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## Predictors of HIV Disclosure in Infected Persons Presenting to Establish Care

LATESHA ELOPRE, MD<sup>1</sup>, ANDREW O. WESTFALL, MS<sup>1</sup>, MICHAEL J. MUGAVERO, MD<sup>1</sup>, ANNE ZINSKI, PHD<sup>1</sup>, GREER BURKHOLDER, MD<sup>1</sup>, EDWARD W. HOOK, MD<sup>1</sup>, and NICHOLAS VAN WAGONER, MD PHD<sup>1</sup>

<sup>1</sup>Division of Infectious Diseases, Department of Medicine, University of Alabama at Birmingham, Birmingham AL

### Abstract

Persons receiving effective HIV treatment experience longevity and improvement in quality of life. For those infected, social support is associated with improved medication adherence. Disclosure of infection status is likely a prerequisite for social support. However, little research describes patterns of HIV disclosure by infected persons. We retrospectively evaluate factors associated with disclosure among patients initiating HIV care at a university-based clinic from 2007-2012. Of 490 persons initiating care, 13% had not disclosed their HIV infection to anyone. Black race significantly predicted non-disclosure and persons living with a significant other or friends were more likely to have disclosed their HIV infection versus those living alone. CD4+ T lymphocyte count <200 was associated with nondisclosure and disclosure only to family members. Future research is needed to better understand factors associated with disclosure of HIV infection status, because this could enhance receipt of social support and contribute to improved HIV health outcomes.

### Keywords

HIV; disclosure; social support; outcomes

## INTRODUCTION

Over 1.1 million people in the United States are living with HIV, with almost 50,000 new cases diagnosed each year.(1) Over the past two decades, the advent and iterative advances of highly active anti-retroviral therapy have changed HIV from a uniformly fatal illness to a chronic disease in which treatment and medication adherence are crucial determinants of survival. In many chronic diseases including cancer, coronary artery disease and depression, social support predicts better health outcomes, in part, due to improved medication and appointment adherence.(2) As with other chronic diseases, social support is believed to improve HIV-related health by increasing engagement in care and medication adherence, fundamental factors for HIV viral load suppression and patient survival.(3, 4)

Corresponding author: Latesha Elope, ZRB 206, 1720 2<sup>nd</sup> Ave South, Birmingham, AL 35294. Phone: (205) 934-5191, Fax: (205) 934-5155, lelope@uabmc.edu.

For persons living with HIV, disclosure of HIV infection status is a likely prerequisite for gaining social support.(5, 6) However, the decision to disclose HIV status is complex and may involve weighing potential costs versus benefits in disclosing to friends, family or sexual partners.(7) Further, persons with HIV may only selectively disclose their HIV status to others as a means of coping with perceived stigma and as a reflection of assumed value and risk of disclosure to different individuals.(8, 9) Despite the pivotal role of social support in adherence to HIV care, little is known about the patterns of disclosure among HIV infected persons newly initiating in care.

We conducted a retrospective analysis at a university-affiliated HIV Clinic in Birmingham, AL aimed toward understanding the social and cultural factors that predict nondisclosure and selective disclosure to identify populations at risk for reduced social support at initiation of care. Our second aim was to understand if nondisclosure and selective disclosure were related to presentation later in the course of infection as reflected by a CD4 + T Lymphocyte (CD4) count < 200 cells/mm<sup>3</sup> at the time of entry into care.

## METHODS

### Study Design and Participants

We conducted a retrospective analysis of data collected from a cohort of HIV infected persons presenting to establish care at a university-based HIV Clinic (1917 Clinic). All patients entering HIV primary care at the 1917 Clinic complete an orientation visit prior to their first medical appointment known as Project CONNECT: Client-Oriented New patient Navigation to Encourage Connection to Treatment, which includes a semi-structured needs assessment interview with a trained staff member, a blood draw for baseline lab values, and a self-administered questionnaire.(10) Domains include socio-demographic characteristics and, potential physical or emotional barriers to sustained engagement in care, which are addressed individually to help tailor planning for HIV primary care attendance.

We included data from patients at least 19 years of age at the date of clinic orientation who did not report a prior history of HIV outpatient medical care and were entering care for the first time between January 2007 and April 2012. Independent and dependent variable values were compiled from the Project CONNECT database and the UAB 1917 Clinic Cohort electronic medical record.(11) This study was approved by the University of Alabama (UAB) Institutional Review Board.

### Outcome Variables

The primary outcome was disclosure of HIV infection status at the time of initial entry into HIV care. Disclosure was categorized into a 3-level variable: nondisclosure, selective disclosure and broad disclosure. Selective disclosure was defined as disclosure to only one potential, support group that was mutually exclusive (i.e. friends, family, or spouse/partner/or significant other [hereafter referred to as a significant other]). Broad disclosure was defined as disclosure to more than one potential support group. To further understand disclosure patterns, we performed a secondary analysis where disclosure was defined by a five-level mutually exclusive disclosure outcome measure with disclosure to: no one, family

only, friends only, significant other only or more than one group. In all models, we classified disclosure to more than one group (referent) as optimal based on previous literature demonstrating that individuals who consistently disclose their serostatus to secondary sexual partners were less likely to engage in unprotected anal intercourse.(16–19)

### Independent Variables

In an effort to characterize relationships between disclosure of HIV status and social support, independent variables were selected based on a four-level social ecology model, which included macro- and micro-system level components.(16, 17) The social ecology model is also endorsed by the NIH for research with lesbian, gay, bisexual, and transgender (LGBT) populations, who represent the majority of our sample.(16) We selected race and church attendance as macro-system variables as both variables may potentially contribute to cultural values in our patient population. Also, church attendance, was previously shown to be associated with later presentation for HIV care in the same cohort for MSM, demonstrating its potential influence on outcomes.(18) Micro-system level variables included age, education level, sexual behavior, and living arrangement. CD4 count and HIV viral load (VL) at presentation to care were included in the model to evaluate the relationship between late presentation for HIV care and disclosure of HIV infection status.

Sexual behavior was defined by sex and self-reported same- or opposite- sex sexual behaviors (i.e. men who have sex with men [MSM], men who have sex with women [MSW] and women who have sex with men [WSM]). There were no women who had sex with women in this sample. These categories were mutually exclusive and men reporting any same sex behaviors were categorize as MSM. CD4 count closest to the patient's orientation visit (-30 to +90 days) were used in the analyses. CD4 count was categorized based on definitions of disease severity and treatment guidelines from the World Health Organization: < 200 cells/mm<sup>3</sup>, 200-350 cells/mm<sup>3</sup> and > 350 cells/mm<sup>3</sup>.(19) Current living arrangement was described using four mutually exclusive categories: 1) alone, 2) with family, 3) with a significant other, or 4) with friends/other. No information was available for housing status in the database. Participants also had the option of reporting that they lived with a friend who was not a sexual partner. Roommates were placed into the friend category. All other living arrangements written in as free text responses (e.g. roommate, brother's partner, partner's brother) were categorized as other (N= 27). Because of the small number of participants reporting "other" living arrangements, living with others and friends were combined.

### Statistical Analysis

Independent variables were summarized using frequencies and percent for categorical variables and medians, with lower and upper quartiles, for continuous variables. Variables were summarized by nondisclosure, selective disclosure and any disclosure of HIV infection status. For the primary 3-level disclosure outcome, multinomial logistic regression models were fit using broad disclosure as the referent. HIV viral load was strongly associated with CD4 count at presentation and employment status was similarly associated with insurance status, therefore, both of the variables were dropped from further analyses to avoid issues of collinearity (data not shown).

For the secondary 5-level disclosure outcome, multinomial logistic regression models were fit using disclosure to more than 1 group as the referent. For both outcomes univariate models were first fit and then, based on the results of the univariate models, multi-variable models were fit. Adjusted odds ratios along with their corresponding 95% confidence intervals are reported. All analyses were performed using SAS v9.3 (Cary, NC).

## RESULTS

Between January 2007 and April 2012, 1,645 patients completed an orientation visit at the 1917 clinic. Of those, 591 (36%) were entering HIV care for the first time, of whom 490 patients met study inclusion and exclusion criteria. The median age of the patient population was 33 years and most were African American (63%) and male (82%). The majority were MSM (60%) and had CD4 counts < 350 (53%; median 277, IQR 64-461) upon entering care. More than half of participants reported current church attendance and at least some college education. Close to half (46%) of the population did not have insurance and only 35% reported current employment. One third of participants reported living with a family member (34%). (Table I)

Most patients (N = 425, 87%) had disclosed their HIV infection status to someone prior to entering HIV care for the first time. However, one in eight patients (N = 65, 13%) had disclosed to no one. Of those who disclosed, most reported only selective disclosure (N=240, 58%). In adjusted models comparing nondisclosure and selective disclosure to broader disclosure, nondisclosure was four times as a common among black compared to white patients (AOR 4.0; 95% CI 1.8, 8.9). Blacks were also almost twice as likely (AOR 1.7; 95% CI 1.0, 2.7) to report selective disclosure. In contrast, patients who lived with a significant other (AOR 0.2; 95% CI 0.1, 0.6) and those who reported living with a friend (AOR 0.2; 95% CI 0.1, 0.8) were 80% less likely to report nondisclosure. (Table II)

We next evaluated variables associated with selective disclosure to a specific group (i.e. disclosure to family only, friends only and significant other only). Of patients reporting selective disclosure, 44(18%) had disclosed only to a significant other, 85 (35%) had disclosed only to family and 111 (46%) had disclosed only to friends. In this adjusted model, the association between black race and nondisclosure remained the same (AOR 4.0; 95% CI 1.8, 8.7). Variables predicting selective disclosure varied by disclosure group (Table III). Living with a significant other predicted disclosure to a significant other only (AOR 12.5; 95% CI 2.7, 56.6). WSM also more often disclosed only to a significant other (AOR 4.2; 95% CI 1.3, 13.1). Selective disclosure to family only was also associated with sexual behavior. MSW (AOR 2.7; 95% CI 1.3, 5.7) and WSM (AOR 3.0; 95% CI 1.3, 7.1) were more likely to disclose to family only when compared to MSM Reporting higher levels of education was the only variable positively associated with disclosing to friends only (AOR 2.1; CI 1.2, 3.8).

Of particular interest was the relationship between disclosure and CD4 count at the time of entry into care. Patients who disclosed to no one (AOR 2.1; 95% CI 1.0, 4.3) as well as patients who selectively disclosed their HIV status, albeit not reaching statistical significance (AOR 1.6; 95% CI 0.9, 2.6), were more likely to present with CD4 counts < 200

cells/mm<sup>3</sup> (Table II). In the 5-level disclosure model, presenting with a CD4 count <200 cells/mm<sup>3</sup> was again associated with nondisclosure (AOR 2.1; 95% CI 1.0, 4.3). In addition, patients who reported selective disclosure to family only were more likely to present with low CD4 counts (AOR 2.5; 95% CI 1.3, 4.9), but this association was not observed for the other selective disclosure groups. (Table III)

## DISCUSSION

As shown for other chronic illnesses, social support is associated with better health outcomes for patients with HIV.(20, 21) However, for some HIV-infected individuals, the perceived barriers for disclosure may outweigh the benefits and preclude or limit disclosure. The consequences of nondisclosure, or even selective disclosure, may include isolation and potentially increased risk of poor HIV-related outcomes.(22) In this study, we identify variables associated with nondisclosure and selective disclosure among patients initiating HIV care. Of particular interest was the relationship between CD4 count as a marker of disease progression and nondisclosure and/or selective disclosure at the time of care entry.

In our study, the majority of patients reported selective disclosure of their HIV status. Both race and CD4 count were associated with nondisclosure and selective disclosure. Black patients were more likely to report nondisclosure and selective disclosure in both the primary and secondary analysis compared to white patients. Additionally, patients who had not disclosed, or who disclosed only to family, were more likely to present with a CD4 count < 200 cell/mm<sup>3</sup>.

Previous literature indicates that racial minorities tend to present later for HIV care with lower CD4 counts.(23–25) Black patients are also more likely to have missed scheduled HIV clinic appointments and less likely to achieve viral load suppression.(25, 26) As such, Black Americans remain not only the population in the United States most at risk for HIV acquisition but also for poor HIV-related health outcomes.(23, 25) These findings suggest that Black Americans may be particularly vulnerable at the earliest stages along the HIV continuum.(27) Our findings also identify this population to be at greater risk of nondisclosure when first entering care, which may portend or mediate worse HIV health outcomes. The decision to not disclose is likely linked to perceived stigma and lack of social support, which may also be associated with delays in HIV testing and care seeking behaviors. (28, 29)

We also observed that persons living with friends or significant others more often disclosed their HIV status than persons living alone. In cases of cohabitation, whether disclosure results from proximity, the strength of relationships or the inability to conceal infection is unclear and deserves further exploration. As social isolation in HIV infected persons has been associated with increased hospitalization and mortality, our findings warrant further exploration of additional services or group-based support for patients presenting to care who live alone or lack social support.(30) It may also be advantageous to evaluate reasons why HIV infected patients who live alone decide not to disclose their status and, when appropriate, to utilize motivational interventions to assist individuals with disclosure decisions.

Studies show that patients initiating care with CD4 counts  $< 200$  cells/mm<sup>3</sup> have higher rates of morbidity and mortality, as well as, blunted immunological responses after initiating ART.(31–34) The vulnerability and concern for this population is further magnified by the findings that nondisclosure is more common in patients presenting with CD4 counts  $< 200$  cells/mm<sup>3</sup>. The decision to selectively disclose HIV status to family may reflect disease progression and greater need for social support. Future studies are needed to understand whether nondisclosure and/or selective disclosure with resulting reduced social support mediate worse HIV related outcomes in person with more advanced disease. For example, internal and external stigmatization of HIV may negatively impact a person's decision to disclose. For persons with higher levels of HIV-related stigmatization, strategies that reduce internal and external stigma may also reduce uneasiness with disclosure.

Our study has several limitations. This is an observational study and as such no causal inferences can be made in the associations that were found, nor can temporality be established. This study was also done at a university based HIV clinic in the Southeastern United States. This may limit the generalizability of our results to other patient populations. However, health care disparities previously described are greatest in this region of the United States. Also, the study design did not allow for more complex statistical analyses, such as factor analysis, that might allow for further characterization of HIV disclosure patterns. Finally, we are unable to account for HIV disclosure after entry into care. Despite these limitations we believe that our data help to characterize early HIV disclosure patterns and provide a foundation for both future interventions and research.

## CONCLUSION

In conclusion, our study provides new insight into the complexity of early disclosure of HIV status among persons newly entering outpatient HIV medical care. We highlight patient populations that may be at increased risk of reduced social support due to decisions to not disclose HIV status, potentiating the risk of poor HIV care adherence and health outcomes. Our findings reinforce the need for evaluating the relationship between disclosure and HIV-related health outcomes and understanding the factors contributing to lower disclosure, specifically among Black Americans and persons with CD4 counts  $< 200$  at entry into HIV care. This early time point may serve as a uniquely effective and impactful intervention period for mitigating downstream health disparities. Expanding awareness of how interpersonal, social and community relationships influence disclosure decisions across groups, particularly in the southeastern United States may contribute to improved HIV-related health outcomes.

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**Table I**

Characteristics of Study Population by HIV Disclosure Status in Patients Newly Presenting for HIV Care (N = 490)

Characteristics	No Disclosure N = 65 n (%)	Selective <sup>a</sup> Disclosure N = 240 n (%)	Broad Disclosure N = 185 n (%)
Median Age, years (Q <sub>1</sub> -Q <sub>3</sub> )	34 (29-46)	33 (26-43)	30 (26-41)
Race <sup>b</sup>			
Caucasian	14 (22)	79 (33)	86 (48)
African American	50 (78)	158 (67)	95 (52)
Sex/Sexual Behavior			
Male, sex with men (MSM)	38 (59)	132 (55)	124 (67)
Male, sex with women (MSW)	12 (18)	59 (25)	36 (19)
Female, sex with men (WSM)	15 (23)	49 (20)	25 (14)
CD4 <sup>+</sup> T Lymphocyte Count (cells/mm <sup>3</sup> )			
> 350	27 (42)	110 (46)	96 (52)
200-350	12 (18)	47 (20)	42 (23)
< 200	26(40)	83 (34)	47 (25)
Church Attendance			
No	29 (45)	94 (39)	91 (49)
Yes	36 (55)	146 (61)	94 (51)
Education <sup>c</sup>			
Diploma/GED or less	25 (39)	99 (42)	76 (42)
Some College or more	39 (61)	139 (58)	103 (58)
Insurance Status			
Private	22 (34)	100 (42)	68 (37)
None	30 (46)	105 (44)	95 (51)
Public	13 (20)	35 (14)	22 (12)
Living Arrangement			
Alone	27 (42)	59 (25)	40 (22)
Family	25 (38)	79 (33)	64 (34)
Partner/Spouse/SO <sup>d</sup>	9 (14)	58 (24)	57 (31)
Friends/Other	4 (6)	44 (18)	24 (13)

<sup>a</sup>Selective disclosure means disclosure to only 1 type of potential support group (i.e. family only, significant other only or friends only). Broad disclosure means disclosure to more than 1 type of potential support group.

<sup>b</sup>Race not reported 8 participants

<sup>c</sup>Education not reported for 9 participants.

<sup>d</sup>SO = significant other

**Table II**

Predictors for Nondisclosure and Selective Disclosure of HIV Status in Patients First Presenting to Establish Care

Characteristics	Disclosure <sup>a</sup>	
	No One N = 65 (95% CI)	Selective Disclosure N = 240 (95% CI)
Age, per 10 years	1.3 (0.9-1.7)	1.0 (0.8-1.2)
Race		
Caucasian	ref <sup>b</sup>	ref
African American	<b>4.0 (1.8-8.9)<sup>c</sup></b>	<b>1.7 (1.0-2.7)<sup>d</sup></b>
Sex/Sexual Behavior		
Male, sex with men (MSM)	ref	ref
Male, sex with women (MSW)	0.7 (0.3-1.8)	1.5 (0.9-2.7)
Female, sex with men (WSM)	1.7 (0.7-4.2)	<b>2.1 (1.1-3.9)<sup>d</sup></b>
CD4 <sup>+</sup> T Lymphocyte Count (cells/mm <sup>3</sup> ) <sup>e</sup>		
> 350	ref	ref
200-350	1.2 (0.5-2.8)	1.0 (0.6-2.8)
< 200	<b>2.1 (1.0-4.3)<sup>d</sup></b>	1.6 (0.9-2.6)
Church Attendance		
No	ref	ref
Yes	0.7 (0.4-1.3)	1.2 (0.8-1.9)
Education		
Diploma/GED or less	ref	ref
Some College or more	1.8 (0.9-3.5)	1.4 (0.9-2.1)
Insurance Status		
Private	ref	ref
None	1.2 (0.6-2.4)	0.8 (0.5-1.2)
Public	1.5 (0.6-3.9)	0.8 (0.4-1.7)
Living Arrangement		
Alone	ref	ref
Family	0.5 (0.2-1.0)	0.7 (0.4, 1.2)
Partner/Spouse/SO	<b>0.2 (0.1-0.6)<sup>c</sup></b>	0.7 (0.4-1.2)
Friends/Other	<b>0.2 (0.1-0.8)<sup>d</sup></b>	1.5 (0.7-2.9)

<sup>a</sup>Multi-variable multinomial logistic regression model modeling the 3-level disclosure outcome with broad disclosure as the referent. Model includes all variables shown in the table.

<sup>b</sup>Ref = Referent group

<sup>c</sup>P-value <0.01

<sup>d</sup>P-value <0.05

**Table III**

Adjusted Predictors for Disclosure of HIV Status in Patients First Presenting to Establish Care

Characteristics	Disclosure <sup>a</sup>			
	No one N = 65 (95% CI)	Significant Other Only N = 44 (95% CI)	Family Only N = 85 (95% CI)	Friends Only N = 111 (95% CI)
Age, per 10 years	1.3 (0.9, 1.7)	1.4 (0.9, 1.9)	0.9 (0.7, 1.2)	0.9 (0.7, 1.2)
Race				
Caucasian	ref <sup>b</sup>	ref	ref	ref
African American	<b>4.0 (1.8, 8.7)<sup>c</sup></b>	1.8 (0.7, 4.8)	1.8 (0.9, 3.7)	1.5 (0.8, 2.7)
Sex/Sexual Behavior				
MSM	ref	ref	ref	ref
MSW	0.7 (0.3, 1.8)	2.4 (0.9, 6.4)	<b>2.7 (1.3, 5.7)<sup>d</sup></b>	0.7 (0.3, 1.5)
WSM	1.7 (0.7, 4.2)	<b>4.2 (1.3, 13.1)<sup>d</sup></b>	<b>3.0 (1.3, 7.1)<sup>d</sup></b>	1.3 (0.6, 3.0)
CD4 <sup>+</sup> T Lymphocyte Count (cells/mm <sup>3</sup> ) <sup>e</sup>				
> 350	ref	ref	ref	ref
200-350	1.2 (0.5, 2.7)	1.5 (0.6, 4.2)	0.6 (0.3, 1.5)	1.0 (0.5, 1.9)
< 200	<b>2.1 (1.0, 4.3)<sup>d</sup></b>	1.5 (0.6, 3.7)	<b>2.5 (1.3, 4.9)<sup>c</sup></b>	1.0 (0.5, 1.9)
Church Attendance				
No	ref	ref	ref	ref
Yes	0.7 (0.4, 1.3)	1.3 (0.5, 3.3)	1.7 (0.9, 3.3)	0.9 (0.5, 1.6)
Education				
Diploma/GED or less	ref	ref	ref	ref
Some College or more	1.7 (0.9, 3.4)	1.1 (0.5, 2.7)	0.9 (0.5, 1.7)	<b>2.1 (1.2, 3.8)<sup>d</sup></b>
Insurance Status				
Private	ref	ref	ref	ref
None	1.1 (0.6, 2.3)	0.9 (0.4, 2.1)	0.6 (0.3, 1.3)	0.8 (0.5, 1.4)
Public	1.5 (0.6, 4.0)	0.8 (0.2, 2.8)	1.0 (0.4, 2.4)	0.6 (0.2, 1.7)
Living Arrangement				
Alone	ref	ref	ref	ref
Family	0.5 (0.2, 1.1)	0.6 (0.1, 4.3)	1.1 (0.5, 2.2)	<b>0.5 (0.2, 0.9)<sup>d</sup></b>
Partner/Spouse/SO	<b>0.2 (0.1, 0.6)<sup>c</sup></b>	<b>12.5 (2.7, 56.6)<sup>c</sup></b>	<b>0.2 (0.1, 0.5)<sup>d</sup></b>	<b>0.3 (0.2, 0.7)<sup>c</sup></b>
Friends/Other	<b>0.2 (0.1, 0.8)<sup>d</sup></b>	2.3 (0.3, 15.4)	1.0 (0.3, 2.6)	1.6 (0.8, 3.5)

<sup>a</sup>Multi-variable multinomial logistic regression model modeling the 5-level disclosure outcome with disclosure to more than 1 group as the referent. Model includes all variables shown in the table.

<sup>b</sup>Ref = Referent group

<sup>c</sup>P-value <0.01

<sup>d</sup>P-value <0.05