' with casual partners of unknown/untested status.

Table III. Disclosure among men with casual partners by partner HIV status.

Status of casual partners	Total		Disclosed to all partners		Disclosed to some partners		Disclosed to no partners	
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
All HIV-positive	346	37.5	234	67.6	57	16.5	55	15.9
At least one HIV-negative/unknown	719	62.5	211	29.3	334	46.5	174	24.2
Total	1065	100	455	41.8	391	36.7	229	21.5

Chi-square = 95.73, $p < 0.000$.

Table IV. Disclosure patterns among men with casual partners engaging in UAS.

	Total		Disclosed to all partners		Did not disclose to all	
	N	%	N	%	N	%
Unsafe with casual partners						
One casual, concordant	33	4.7	32	97.0	1	3.0
One casual, discordant/unknown	14	20.0	7	50.0	7	50.0
Multiple, all concordant	153	22.0	97	63.4	56	36.6
Multiple, some discordant/unknown	427	60.9	125	29.3	302	70.7
Subtotal	627	89.4	261	41.6	366	58.4
Unsafe with main partner only						
Multiple, some discordant/unknown, unsafe with concordant main partner only	69	9.8	68	98.5	1	1.5
Multiple, some discordant/unknown, unsafe with discordant main partner only	2	0.3	1	50.0	1	50.0
Multiple, some discordant/unknown, unsafe with untested main partner only	3	0.4	1	33.0	2	67.0
Subtotal	74	10.6	70	94.6	4	5.4
Total	701	100.0	331	47.2	370	52.8

P < 0.001.

Yet, unfortunately, the fact that HIV continues to spread, particularly among young MSM (Center for Disease Control, 2001), suggests that the ‘code of the condom’ approach has not wholly worked. Hence, questions arise as to the tenability of the notion that disclosure is ‘unnecessary.’ Indeed, in the present study, this pattern was in fact less common than ‘not telling and practicing unsafe sex’. Thus, for some, the ‘code of the condom’ may seem to justify a ‘code of silence’ that may in fact facilitate future HIV transmission. Specifically, these data suggest that non-disclosure in conjunction with unsafe sex occurs among one-fifth of HIV-infected MSM, and that these behaviors thus need to be targeted for interventions. In short, infected MSM do not necessarily need to disclose but, if they do not do so while practicing UAS with partners of unknown or HIV-negative serostatus, they should realize that they are potentially endangering others and spreading the epidemic further and that these partners may later become aware of this behavior, with a variety of consequences.

Disclosure is associated with knowledge of a partner’s positive status. This finding may reflect partners having a discussion about HIV more generally, during the course of which disclosure occurred, rather than disclosure taking place in isolation, suggesting that disclosure between partners thus appears to be mutual. Hence, promoting discussions about HIV—possibly more than disclosure *per se*—may be beneficial. Further research can help substantiate and identify predictors of such discussions (e.g. social and temporal contexts—how they are initiated, whether directly or indirectly, planned or spontaneous).

In the case of UAS with casual partners, disclosure increased with the number of years since one tested positive, suggesting that having a longer time to adjust to living with a positive status may enhance the ability, ease or motivation to disclose.

Those men who self-identify as bisexual (versus homosexual) may seek to protect themselves and their partners more, in part because they are having sex with women, who may be less aware of HIV risks

Table V. Factors associated with disclosure among men with casual only partners engaging in UAS.

	Exp (B)	95.0% C.I. for Exp (B)		Sig.
		Lower	Upper	
All partners concordant (versus not)	4.571	3.092	6.758	0.000
Homosexual (versus bisexual) orientation	0.547	0.337	0.888	0.015
Aware of status <5 years (versus longer)	0.672	0.453	0.997	0.048
Total number male partners	0.987	0.975	1.000	0.056
If controlling for site				
All partners concordant (versus not)	0.514	0.317	1.067	0.007
Homosexual (versus bisexual) orientation	0.682	0.460	0.832	0.056
Aware of status <5 years (versus longer)	4.834	3.289	1.010	0.000

and thus be vulnerable to placing themselves at greater risks.

Some research has raised questions about the importance of disclosure in post-test counseling (Marks & Crepaz, 2001). Yet our work suggests that disclosure is indeed an important component of HIV prevention, though it must be viewed and done in context, not as an isolated event. Moreover, since most UAS behavior occurs in main, seroconcordant relationships, interventions are needed to target UAS with partners of unknown or negative serostatus. This finding also highlights the possible importance of discussions about HIV status and disclosure in prevention efforts.

These data can help enrich the literature on disclosure. For example, to date much debate has focused on whether disclosure increased or decreased the occurrence of unsafe sex. Marks and Crepaz (2001), for example, have found that there was *no* relationship between disclosure and safer sex. Yet the present data indicate that disclosure is in fact associated with unsafe sex, *depending on the partners' status*. Specifically, among participants engaging in UAS with casual partners, most participants with concordant partners disclosed, while most who had partners of negative or unknown status did not disclose ($p < 0.000$). Hence, the question addressed in the past literature needs to be revised to consider this other variable of partners' HIV status. Moreover, as framed, this question—whether disclosure increases the likelihood of safer sex occurring implies a causal relationship that has not yet been supported empirically one way or the other but may depend on these other variables.

We found also that the proportion of those having unsafe sex with partners of unknown or negative status without disclosing was much higher than reported previously by Marks et al. (1994) in their paper based on data pre-HAART (2.3% versus 20% in the current study). This increase may be due to the fact that in the post-HAART era, men may feel that, though they are infected, they are not of risk to these partners because of being on HAART and possibly having low viral loads. Yet, though some infected men may indeed have undetectable viral loads and hence be at lower risk, others may have missed doses and thus have detectable viral loads and be at risk to unprotected partners. Moreover, the assumption that medication makes unprotected sex safe negates the possibility of other STDs being spread. Indeed, increased rates of syphilis have been reported in MSM communities (CDC, 2002). The finding that one-fifth of men are having unsafe sex and not disclosing is of concern too since, in the post-HAART era, norms may change such that having unsafe sex may come to be seen as permis-

sible if one is on HAART. Disclosure can potentially help counter such trends.

These data suggest possible avenues for developing interventions to address those who continue to engage in high-risk behaviors. Our finding that disclosure in conjunction with UAS is lower among men who have known about their HIV status for less than five years underscores the need to target interventions for this group. Such interventions to assist men with disclosure can incorporate suggestions made in other research. For example, many positive men have developed disclosure strategies (Klitzman & Bayer, 2003; Serovich et al., 2005), e.g. setting the stage or seeking other HIV-infected men (though this last approach would not apply with partners of negative or unknown status, who are also assessed here). Interventions can foster notions of MSM having responsibility toward their partners (Wolitski et al., 2003) and need to address obstacles such as community norms against disclosure (Sheon & Crosby, 2004). In psychotherapy—and hence, potentially, other interventions—ambivalence toward behavior change can be addressed (Sheon & Crosby, 2004; Suarez & Kauth, 2001) and healthy behavior that does not involve potential transmission of HIV to partners can be affirmed (Suarez & Kauth, 2001). As the post-HAART world continues to evolve, further studies in this area are also increasingly important.

This study has several potential limitations. We relied on self-reporting of whether individuals self-disclosed and what sexual behavior they engaged in. We do not have data on what exactly they said or their reasons for their disclosure decisions. Self-reports of risk behaviors may also be affected by social desirability, however, we countered this potentiality by assuring participants confidentiality, carefully constructing assessment items and using ACASI, as recommended by the NIH (Pequegnat et al., 2000). We did not use biological endpoints such as partner seroconversion or partner acquisition of sexually transmitted infections (STIs) to attempt to verify all reports of risk behavior. We assessed STIs at baseline and determined that the prevalence was low (12 cases of chlamydia and one of gonorrhea). It was not feasible in this trial to assess seroconversion among partners of HIV-infected individuals, given the practical challenges of recruiting and maintaining a cohort of such individuals.

Clearly, these data have several critical implications for future research. We found that partners of 42% of men having UAS with partners of unknown/untested status are disclosed to but then, nonetheless, engage in UAS. The reasons for these partner's unsafe behavior despite reported disclosure are unclear. Participants may be reporting to in-

investigators that they disclosed when they in fact did not do so clearly and explicitly. Indeed, our prior qualitative research (Klitzman & Bayer, 2003) found that definitions of disclosure varied widely, such that some HIV-infected individuals reported that they 'disclosed' when they in fact only 'dropped hints' or disclosed indirectly or in code (e.g. saying 'I have a problem with my immune system'). Listeners may not interpret such statements as full and explicit disclosure. This phenomenon of negative/untested men being disclosed to but then practicing unsafe sex needs to be further explored in future studies and may be related to the phenomenon of barebacking (Carballo-Diéguez & Bauermeister, 2004).

These data also suggest that HIV-negative men may assume that infected partners will disclose to them, particularly if these partners wish to engage in UAS. Yet interventions should encourage uninfected MSM to be aware that infected partners may not disclose. These expectations are in need of further investigation as well.

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