

## The Role of Early HIV Status Disclosure in Retention in HIV Care

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### Abstract

The objective of this study was to evaluate whether nondisclosure or selective disclosure of HIV status to others is associated with retention in HIV care. This retrospective analysis evaluated the relationship of self-reported disclosure of HIV status as an indicator for poor retention in care (a gap in care >180 days) during the 12 months following initial entry into HIV care. Nondisclosure (disclosure to no one) and selective disclosure were compared to broad disclosure (referent). Univariate and multivariable (MV) logistic regression models were fit, including factors known to be associated with disclosure and retention in care. From 2007 to 2013, 508 HIV-infected patients presented to initiate care, of whom 63% were black, 54% had a CD4+T lymphocyte count <350, and 82% were men (60% of whom were men who have sex with other men). Of these, 65 (13%) reported nondisclosure, 258 (49%) reported selective disclosure, and 185 (38%) reported broad disclosure. In MV analyses, nondisclosure was associated with poor retention in care (AOR 2.2; 95% CI 1.2, 4.2). Evaluating disclosure patterns among patients establishing HIV care may help predict and prevent inconsistent care. Further work is needed to understand the relationship between disclosure and retention in care in order to guide future interventions to improve HIV-outcomes.

### Introduction

**I**N A DISEASE THAT WAS ONCE universally fatal, the advent of anti-retroviral therapy (ART) has made HIV a manageable chronic illness for those who initiate and continue effective therapy.<sup>1</sup> However, data indicate that of persons diagnosed with HIV in the United States, only 51% are retained in HIV care (multiple medical visits in 6-month intervals).<sup>2</sup> For those individuals who are not retained in care, the potential for increased longevity associated with viral load suppression is compromised.<sup>3,4</sup> The importance of retention in HIV care is echoed by the current US National HIV/AIDS Strategy, which emphasizes the need for more research in this area.<sup>5</sup>

Several studies have shown that increased levels of social support predict improved engagement in care and medication adherence for people living with HIV.<sup>6,7</sup> In one study of Latino and black American men who have sex with men (MSM) in Los Angeles, increased disclosure of HIV status to social network members was associated with better retention in care (defined as two or more primary care visits in the last 6 months).<sup>8</sup> The authors of this study suggested that disclosure and removing the need to conceal HIV status improved retention in care.

Although this and other works have evaluated the role of disclosure in persons already established in HIV care, less is understood about early disclosure of HIV status to others (i.e., prior to or soon after entry into HIV care) and its relationship to future retention in care.<sup>9-11</sup> Representing a crucial juncture in the HIV care continuum, identifying factors that predict retention for patients newly initiating HIV care may help providers address concerns and reduce loss to follow up.

We performed an analysis of disclosure patterns among persons first establishing HIV care at a university-affiliated clinic in Birmingham, AL, and assessed their retention in care for the first 12 months of care, in order to evaluate the relationship between early disclosure and retention in care. We hypothesized that patients who reported nondisclosure at the time of care entry would be more likely to have poor retention in care in the subsequent 12 months.

### Methods

#### *Study design and participants*

A retrospective analysis of data collected from each patient over a 12-month period was performed for all patients entering HIV care at our university-based HIV clinic for the first

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time from January 2007 to April 2012. Briefly, the study population included persons entering care at the 1917 clinic through Project CONNECT (Client-Oriented New patient Navigation to Encourage Connection to Treatment), which is performed at an orientation visit prior to their first medical appointment.<sup>12</sup> The orientation visit included a semi-structured needs assessment interview with a trained staff member, a blood draw for baseline lab values, and a self-administered questionnaire. Domains in the survey included socio-demographic characteristics, potential physical and/or emotional barriers to sustained engagement in care and disclosure status (i.e., whether a patient has disclosed and prompted questions about who they disclosed to).

Data for participants aged greater than 19 years with no previous outpatient HIV medical care were included in the final analysis. Independent and dependent variable values were compiled from the Project CONNECT database and the patient's electronic medical record to assess retention in care 12 months after each participant's orientation visit. This study was approved by the University of Alabama at Birmingham's (UAB) Institutional Review Board.

For our primary analyses, our *a priori* independent variable was disclosure status. A three-level disclosure variable was used. The mutually exclusive categorization was based on participants' self-reported disclosure to: no one, selectively to only one person/group (i.e., to family only, friends only, or significant other/partner/spouse only), or to more than one group.<sup>13</sup> Nondisclosure was defined as disclosure to no one. Broad disclosure (referent) was defined as disclosure to two or more groups. Covariates used in modeling included age, level of education, sexual behavior, living arrangement, race, church attendance, initial CD4 count, insurance status and disclosure status.

To address potential confounders, independent variables were selected based on a four-level social ecology model and on previous research in this cohort showing significant associations between the aforementioned variables and disclosure in univariate analyses.<sup>13,14</sup> Also, church attendance was previously shown to be associated with later presentation for HIV care in the same cohort for men who have sex with men, demonstrating its potential influence on outcomes.<sup>15</sup> 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 categorized as MSM.

The outcome of interest was retention 12 months after initiating HIV care. This was defined as not having missed appointments (i.e., appointments not cancelled or rescheduled) with an HIV primary care provider after a patient's initial orientation visit for at least 6 months ( $\geq 180$  days) at any point during the 12 months following a patient's orientation visit.<sup>16</sup>

#### Statistical analysis

Independent variables were summarized using frequencies and percentages for categorical variables and medians, with lower and upper quartiles, for continuous variables. Logistic regression models were fit using broad disclosure as the referent. Univariate models were first fit. Then multi-variable

models were fit, selecting variables not only statistically significant in univariate analyses but also that were previously associated with disclosure status in this cohort. Unadjusted and adjusted odds ratios along with their corresponding 95% confidence intervals are reported. All analyses were performed using SAS v9.3 (Carey, NC).

#### Results

Of 1645 total patients establishing care between January 2007 and April 2012, 508 eligible patients initiated HIV care for the first time. Participants' characteristics are presented in Table 1. The median age was 33 years, and most participants were black (64%) and male (82%). Among males, 74% were MSM based on sexual behavior. More than half (54%) of participants initially presented with a CD4 count  $< 350$  cells/mm<sup>3</sup>. Also, 57% of the sample reported church attendance,

TABLE 1. CHARACTERISTICS OF STUDY POPULATION

| Characteristics   | Total = 508<br>N (%) |
|---|----------------------|
| Median age, years (Q <sub>1</sub> -Q <sub>3</sub> )                       | 33 (26.0, 43.0)      |
| Race <sup>a</sup>   |                      |
| Caucasian   | 186 (37.3)           |
| African American  | 313 (63.7)           |
| Sex/sexual behavior   |                      |
| Male, sex with men (MSM)  | 307 (60.4)           |
| Male, sex with women (MSW)  | 109 (21.5)           |
| Female, sex with men (WSM)  | 92 (18.1)            |
| Log <sub>10</sub> viral load  | 4.4 (3.8, 5.2)       |
| CD4 <sup>+</sup> T lymphocyte count (cells/mm <sup>3</sup> ) <sup>b</sup> |                      |
| $> 350$   | 232 (46.3)           |
| 200–350   | 106 (21.2)           |
| $< 200$   | 163 (32.5)           |
| Church attendance   |                      |
| No  | 221 (43.5)           |
| Yes   | 287 (56.5)           |
| Education <sup>c</sup>  |                      |
| Diploma/GED or less   | 203 (41.1)           |
| Some college or more  | 291 (58.9)           |
| Employed <sup>d</sup>   |                      |
| No  | 198 (52.8)           |
| Yes   | 177 (47.2)           |
| Insurance status  |                      |
| Private   | 196 (38.6)           |
| Public  | 72 (14.2)            |
| None  | 240 (47.2)           |
| Living arrangement <sup>e</sup>   |                      |
| Alone   | 131 (26.4)           |
| Family  | 172 (34.7)           |
| Partner/spouse/SO <sup>f</sup>  | 129 (26.0)           |
| Friends/other   | 64 (12.9)            |
| Disclosure <sup>g</sup>   |                      |
| None  | 65 (13.3)            |
| Partner/spouse/SO only  | 44 (9.0)             |
| Family only   | 85 (17.3)            |
| Friends only  | 111 (22.7)           |
| More than one group   | 185 (37.8)           |

<sup>a</sup>Frequency missing, 9; <sup>b</sup>frequency missing, 5; <sup>c</sup>frequency missing, 14; <sup>d</sup>frequency missing, 133; <sup>e</sup>frequency missing, 12; <sup>f</sup>SO, significant other; <sup>g</sup>frequency missing, 18.

and 59% reported at least some college education. Only 47% were employed, and 61% had public or no insurance. Living arrangements varied, with 35% of participants reporting living with family.

One in eight patients ( $N=65$ , 13%) had not disclosed their HIV status at the time of entering care. Of the 425 participants who reported any disclosure, over half ( $N=240$ , 56%) had disclosed selectively: 85 disclosed only to family, 111 disclosed only to friends and 44 disclosed only to a partner/spouse/significant other. Broad disclosure was reported by 185 (38%) participants at the time of their orientation visit.

About one-third ( $N=171$ , 34%) met criteria for poor retention during the first 12 months in care. In multivariable analyses, participants who reported nondisclosure were twice as likely (AOR 2.1; 95% CI 1.1, 4.1) to have poor retention in

care as compared to persons who reported broad disclosure. Other factors associated with poor retention in care included public insurance compared to private insurance (AOR 2.0; 95% CI 1.0, 3.9) and being MSW as compared to MSM (AOR 2.4; 95% CI 1.4, 4.2).

Persons reporting living with a significant other were less likely to have poor retention in care (AOR 0.5; 95% CI 0.3, 0.9) (Table 2). When specifically looking at different types of selective disclosure, no association was found between disclosing to different types of support groups and retention in care, but the relationship between nondisclosure and poor retention in care remained (Table 3).

## Discussion

Our findings suggest that at the time of first seeking HIV care, total nondisclosure of HIV infection status to others may predict poor retention in care. We also observed that MSW compared to MSM and persons reporting public

TABLE 2. CHARACTERISTICS ASSOCIATED WITH POOR RETENTION IN CARE FOR NEW PATIENTS ESTABLISHING CARE (3-LEVEL DISCLOSURE)

| Characteristics  | Poor retention in care unadjusted OR (95% CI) | Poor retention in care AOR (95% CI) |
|--|---|-------------------------------------|
| Age, per 10 years  | 0.9 (0.8, 1.1)                                | 1.35 (0.9, 2.0)                     |
| Race   |   |                                     |
| Caucasian  |   | Ref                                 |
| African American   | 1.0 (0.7, 1.5)                                | 0.7 (0.4, 1.1)                      |
| Sex/sexual behavior  |   |                                     |
| Male, sex with men (MSM)                                     |   | Ref                                 |
| Male, sex with women (MSW)                                   | <b>1.7 (1.1, 2.7)</b>                         | <b>2.4 (1.4, 4.2)<sup>a</sup></b>   |
| Female, sex with men (WSM)                                   | 1.4 (0.9, 2.3)                                | 1.4 (0.8, 2.7)                      |
| CD4 <sup>+</sup> T lymphocyte count (cells/mm <sup>3</sup> ) |   |                                     |
| >350   |   | Ref                                 |
| 200–350  | 1.0 (0.6, 1.7)                                | 1.1 (0.7, 1.8)                      |
| <200   | 0.7 (0.5, 1.1)                                | 0.7 (0.4, 1.1)                      |
| Church attendance  |   |                                     |
| No   |   | Ref                                 |
| Yes  | 0.9 (0.6, 1.3)                                | 1.1 (0.7, 1.8)                      |
| Education  |   |                                     |
| Diploma/GED or less  |   | Ref                                 |
| Some college or more   | 0.7 (0.5, 1.0)                                | 0.7 (0.5, 1.2)                      |
| Insurance status   |   |                                     |
| Private  |   | Ref                                 |
| Public   | <b>2.3 (1.3, 4.0)</b>                         | <b>2.0 (1.0, 3.9)<sup>b</sup></b>   |
| None   | <b>1.6 (1.1, 2.4)</b>                         | 1.5 (0.9, 2.4)                      |
| Living arrangement   |   |                                     |
| Alone  |   | Ref                                 |
| Family   | 0.8 (0.5, 1.3)                                | 0.7 (0.4, 1.2)                      |
| Partner/spouse/SO  | 0.6 (0.4, 1.0)                                | <b>0.5 (0.3, 0.9)<sup>b</sup></b>   |
| Friends/other  | 0.8 (0.4, 1.5)                                | 0.6 (0.3, 1.3)                      |
| Disclosure   |   |                                     |
| More than one group  |   | Ref                                 |
| Selective  | 0.9 (0.6, 1.4)                                | 0.9 (0.6, 1.5)                      |
| No one   | <b>2.0 (1.1, 3.6)</b>                         | <b>2.1 (1.1, 4.1)<sup>b</sup></b>   |

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.

Ref, referent group; SO, significant other; <sup>a</sup> $p < 0.01$ ; <sup>b</sup> $p < 0.05$ .

TABLE 3. CHARACTERISTICS ASSOCIATED WITH POOR RETENTION IN CARE AND VIREMIA FOR NEW PATIENTS ESTABLISHING CARE (5-LEVEL DISCLOSURE)

| Characteristics  | Poor retention in care AOR (95% CI) |
|--|-------------------------------------|
| Age, per 10 years  | 0.8 (0.7, 1.0)                      |
| Race   |                                     |
| Caucasian  | Ref                                 |
| African American   | 0.7 (0.4, 1.1)                      |
| Other/unknown  | 1.7 (0.3, 8.9)                      |
| Gender/sexual preferences                                    |                                     |
| Male, sex with men (MSM)                                     | Ref                                 |
| Male, sex with women (MSW)                                   | <b>2.3 (1.3, 4.0)<sup>a</sup></b>   |
| Female, sex with men (WSM)                                   | 1.4 (0.8, 2.6)                      |
| CD4 <sup>+</sup> T lymphocyte count (cells/mm <sup>3</sup> ) |                                     |
| >350   | Ref                                 |
| 200–350  | 1.2 (0.7, 2.0)                      |
| <200   | 0.6 (0.4, 1.1)                      |
| Church attendance  |                                     |
| No   | Ref                                 |
| Yes  | 1.1 (0.7, 1.8)                      |
| Education  |                                     |
| Diploma/GED or less  | Ref                                 |
| Some college or more   | 0.7 (0.5, 1.1)                      |
| Insurance status   |                                     |
| Private  | Ref                                 |
| Public   | <b>2.0 (1.0, 4.0)<sup>b</sup></b>   |
| None   | 1.5 (0.9, 2.5)                      |
| Living arrangement   |                                     |
| Alone  | Ref                                 |
| Family   | 0.6 (0.3, 1.1)                      |
| Partner/spouse/SO  | 0.6 (0.3, 1.2)                      |
| Friends/other  | 0.6 (0.3, 1.3)                      |
| Disclosure   |                                     |
| More than one group  | Ref                                 |
| None   | <b>2.2 (1.2, 4.3)<sup>a</sup></b>   |
| Spouse/partner/SO  | 0.6 (0.3, 1.6)                      |
| Family only  | 1.2 (0.6, 2.2)                      |
| Friends only   | 0.9 (0.5, 1.6)                      |

Ref, referent group; SO, significant other; <sup>a</sup> $p < 0.01$ ; <sup>b</sup> $p < 0.05$ .

insurance compared to private were more likely to have poor retention in care. Persons living alone were more likely to have poor retention in care compared to persons living with a significant other.

Currently, the National HIV/AIDS Strategy highlights the need for HIV prevention strategies focusing on viral load suppression in those infected. Retention in care is a crucial facilitator for HIV viral load suppression and identifying potential barriers is necessary.<sup>17</sup> This is supported by poor retention in care being linked to increased morbidity and independently predicting survival.<sup>18,19</sup>

In this study, we chose to focus on HIV disclosure in persons new to HIV care for two reasons. First, this is a critical time when patients are learning about HIV and its implications for their health, initiating ART, and building trust with their care team. Second, understanding patient-level variables that predict poor retention at the outset of HIV care may help the healthcare team identify at-risk persons at their first clinic visit whom may benefit from enhanced or specially targeted intervention strategies. To our knowledge, this is the first study to evaluate the relationship between disclosure of HIV status at the time of entry into HIV care and a patient's early retention in care.

Disclosure of HIV infection status and decisions as to whom one should disclose to are complex, especially for persons living in communities with high levels of HIV-related stigma.<sup>20,21</sup> Although disclosure may be necessary for gaining emotional and physical support that aids in retention in HIV care, disclosure also has perceived and real risks including potential loss of relationships, loss of confidentiality, and shame.<sup>22</sup>

Furthermore, based on the type of support groups, the perceived costs of disclosure may vary.<sup>23</sup> For some persons living with HIV, the perceived risks of disclosure may overshadow its benefits and lead to social isolation for individuals infected and initiating HIV care.<sup>24</sup> Previous studies have already linked nondisclosure with higher rates of unprotected anal sex and worse medication adherence.<sup>25–27</sup> As shown for other chronic diseases, support, both physical and emotional, associates with improved outcomes.<sup>28</sup> While disclosure of infection status may be associated with less internal stigmatization of HIV, most patients report increased support after disclosure.<sup>29</sup>

Previous research in this cohort showing that patients were more likely to present with progressed disease (CD4 counts <200) if they reported only selective disclosure of their HIV status to only family or friends, prompted further evaluation in this study for potential associations between different types of selective disclosure and retention in care. However, we did not observe a relationship between retention in care and selective disclosure to only family, friends, or a significant other. These findings may suggest that the ability to have interpersonal relationships with strong emotional bonds, regardless of the type, may lead to better retention in care. When counseling patients about disclosure, with the goal of strengthening retention in care, helping patients identify a single person or group to share their HIV status may offer equivalent benefits to wider disclosure. This concept is supported by research done in young black gay and bisexual men who gained resilience through enlisting social support from others.<sup>30</sup>

We also found that MSW and patients with public insurance were more likely to have poor retention in care. These findings were expected and have previously been described in the literature.<sup>31,32</sup> It was unexpected that people who reported

no insurance were not more likely than patients with private insurance to have poor retention in care. This may be due to the fact that, at the study clinic, more services are available for those who lack insurance through Ryan White compared to patients who have public insurance. This may lead to more financial obligations for those reporting public insurance, resulting in worse retention in care.

Our study had several limitations. Causality cannot be established from our results. It is known that substance abuse disorders and poor mental health are also associated with poor retention in care.<sup>19</sup> Unfortunately, these data were missing for more than one-third of our sample and, as a result, we could not include these variables in our analyses. However, we were able to statistically control for other factors that have previously been shown to be associated with poor retention in care such as race, younger age, heterosexual orientation (defined by self-identification), less education, lack of health insurance, and higher CD4 counts.<sup>32–35</sup>

Also, we were unable to assess the role of HIV-related stigma on retention in care. Previous research has shown that negative self-image among young gay and bisexual MSM was associated with reduced adherence to medical appointments.<sup>36</sup> As such, a potential mediating relationship may exist between stigma and disclosure. In addition, this study was performed at a comprehensive university-based HIV clinic in the Southeastern United States. This may limit the generalizability of these observations to other clinics. However, the HIV epidemic is currently affecting this part of the United States the most and this study may provide some insight into this particularly vulnerable population.

In conclusion, our study provides some insight into the complexity of HIV disclosure and its relationship with early retention in care. We have shown that patients who have not disclosed their HIV status to anyone at the time of care initiation may be at increased risk for poor retention during the first year of HIV care. More research is needed to better understand the basis for this association and to evaluate if disclosure could potentially be a surrogate of another underlying measure such as stigma, depression, or represents social connectedness. Needless to say, more than 30 years into the epidemic nondisclosure of infection status remains a major barrier to care.

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### Author Disclosure Statement

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