HHS Public Access

Author manuscript

J Consult Clin Psychol. Author manuscript; available in PMC 2016 November 04.

Published in final edited form as:

J Consult Clin Psychol. 1995 June ; 63(3): 474–478.

Women's Self-Disclosure of HIV Infection: Rates, Reasons, and Reactions

Jane M. Simoni, **Hyacinth R. C. Mason**, **Gary Marks**, **Monica S. Ruiz**, **Jean L. Richardson**, and **Deborah Reed**

Department of Preventive Medicine, University of Southern California

Abstract

A survey of 65 ethnically diverse women at two outpatient HIV clinics revealed relatively low rates of disclosure of HIV positive serostatus to extended family members; somewhat higher rates for immediate family members; and highest rates for lovers and friends. Spanish-speaking Latinas were less likely to disclose their serostatus or to discuss HIV-related worries with others than English-speaking Latinas, African Americans, and Anglos. Reasons for disclosure and nondisclosure varied by target. In general, targets reacted positively to disclosure. Implications for clinicians treating women with HIV infection are discussed.

Keywords

AIDS; HIV; women; Latinas; disclosure; social support

Women constitute 12.2% of the acquired immunodeficiency (AIDS) cases in the United States and are becoming infected with human immunodeficiency virus (HIV), the presumed cause of AIDS, at an increasingly rapid rate (Centers for Disease Control [CDC], 1993). African-American and Latina women are at disproportionate risk; although these groups comprise approximately 20% of the female population, they account for 74% of female AIDS cases (CDC, 1993). Despite the spiraling incidence rates, empirical data on women infected with HIV are scarce (Hankins & Handley, 1992; Ickovics & Rodin, 1992).

Compared to their male counterparts, a greater proportion of women with HIV are indigent, undereducated, injection drug users, and members of ethnic minority groups (CDC, 1993). Moreover, HIV seropositive women are often burdened by responsibilities related to their gender role, such as parenting and caring for family members, some of whom may be seropositive (Anastos & Palleja, 1991). Therefore, in addition to facing the biological, social, and psychological challenges of HIV disease that men face, seropositive women also must deal with the stigma and stressors unique to their disadvantaged social position (Ickovics & Rodin, 1992; Mays & Cochran, 1988).

Given these circumstances, many HIV-infected women may be reluctant to disclose their serostatus. Nondisclosure may prevent potentially negative social, personal, and material

Correspondence concerning this article should be addressed to Jane M. Simoni, Department of Preventive Medicine, University of Southern California, Parkview Medical Building A-301, 1420 San Pablo Street, Los Angeles, CA 90033-1042.

consequences, but it also decreases opportunities for social support, an important factor in coping and recovery from physical illness (Cohen, 1988; Kulik & Mahler, 1989). Satisfaction with social support has been found to buffer the effects of HIV-related physical symptoms on depressive symptomatology (Hays, Turner, & Coates, 1992). Further, people with HIV who are integrated in social networks have higher levels of psychological well-being than those who are not (Kelly et al., 1993).

An understanding of patterns of self-disclosure and perceived outcomes of disclosure is imperative if clinicians are to intervene effectively in the lives of women with HIV. The relevant literature deals exclusively with men (Chervenak & Weiss, 1989; Hays et al., 1993; Marks, Richardson, & Maldonado, 1991; Marks et al., 1992; Schnell et al., 1992; Mason, Marks, Simoni, & Ruiz, 1994; Stempel, Moulton, Bacchetti, & Moss, 1989). Findings indicate that seropositive men are more likely to inform intimate lovers, spouses, and close friends than to tell “casual” sexual partners, immediate family members, or coworkers. Employers, religious leaders, and landlords are least likely to be informed. After controlling for sociodemographic and medical variables, less acculturated Latino men with HIV were more likely than their more acculturated counterparts and White seropositive men to withhold their serostatus from significant others, especially from family members, suggesting that cultural values may influence disclosure. We wondered whether women would report similar patterns of disclosure and if less acculturated Latinas specifically would inform fewer people about their HIV diagnosis.

In the present study, we surveyed an ethnically diverse sample of 65 HIV-infected women, to assess (a) rates of self-disclosure of HIV infection to friends, lovers, and family members; (b) reasons for disclosure and nondisclosure; and (c) reactions of individuals informed to disclosure. Additionally, we collected information on potential sources of HIV-related social support.

Method

Sample Recruitment

The study was conducted at two HIV outpatient clinics in Los Angeles during 1991–1992. One clinic was part of a large health maintenance organization, and the other was part of a large public medical center serving indigent and under-insured individuals. Two female bilingual research assistants (RAs) attempted to recruit all women on each clinic’s daily appointment schedule who were (a) HIV seropositive for more than two months, (b) English or Spanish speakers, (c) at least 18 years of age, and (d) judged by medical providers at the clinics to be physically and mentally able to provide reliable questionnaire responses. Only one woman was ineligible based on these criteria; 92% (65 of 71) of the eligible women approached agreed to participate. Those who declined were asked to provide confidential data on their education, age, and ethnicity, which revealed that those who declined did not differ significantly from respondents on these characteristics.

Sample

The analytic sample consisted of 41 Latinas (30 of whom used a Spanish-language version of the questionnaire), 13 African Americans, and 11 Anglos. Over 85% were from the public clinic. Most of the 54% of the sample who were foreign-born immigrated from Mexico and Central America; on average, they had been living in the United States for 10.6 years. Respondents ranged in age from 18 to 69 (median age = 31 yrs). The educational level of the sample was low to moderate, with 70% having less than a high school diploma. Approximately 35 percent had tested seropositive during the past year (1–2 years ago = 30%; 2–4 years ago = 35%). About 74% of the sample were HIV positive with minimal symptoms, 14% had AIDS-Related Complex, and 12% were diagnosed with AIDS according to the 1987 case definition (CDC, 1987).

Self-reports indicated that 61% of the women had been infected through heterosexual contact, 17% through injection drug use, and 22% via blood transfusion. Exclusively heterosexual sexual behavior was reported by 87% of the sample; the others reported having had both male and female sexual partners. Fifty-five percent were currently in a committed relationship.

Questionnaire Administration

The questionnaire was written in English, translated into Spanish, and then independently back-translated to identify ambiguity of meaning. To encourage candor, the RAs instructed respondents to complete the questionnaire independently in a quiet section of the waiting room, use a self-generated numerical identifier rather than their name, and seal the completed questionnaire in an envelope before depositing it into a collection box.

Measures

As a measure of disclosure, respondents indicated whether or not they had revealed their HIV infection to the following nine targets: mother, father, brother, sister, cousin, aunt or uncle, grandparent, closest friend with whom they had not had sexual relations, and lover defined as a person with whom they were emotionally but not necessarily sexually involved. If the target was not applicable for a respondent (e.g., no brother, mother not alive), the respondent was excluded from the analysis of that specific target. An overall disclosure index was created by calculating the percentage of targets informed after deleting nonapplicable targets. Respondents wrote out their reasons for disclosing or not disclosing to their mother, father, friend, and lover in response to one of two open-ended items for each target (i.e., “Why did you tell your [target]?”; “Why didn’t you tell your [target]?”).

In order to assess emotional and interpersonal reactions of these four targets to disclosure, we asked, “If your [target] knows that you have HIV, how has s/he reacted?” For each target, respondents rated on a scale from never (0) to always (3) the following reactions: (a) “provide emotional support to you”, (b) “withdraw from you”, and (c) “angry at you”. Respondents who informed their lovers were also asked whether or not their lovers had reacted by leaving them.

To assess potential sources of HIV-related support, respondents indicated (yes or no) whether they had talked about HIV-related worries and concerns with any of the following six targets: friend, family member(s), social worker, doctor or nurse who were or were not treating their HIV-infection, religious leader, and professional counselor. All targets were assumed to be applicable for each respondent. We created an overall index by calculating the percentage of the six targets for which the respondent checked yes.

Finally, respondents used standard response formats to indicate sociodemographic information.

Results

Rates of Disclosure and HIV-Related Support

Similar to previous findings among HIV-infected men, disclosure rates were relatively low for extended family members, somewhat higher for immediate family members, and highest for lovers and friends (see Table 1). On average, respondents disclosed to 44.9% (SD = 32.0) of the applicable targets. Almost 13% of the sample had disclosed to no one and 30% had disclosed to only one person; the median response was two targets.

With respect to potential sources of HIV-related support, on average, respondents reported talking with 37.9% (SD = 24.5) of the six targets. About 6% of the sample talked with no one and 32% talked with only one person; the median was two targets. Analyses of individual targets revealed that the majority of respondents (62%) reported talking with doctors or nurses about their HIV-related worries and concerns. About half the sample indicated that family (49%), social workers (46%), and friends (44%) were sources of HIV-related support, but far fewer reported talking with counselors (17%) and religious leaders (14%).

To examine predictors of disclosure, we conducted a multiple regression analysis of the overall disclosure index. The following six sociodemographic and medical variables were entered into the equation simultaneously: age, education, length of time since testing seropositive, HIV diagnostic category (minimal symptoms or ARC/AIDS), sexual partners (males only or males and females), and language of questionnaire. The overall model (conducted on the 63 women for whom complete data were available) was highly significant, $F(6,56) = 5.20$, $p < .001$, and accounted for 36% of the variance in the dependent variable. Two significant independent effects emerged. Younger respondents were more likely than older respondents to disclose ($b = -.010$, SE = .003, $p < .01$), and English speakers were more likely than Spanish speakers to disclose ($b = .409$, SE = .115, $p < .001$). An identical regression analysis conducted on the index of targets with whom respondents talked about HIV-related worries also was significant, $F(6,56) = 2.38$, $p < .05$, $R^2 = .20$, and revealed a similar independent language effect ($b = .187$, SE = .099, $p = .064$). No other predictor variables were significant. Source of HIV infection was not related to disclosure or number of persons with whom respondents spoke.

To provide a more detailed analysis of the language effect, we compared the Spanish speakers (who were all Latinas) with the three groups of English speakers (other Latinas,

Anglos, and African Americans). As presented in Table 2, one-way ANOVAs and post-hoc comparisons revealed that, with one exception, Spanish-speaking Latinas disclosed to fewer targets, $F(3, 61) = 7.60$, $p < .001$, and talk with fewer targets about their HIV-related concerns, $F(3, 61) = 3.75$, $p < .05$, than women in each of the three groups of English speakers. The exception was that African Americans did not differ from any of the other groups on this dimension.

Reasons for Disclosure and Nondisclosure

Our framework for analyzing reasons for disclosure and nondisclosure to mothers, fathers, friends, and lovers highlighted reasons reflecting a desire to avoid negative consequences to and enhance positive outcomes for one's self ("self-focused") or others ("other-focused"). The categories of negative relationship, positive relationship, medical reasons, and "other" also were included. These open-ended reasons were categorized by two independent raters, with disagreements between them categorized by a third independent rater. Overall interrater agreement ranged from 82% to 93%, and kappas (Cohen, 1960) ranged from .76 to .92, all significant at the .0001 level. Because of the small sample size, description of the data is qualitative and preliminary.

Reasons for disclosure—Reasons for disclosure differed according to the target. For lovers, other-focused reasons such as ethical responsibility (e.g., "He has a right to know") and concern for lover's health (e.g., "He has to get himself tested") were most often cited. In contrast, self-focused reasons emphasizing a desire for support (e.g., "There is no one else I can talk to") were more commonly cited for disclosing to parents and friends than to lovers. Additionally, medical reasons related to one's progressing HIV infection (e.g., "I was getting sick") were sometimes given as the reason for disclosure to parents and friends but not to lovers.

Reasons for nondisclosure—Reasons for withholding disclosure also differed according to target. Nondisclosure to lovers and friends was mainly attributed to self-focused reasons such as a desire to avoid personal rejection or to maintain secrecy (e.g., "She's a gossip"). Withholding disclosure from parents, on the other hand, more often reflected other-focused concerns (e.g., "Not to worry her"; "I don't want to cause her problems". In reference to nondisclosure to parents, respondents also referred to the stigma (e.g., "I'm embarrassed to tell her"; "Shame") and ignorance (e.g., "They don't know much about AIDS"; "She's old--she doesn't understand") surrounding HIV infection.

Reactions to Disclosure

Data regarding reactions to disclosure are displayed in Table 3. Although statistical comparisons of targets were not possible because different respondents rated each target, some trends appeared. Mothers, fathers, and friends frequently reacted by providing emotional support and rarely responded by becoming angry or withdrawing. Although lovers appeared to be as frequently emotionally supportive as other targets, the data suggest they were more likely to become angry and withdraw upon learning of the respondent's HIV infection. In fact, 20% (6 of 30) of the lovers reacted to a disclosure by leaving the respondent, suggesting that some respondents' fear of being rejected may be accurate.

Discussion

The 65 HIV-infected women in our sample reported patterns of disclosure similar to those found among HIV-infected men (Hays et al., 1993; Marks et al., 1992; Mason et al., 1994), with rates relatively low for extended family members, somewhat higher for immediate family members, and highest for lovers and friends. Reasons for disclosing to parents and friends were often self-focused, while respondents more often reported other-focused reasons for disclosing to lovers. Mainly self-focused reasons were given for nondisclosure to friends and lovers, but respondents reported mostly other-focused reasons for not disclosing to parents. Reactions to disclosure were generally positive, which is encouraging given the stigma of HIV disease. Of course, women in our sample who chose not to disclose may have been accurately anticipating more negative reactions.

The most salient finding was that Spanish-speaking Latinas reported lower levels of disclosure of HIV infection and fewer people with whom they discussed their HIV-related concerns than English-speaking Latinas, African Americans, and Anglos. The social isolation of HIV-positive Spanish-speaking Latinas is particularly troubling given the accelerating rates of infection in this group. The level of disclosure observed among Spanish-speaking Latinas is highly similar to the level observed among Spanish-speaking gay and bisexual Latino men with HIV (Marks et al., 1992). Considerably higher rates of disclosure have been found among more acculturated Latino and Anglo men who are gay or bisexual (Hays et al., 1992; Mason et al., 1994). These differences suggest that cultural factors may play an important role in self-disclosure of HIV infection.

The limited sample size precluded assessing ethnic differences in reasons for disclosure or nondisclosure, and we did not directly assess acculturation or cultural values. Further research will need to address these issues. However, we speculate that the influence of cultural factors such as simpatía and familism may have inhibited disclosure among Spanish-speaking Latinas, especially disclosure to family members. Simpatía emphasizes the need for behaviors that promote smooth and pleasant social relationships and is reportedly stronger among Latinos than Anglos (Triandis, Marín, Lisansky, & Betancourt, 1984). An individual who is simpàtico strives for harmony in interpersonal relations and avoids interpersonal conflict, which may arise upon the disclosure of HIV infection. Familism describes the solid identification and attachment of individuals to their families and the strong feelings of loyalty, reciprocity, and solidarity among family members (Sabogal, Marín, Otero-Sabogal, VanOss Marín, & Perez-Stable, 1987). For many Latinos, familism leads to membership in a supportive extended network of kin, which usually provides a sense of security and social connectedness. For Latinas with HIV, however, the family also may be a source of conflict and stress (Diaz, 1993). Spanish-speaking Latinas may fear that disclosure of their HIV will shame and disappoint their parents, blemish the honor and reputation of the family, and disrupt familial harmony (Kaminsky et al., 1990). This fear may be exacerbated by the belief that the secret of the diagnosis, once disclosed, will spread quickly in small, tight-knit communities.

Additionally, lower rates of disclosure among Spanish-speaking Latinas may be related to family members' lack of information regarding HIV infection (Corea, 1992; Marín & Marín,

1990). Because it often requires a high school reading proficiency, much public information regarding HIV may be inaccessible to Latinos (Richwald, Schneider-Munoz, & Burciaga Valdez, 1989). Ignorance regarding HIV may promote beliefs in casual transmission and HIV being a disease exclusive to gay Anglo men. Less acculturated Latinos also may espouse traditional values which denounce homosexuality on religious grounds and proscribe discussions of sexuality ("sexual silence" according to Diaz, 1993). These factors may further increase the stigma of HIV infection and discourage Spanish-speaking Latinas from informing family members.

The findings of ethnic differences in disclosure of HIV serostatus highlight the need for culturally sensitive clinical practice. Clinicians may need to offer counseling and educational resources to help the Spanish-speaking Latina educate family members about HIV infection and eventually broach the topic with them. Guiding the patient in developing practical strategies to gradually involve her family or to identify potentially more receptive family members also may be needed. Toward this end, the process of Life Enhancement Counseling (Kaminsky et al., 1990), which aims to mobilize the family and other support systems to assist the patient in adopting health promoting behaviors, may be helpful. Women who engage in stigmatized behaviors such as intravenous drug use or sex with other women may be even less likely to disclose. With respect to these women, clinicians may be more successful in encouraging disclosure to non-family members or suggesting alternate sources of social support such as community HIV groups.

Because social support has been shown to promote mental health and buffer psychological distress (Greenblatt, Becerra, & Serafetinides, 1982), it is important that clinicians help HIV seropositive women develop and utilize supportive social networks. Our data suggest that Spanish-speaking Latinas are particularly in need of such interventions. Of course, our findings are open to alternative interpretations. The Spanish-speaking Latinas in our sample with low disclosure rates or few people with whom they discussed their HIV-related concerns may nevertheless have sufficient social support. At the same time, the higher disclosure rates and number of people talked with noted among other women does not guarantee they have adequate support. Clearly, the quality of support is more important than the quantity of individuals informed or talked with. More comprehensive research on cultural and psychosocial factors that influence the availability, quality, and use of social resources will assist clinicians in helping women better adjust to living with HIV.

Acknowledgments

This research was supported by National Institute of Mental Health Grant 2-R01-MH042023. We acknowledge Norma Maldonado and Maria Sotelo for their assistance in conducting this study.

References

Anastos K, Palleja SM. Caring for women at risk for HIV infection. Journal of General Internal Medicine. 1991; 6:S40–S46. [PubMed: 2005477]

Centers for Disease Control. HIV/AIDS surveillance report. 1993; 5:1–19.

Centers for Disease Control. Revision of the CDC surveillance case definition of acquired immunodeficiency syndrome. Morbidity and Mortality Weekly Report. 1987; 36:3–14.

Chervenak, JL.; Weiss, SH. Sexual partner notification: Attitudes and actions of HIV-infected women. Paper presented at the fifth International Conference on AIDS; Montreal, Quebec, Canada. 1989.

Cohen J. A coefficient of agreement for nominal scales. Educational and Psychological Measurement. 1960; 20:37–46.

Cohen S. Psychological models of the role of social support in the etiology of physical disease. Health Psychology. 1988; 7:269–297. [PubMed: 3289916]

Corea, G. The invisible epidemic: The story of women and AIDS. New York: Harper Collins; 1992.

Diaz, RM. Latino Gay men and the psycho-cultural barriers to AIDS prevention. Stanford University and University of California at San Francisco, Center for AIDS Prevention Studies; 1993. Unpublished manuscript

Greenblatt M, Becerra RM, Serafetinides EA. Social networks and mental health: An overview. American Journal of Psychiatry. 1982; 139:977–984. [PubMed: 7046481]

Hankins CA, Handley MA. HIV disease and AIDS in women: Current knowledge and a research agenda. Journal of Acquired Immune Deficiency Syndromes. 1992; 5:957–971. [PubMed: 1453325]

Hays RB, McKusick L, Pallack L, Hilliard R, Hoff C, Coates TJ. Disclosing HIV seropositivity to significant others. AIDS. 1993; 7:425–431. [PubMed: 8471207]

Hays RB, Turner HA, Coates TJ. Social support, HIV symptoms and depression among gay men. Journal of Consulting and Clinical Psychology. 1992; 60:463–469. [PubMed: 1619100]

Ickovics JR, Rodin J. Women and AIDS in the United States: Epidemiology, natural history, and mediating mechanisms. Health Psychology. 1992; 11:1–16.

Kaminsky S, Kurtines W, Hervis OO, Blaney NT, Millon C, Szapocznik J. Life Enhancement Counseling with HIV-infected Hispanic Gay males. Hispanic Journal of Behavioral Sciences. 1990; 12:177–195.

Kelly JA, Murphy DA, Bahr GR, Koob JJ, Morgan MG, Kalichman SC, Stevenson LY, Brasfield TL, Bernstein BM, St Lawrence JS. Factors associated with severity of depression and high risk sexual behavior among persons diagnosed with Human Immunodeficiency Virus (HIV) infection. Health Psychology. 1993; 12:215–219. [PubMed: 8500451]

Kulik JA, Mahler HM. Social support and recovery from surgery. Health Psychology. 1989; 8:221–238. [PubMed: 2786808]

Marín BV, Marín G. Effects of acculturation on knowledge of AIDS and HIV among Hispanics. Hispanic Journal of Behavioral Sciences. 1990; 12:110–121.

Marks G, Bundek NI, Richardson JL, Ruiz MS, Maldonado M, Mason HRC. Self-disclosure of HIV infection: Preliminary results from a sample of Hispanic man. Health Psychology. 1992; 11:300–306. [PubMed: 1425547]

Marks G, Richardson JL, Maldonado N. Self-disclosure of HIV infection to sexual partners. American Journal of Public Health. 1991; 81:1321–1322. [PubMed: 1928534]

Mason HRC, Marks G, Simoni JM, Ruiz MS. Culturally sanctioned secrets? Latino men's nondisclosure of HIV infection to family, friends, and lovers. 1994 Manuscript submitted for publication.

Mays VM, Cochran SD. Issues in the perception of AIDS risk and risk reduction activities by Black and Hispanic/Latina Women. American Psychologist. 1988; 43:949–957. [PubMed: 3214007]

Richwald GA, Schneider-Munoz M, Burciaga Valdez R. Are condom instructions in Spanish readable? Implications for AIDS prevention. Hispanic Journal of Behavioral Sciences. 1989; 11:70–82.

Sabogal F, Marín G, Otero-Sabogal R, VanOss Marín B, Perez-Stable EJ. Hispanic familism and acculturation: What changes and what doesn't? Hispanic Journal of Behavioral Sciences. 1987; 9:397–412.

Schnell DJ, Higgins DL, Wilson RM, Goldbaum G, Cohn DL, Wolitski RJ. Men's disclosure of HIV test results to male primary sex partners. American Journal of Public Health. 1992; 82:1675–1676. [PubMed: 1456347]

Stempel, R.; Moulton, J.; Bacchetti, P.; Moss, AR. Disclosure of HIV-antibody test results and reactions of sexual partners, friends, family, and health professionals. Paper presented at the fifth International Conference on AIDS; Montreal, Quebec, Canada. 1989.

Triandis HC, Marín G, Lisansky J, Betancourt H. Simpatía as a cultural script of Hispanics. Journal of Personality and Social Psychology. 1984; 47:1363–1375.

Table 1

Women's Disclosure of HIV Infection to Applicable Targets

Target	%	no.
Lover	86.8	(33 of 38)
Friend	78.0	(32 of 41)
Mother	58.7	(27 of 46)
Sister	53.7	(29 of 54)
Brother	49.2	(30 of 61)
Father	30.6	(11 of 36)
Cousin	28.3	(17 of 60)
Grandparents	23.5	(12 of 51)
Aunt or uncle	22.0	(13 of 59)

Table 2

Women's Disclosure of HIV Infection by Ethnic and Language Subgroups

	Spanish Speakers	English Speakers		
Indices	**Latinas (n = 30)**	**Latinas (n = 11)**	**Anglos (n = 11)**	**African Americans (n = 13)**
Targets informed[1] (%)				
M (SD)	27.7[a] (25.7)	53.4[b] (35.4)	56.8[b] (30.1)	67.4[b] (24.2)
Targets talked with[2] (%)				
M (SD)	28.3[a] (20.6)	51.2[b] (19.8)	48.5[b] (28.3)	39.7[ab] (25.9)

Note. Means in a given row that do not share a common superscript differ at the .05 level (Duncan test).

[1]The percentage of applicable targets informed of nine possible (see Table 1).

[2]The percentage of six possible targets talked with (all six were assumed to be applicable).

Table 3

Reactions to Women's Disclosure of HIV Infection

	Reactions to Disclosure[1]		
	Provided emotional support	Became angry	Withdrew from you
Target	M (SD)	M (SD)	M (SD)
Friend (n = 38)	2.8 (0.6)	0.1 (0.3)	0.1 (0.3)
Lover (n = 36)	2.5 (0.9)	1.1 (1.0)	0.5 (0.9)
Father (n = 35)	2.4 (1.1)	0.1 (0.3)	0.1 (0.3)
Mother (n = 45)	2.1 (1.3)	0.3 (0.6)	0.2 (0.6)

Note. The ns for each target differ slightly from those reported in Table 1 due to missing data for the reaction items.

[1] Scored from never (0) to always (3).