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Serostatus Disclosure Among Adults with HIV in the Era of HIV Therapy

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Abstract

Serostatus disclosure is an important component of secondary HIV prevention with potential benefits for both the individual by experiencing increased social support and society by reducing HIV transmission risk behaviors. This cross-sectional study assessed disclosure patterns to sex partners, family members, and friends by sociodemographic and HIV-related factors among an urban, Midwestern U.S. HIV clinic population ($n=809$); a majority of whom were African American and male with a mean age of 41 years. Almost three quarters ($n=596$) of the sample was currently receiving HIV therapy, with 68% ($n=404$) successfully suppressing their HIV viral loads. Among sexually active individuals, 97% reported disclosing their serostatus to sex partners. This high rate of disclosure to sex partners suggests that social desirability may play a role in this self-reported measure. Approximately half of the sample ($n=359$) disclosed to at least one family member and 60% ($n=474$) disclosed to at least one friend. Disclosing to family members occurred more often among participants who were unemployed and endorsed depressive disorder symptoms ($p<0.05$ for all). Disclosing to friends occurred more frequently among women, Caucasians and those who completed higher levels of education ($p<0.001$ for all). HIV disclosure and disease severity were unassociated. Given the chronic nature of HIV care, additional research is needed to develop interventions to facilitate timely disclosure of HIV serostatus.

Introduction

THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) estimates that 1.2 million individuals are living with HIV in the United States, with 1 in 5 unaware of their diagnosis.¹ Despite recommendations for routine HIV testing and aggressive prevention strategies, incident cases of HIV infections remain stable at 56,000 annually. One of the recommended strategies for secondary prevention is the disclosure of HIV serostatus to potential sex partners. HIV serostatus disclosure has been associated with the reduction in HIV transmission,^{2–4} improved engagement in medical care, adherence to medication, and reduction in levels of psychological distress.^{5,6} Additionally, disclosure provides individuals with opportunities for social support.^{7–11} From a public health perspective, disclosure may motivate sexual partners to seek testing and reduce HIV transmission behaviors.¹²

Timing of HIV serostatus disclosure and to whom that disclosure has occurred have previously been examined. Most often, those who have reported non-disclosure attribute this to fear of stigma, shame, and rejection.^{4,13} Individuals with HIV infection are more likely to report serostatus disclosure when engaged in a sustained, long-term sexual relationship compared to brief or casual sexual relationships.^{2,14,15} While disclosure to family and friends does not directly reduce the risk of HIV transmission, individuals with HIV may experience significant benefit by expanding their potential support network. Similar fears of stigma and rejection have been reported regarding disclosure of HIV serostatus to family members and friends.¹⁶ Older adults were less likely to disclose their serostatus to partners, relatives, and friends.¹⁷ Individuals with advanced HIV disease or AIDS were more likely to disclose their status than persons with asymptomatic HIV disease.^{15,18} HIV serostatus disclosure to family members has commonly occurred in later stages of illness,^{19,20}

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suggesting that parental disclosure may be related to heightened need for parents as caregivers.^{15,16,21}

Since much of the research regarding HIV disclosure status comes from the era before combination antiretroviral therapy (cART), additional research needs to examine the process of disclosure patterns among populations with HIV. The impact of cART on the course of HIV disease is profound and has altered the expectations for someone diagnosed with HIV.²² Correspondingly, issues surrounding HIV disclosure are changing as HIV testing becomes de-stigmatized as a part of routine medical care. Furthermore, as individuals with HIV are expected to live longer, a greater number of opportunities for disclosure may arise.^{1,22} The current study examines the patterns of HIV serostatus disclosure to sex partners, family, and friends among a sample of individuals with HIV engaged in care during the cART era. The study was conducted in an effort to augment research conducted earlier in the epidemic. Given the transformation of HIV from a rapidly fatal illness to a chronic manageable disease, a better understanding of the dynamics of disclosure patterns remains an urgent need.

Methods

This cross-sectional study assessed the associations between disclosure to sex partners, family, and friends and sociodemographic and HIV-related factors among an HIV clinic population. As part of standard-of-care, all patients who attended the Washington University HIV Clinic (WU HIV Clinic) in St. Louis, Missouri, between June and December 2008 completed a behavioral assessment during routine clinic visits. These assessments were conducted by trained interviewers while individuals were waiting to be seen by their health care providers. This study was approved by Washington University School of Medicine Human Research Protection Office.

The assessments included measures of demographic characteristics (gender, race/ethnicity, employment, education, and annual income) and depressive symptomatology as measured by the Patient Health Questionnaire (PHQ-9).²³ The PHQ-9 is used to calculate severity and symptom counts that signify major depressive disorder (MDD) and other depressive disorders (ODD). In these analyses we dichotomized the PHQ-9 results to no or mild symptoms and MDD/ODD. Disclosure patterns for sex partners, family, and friends were analyzed separately. Specific questions about HIV serostatus disclosure to casual and primary sex partners were evaluated only among participants who reported sexual activity in the previous 3 months.

Current CD4 cell count, plasma HIV RNA viral load, use, and types of prescribed antiretroviral therapies were collected at time of the visit. cART was defined as the use of at least three drugs from two different antiretroviral drug classes or the use of more than three nucleoside reverse transcriptase inhibitors (NRTI).

Statistical analyses

Bivariate analyses (Pearson's χ^2) were used to assess differences in HIV serostatus disclosure to sex partners, family, or friends by sociodemographic factors and HIV-related measures (HIV RNA viral load and CD4 cell counts). Analyses related to virologic suppression (<400 copies per milliliter) were conducted only with individuals who were on

cART. HIV viral loads were dichotomized (<400 copies per milliliter and >400 copies per milliliter). Education levels were dichotomized by less than or equal to high school graduate/GED or higher than a high school degree.

Employment status was dichotomized into unemployed (including receiving disability benefits) and employed (part or full time). Annual income was dichotomized into less than or equal to and more than \$10,000. Depression severity was dichotomized to those who expressed symptoms of major or other depressive disorders (MDD/ODD) within the past 2 weeks and those who did not. Stepwise logistic regression analyses were conducted to assess independent associations with disclosure; univariate variables were included with $p < 0.1$. Additional analyses were conducted among recently sexually active participants (within 3 months) to identify sociodemographic differences between individuals who have had reported seronegative and seropositive partners. All tests were two-tailed and $p < 0.05$ was considered significant. Data analyses were performed using SPSS software (version 17.0, SPSS Inc., Chicago, IL).

Results

A total of 809 individuals completed the interview with a mean age of 42 years. The majority were male ($n=544$; 67%) and African American ($n=530$; 71%). Almost three-quarters of the sample was currently receiving cART ($n=596$; 74%), with 68% ($n=405$) achieving virologic suppression (<400 copies per milliliter). The median length of time individuals had received their current cART regimen was 1.0 year (interquartile range [IQR]: 0, 2.4). See Table 1 for further description of the study sample.

Among the individuals reporting sexual activity in the previous 3 months ($n=344$), 97% reported disclosing their HIV serostatus to all sex partners (primary and causal).

TABLE 1. SAMPLE DESCRIPTION ($n=809$)^a

	<i>n</i>	%
Gender		
Male	544	67.2
Female	265	32.8
Race		
African American/other	576	71.2
Caucasian	230	28.4
Unemployed	423	52.3
Annual income ≤\$10,000	425	52.5
≤High school diploma/GED	439	54.3
MDD/ODD symptoms	289	35.7
Sex in last 3 months	344	42.5
Condom used at last sex	281	81.9
Receiving cART ($n=596$)	596	73.7
Viral load <50 copies/mL	336	56.4
>50 <400 copies/mL	67	11.2
>400 copies/mL	192	32.2
CD4 cell count		
0–199 cells/mm ³	153	18.9
200–349 cells/mm ³	152	18.8
350–499 cells/mm ³	173	21.4
500+ cells/mm ³	327	40.4

SD, standard deviation; cART, combination antiretroviral therapy.

^aMean age±SD, 41.6±11.0.

Approximately half of the sample ($n=359$) endorsed disclosing to at least one family member (parents, grandparents, siblings, aunts/uncles, cousins). Almost 60% reported disclosing their serostatus to at least one friend ($n=479$). A small proportion of the sample ($n=50$; 6%) reported that no one knew of their HIV status.

There were no significant factors associated with disclosure to sex partners. The majority of participants who reported having casual sex partners endorsed disclosing their HIV status ($n=46$; 75%). The majority (89%) reported using a condom during their last sex event. Of those who reported receptive or insertive vaginal sex, 79% and 72% reported always using condoms, respectively; among those who reported receptive or insertive anal sex, 91% and 96% participants, respectively, endorsed always using condoms. Of the individuals who reported being sexually active in the last 3 months ($n=344$), 23 (7%) did not have a primary sex partner and 14 (4%) did not know their sex partner's HIV status. Subanalyses were conducted to assess socio-demographic differences among individuals who had and knew their primary sex partner's HIV status ($n=313$). Of these individuals, the majority had HIV-negative sex partners ($n=180$; 58%). African Americans more often reported primary sex partners that were HIV-positive (44% versus 29%; $p<0.05$) compared to Caucasian participants. Additionally, individuals with an annual income less than or equal to \$10,000 more often reported having HIV-positive partners (46% versus 32%; $p<0.05$) than those with higher incomes. These relationships are depicted in Table 2.

As noted above, a majority of persons had not disclosed their serostatus to a family member. Disclosing to family

members occurred least often among individuals who were older than 45 years of age compared to their younger counterparts, 18–24 and 25–44 years (37% versus 49% and 50%; $p<0.05$). Individuals who were unemployed were more likely to disclose their status than those who were employed (50% versus 37%; $p<0.001$) and similarly, individuals who reported $\leq \$10,000$ annual income than those who reported more (48% versus 40%; $p<0.05$). Individuals who reported significant depressive symptoms were more likely to disclose their status to family members than those who were not depressed (54% versus 38%; $p<0.001$). There were no significant associations between disclosure patterns to family members and viral loads or CD4 cell counts. When controlling for gender, age, education, and income, unemployed individuals were 1.45 times more likely and individuals who expressed depressive symptoms were 1.67 times more likely to disclose to family members (Table 3).

Disclosing to friends occurred more often among men than women (64% versus 48%; $p<0.001$). Caucasians were more likely to disclose than African Americans (71% versus 54%; $p<0.001$). Individuals with greater education were more likely to disclose their status to friends (67% versus 51%; $p<0.001$). Individuals with income greater than \$10,000 reported were more likely to disclose (64% versus 54%; $p<0.05$). When controlling for income, women were 1.62 more likely to disclose, Caucasians were 1.96 more likely, and individuals who completed greater education were 1.67 times more likely to disclose their HIV status to their friends. There were no significant associations between disclosure to friends and HIV stage (as measured by viral loads and CD4 cell counts). Table 4 describes the associations between factors of disclosing to friends. Half of the participants disclosed to both their family members and friends ($n=280$); while 10% disclosed only to their family members and 24% only to their friends. Individuals who expressed depression symptoms were more likely to disclose to both family members and friends (58% versus 46%; $p=0.006$).

TABLE 2. COMPARISONS OF INDIVIDUALS WITH SEROPOSITIVE AND SERONEGATIVE SEX PARTNERS ($n=313$)

	HIV – partners ($n=180$)		HIV + partners ($n=133$)		<i>p</i> Value
	<i>n</i>	%	<i>n</i>	%	
Gender					
Male	102	59.6	69	40.4	0.491
Female	77	63.6	44	36.4	
Age					0.400
18–24 years	14	50.0	14	50.0	
25–44 years	111	61.7	69	38.3	
≥ 45 years	54	64.3	30	35.7	
Race	<i>n</i>	%	<i>n</i>	%	0.017
African American/other	107	56.3	83	43.7	
Caucasian	72	70.6	30	29.4	
Employment status					0.321
Unemployed	90	58.8	63	41.2	
Employed	89	64.5	49	35.5	
Income					0.020
$\leq \$10,000$	79	54.5	66	45.5	
$> \$10,000$	99	67.8	47	32.2	
Education					0.522
\leq High school diploma/GED	85	59.4	58	40.6	
$>$ High school diploma	94	63.1	55	36.9	

All percentages shown are row percentages.

Discussion

The current study sought to examine HIV serostatus disclosure patterns to sexual partners, family members, and friends in the era of cART among individuals with HIV who are engaged in care. As individuals are living longer with HIV and with less morbidity, few examinations of serostatus disclosure patterns have been conducted.^{13,16,24,25} We found overall high rates of HIV disclosure to sex partners, family members, and friends, which varied by sociodemographic factors and depressive symptoms. This study found different factors are significantly associated in disclosing HIV status to family members and friends.

Nearly all individuals reported disclosure to sex partners. This finding raises issues of questionable validity. Although legislation has been implemented at the state level in the United States (including Missouri where this study was conducted) to compel individuals with HIV/AIDS to disclose their status prior to engaging in sexual activity, previous studies have reported lower rates of disclosure to sex partners.^{26,27} Case managers are required to review these mandates annually with their clients.²⁸ Fear of this enforcement is likely to influence the social desirability regarding discussions of patterns of disclosure of HIV serostatus to sex partners. Our study population is highly disenfranchised as they live in

TABLE 3. DISCLOSURE PATTERNS TO FAMILY MEMBERS (*n* = 809)

	<i>Did not disclose</i>		<i>Disclosed</i>		<i>p Value</i>	<i>Unadjusted odds ratios</i>	<i>Adjusted odds ratio of less likely to disclose</i>
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>			
Gender							
Male	314	57.7	230	42.3	0.097	1.30 (1.04, 1.74)	
Female	136	51.3	129	48.7		Ref	
Age							
18–24 years	29	50.9	28	49.1	0.002		
25–44 years	212	50.4	209	49.6			
≥45 years	209	63.1	122	36.9			
Race							
African American/other	323	56.1	253	43.9	0.754	Ref	
Caucasian	126	54.8	104	45.2		1.05 (1.29, 1.43)	
Employment status							
Unemployed	236	50.5	231	49.5	0.001	Ref	Ref
Employed	213	62.6	127	37.4		1.64 (1.23, 2.18)	1.45 (1.08, 1.96)
Education							
≤High school diploma	218	52.7	196	47.3	0.089	Ref	
>High school diploma	232	58.7	163	41.3		1.28 (1.03, 1.69)	
Income (<i>n</i> = 794)							
≤\$10,000	219	51.5	206	48.5	0.015	Ref	
>\$10,000	222	60.2	147	39.8		1.42 (1.07, 1.88)	
Depressive symptoms							
Mild-no symptoms	281	61.9	173	38.1	0.001	1.90 (1.43, 2.54)	1.67 (1.24, 2.25)
MDD/ODD symptoms	151	46.0	177	54.0		Ref	Ref
Current receipt of cART	331	55.5	265	44.5	1.000	1.01 (1.35, 1.39)	
Viral load >400 copies/mL (<i>n</i> = 596)	107	55.4	86	44.6	0.974	1.01 (1.40, 1.42)	
CD4 cell count (<i>n</i> = 805)							
0–199 cells/mm ³	81	52.9	72	47.1	0.138		
200–349 cells/mm ³	93	61.2	59	38.8			
350–499 cells/mm ³	104	60.1	69	39.9			
500+ cells/mm ³	170	52.0	157	48.0			

Associations indicate less likely to disclose to family members.

MDD, major depressive disorder; ODD, other depressive disorders.

impoverished communities and experience stigma related to their sexual orientation (in cases of MSM) and HIV infection. Thus, being asked questions about disclosure patterns within the context of a clinic visit and knowing the mandates is likely to increase discomfort in responding. Additionally, these structural interventions may also serve as barriers to actual disclosure to sex partners for fear of prosecution, violence, and stigma.²⁹ Other research has found that part of the process for individuals with HIV to feel comfortable and confident to disclose their status to sexual partners, they need to have psychologically processed their infection, how their identity may have changed, and how this infection now influences their responsibility in sexual relationships; these findings may be useful in development of interventions that may be developed to address disclosure patterns among identified individuals in need.¹³

While there was no variation in reported disclosure to sex partners, this study found that individuals disclosed their HIV status to family members more often when they expressed depressive symptoms and were unemployed. These findings suggest that the independence of employment, which likely protects individuals from other distress symptoms,³⁰ may not promote disclosure to family members. Unemployed individuals may require greater assistance

from family members for basic needs. Relating the consequences and challenges of living with HIV may be necessary to receive familial support in these situations. Individuals who report more symptoms of depression may also be expressing more symptoms of or challenges with managing their HIV,^{31–33} or perhaps express their need for psychological support due to their distress, as well as the disease. Interestingly, the only significant difference among individuals that disclosed to family members and friends was endorsing severe depressive symptoms. Requesting assistance or support likely serves as a benefit for enhanced HIV management.

Disclosure to friends occurred more often among Caucasians, men, individuals who expressed depressive symptoms, and those who attained higher levels of education. These findings suggest how HIV has become less stigmatized in some sub-populations in the United States, yet not in others. More common disclosure to friends among Caucasian men, specifically MSM, is not surprising given the well-documented epidemiology of the early HIV epidemic. Again, individuals who express depressive symptoms are disclosing more often to friends. These depression-related findings provide an intervention opportunity, as family members and friends may provide needed support to the continued

TABLE 4. DISCLOSURE PATTERNS TO FRIENDS (*n*=809)

	<i>Did not disclose</i>		<i>Disclosed</i>		<i>p Value</i> 0.001	<i>Unadjusted</i> <i>odds ratios</i>	<i>Adjusted odds ratio</i> <i>of less likely to disclose</i>
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>			
Gender							
Male	198	36.4	346	63.6		Ref	Ref
Female	137	51.7	128	48.3		2.86 (1.39, 2.52)	1.62 (1.19, 2.20)
Age					0.184		
18–24 years	18	31.6	39	68.4			
25–44 years	184	43.7	237	56.3			
>45 years	133	40.2	198	59.8			
Race					0.001		
African American/other	267	46.4	309	53.6		2.15 (1.55, 2.99)	1.96 (1.39, 2.776)
Caucasian	66	28.7	164	71.3		Ref	Ref
Employment status					0.172		
Unemployed	204	43.7	263	56.3		1.25 (1.06, 1.67)	
Employed	130	38.2	210	61.8		Ref	
Education					0.001		
≤High school diploma/GED	204	49.3	210	50.7		1.96 (1.47, 2.60)	1.67 (1.20, 2.18)
>High school diploma	131	33.2	264	66.8		Ref	Ref
Income					0.007		
≤\$10,000	194	45.6	231	54.4		1.49 (1.12, 1.98)	
>\$10,000	133	36.0	236	64.0		Ref	
Depressive symptoms							
Mild-no symptoms	196	43.2	258	56.8	0.239	Ref	
MDD/ODD Symptoms	127	38.7	258	61.3		1.20 (1.11, 1.61)	
Receipt of cART	250	74.6	346	72.9	0.627	0.360 (0.137, 0.198)	
Viral load >400 copies/mL (<i>n</i> =596)	86	44.6	107	55.4	0.377	0.833 (0.393, 0.972)	
CD4 cell count							
0–199 cells/mm ³	66	43.1	87	56.9	0.230		
200–349 cells/mm ³	65	42.8	87	57.2			
350–499 cells/mm ³	81	46.8	92	53.2			
500+ cells/mm ³	123	37.6	204	62.4			

MDD, major depressive disorders; ODD, other depressive disorders.

management of HIV. Having attained higher levels of education likely alleviates some of the stigma surrounding HIV infection and the risks of transmission. Intuitively, friends are likely to provide social support, and previous research has shown that friends are the most common recipients of HIV disclosure.¹⁸ While it was not associated with HIV management, the association of combined disclosure to friends and family members suggests the existence of a larger support network. These findings also support a better understanding for needed interventions for the types of individuals who are not disclosing their serostatus to family members and friends. In the era of cART, perhaps the patterns of disclosure have changed. Specifically, previous studies have indicated that disclosure levels to friends are much lower than we have reported here.¹⁵ It is likely that previous research was conducted in the pre-cART era, where there seemed to be more stigma associated with HIV diagnosis due to limited available treatments. Additionally, HIV infection may have been introduced at a much earlier age for many people in schools and through media, although these messages are not recently prevalent. The differential patterns of HIV status disclosure to friends suggest a complex set of influences that has changed over time and requires further investigation.

Our data suggest that serostatus disclosure continues to be difficult for some sub-populations, likely attributable to many

factors including stigma and fear. Yet, overall we identified high rates of disclosure. The finding that African Americans are less likely to disclose to friends, highlights other research suggesting that homophobia is more pernicious in African American communities, specifically men, older individuals, and those living in rural areas.³⁴ Moreover, overall HIV-related stigma has also been prevalent in African American communities, which may also play an integral role in disclosing HIV status.³⁵ HIV-related stigma, fear of alienation and ostracism, although not examined in this study, still serve as a barrier to prevention efforts and likely impact non-disclosure rates particularly in our study among African Americans, those who are less educated, have lower income, and are younger.

Limitations

This was a cross-sectional study that was conducted from one clinic population. The validity and reliability of questions related to disclosure patterns to sex partners, family members, and friends has not been widely studied. We expect that we had questionable validity in the responses of disclosure to sex partners, due to social desirability. It is unclear whether those patterns are expected when surveying patients about their disclosure to family members and friends. While our findings suggest some variation of what

has been known regarding disclosure, this study increases understanding of the patterns that occur today in the era of successful HIV therapy.

This study provides insight to family and friend HIV disclosure patterns that have not been discussed in the context of recent medical advancements. Furthermore, disclosure of serostatus to sex partners is complicated not only by fear of rejection and stigma but also by fear of prosecution for reporting nondisclosure. The recently announced National HIV/AIDS Strategy for the United States highlights efforts to increase awareness of HIV today by focusing primarily on increasing HIV testing, and secondary prevention efforts remain critical to success as well.³⁶ Unfortunately, despite advances in medical care, stigma and fear of HIV persist as is suggested in incomplete HIV disclosure to family members and friends. The high rates of HIV serostatus disclosure in our study illustrate that many individuals with HIV have disclosed their status with the potential to improve social support through disclosure. These findings suggest that we can identify patterns of disclosure based on sociodemographic and HIV-related characteristics, which may help providers support their patients and clients in developing appropriate support networks and secondary prevention interventions. Without the support needed in managing HIV, self-care behaviors are likely to be ignored, and thus poorly impacting HIV-related health outcomes and increasing HIV transmission risk behaviors. Additionally, secondary prevention efforts to address serostatus disclosure both for sex partners and overall social networks in order to provide avenues for support as individuals with HIV managing HIV infection and its comorbidities is complicated. Serostatus disclosure is an integral component in the secondary prevention effort to reduce incident HIV infections.

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