

Disparities in Reported Reasons for Not Initiating or Stopping Antiretroviral Treatment Among a Diverse Sample of Persons Living with HIV

Mallory O. Johnson¹, Margaret A. Chesney¹, Torsten B. Neilands¹, Samantha E. Dilworth¹, Robert H. Remien², Lance S. Weinhardt³, F. Lennie Wong⁴, Stephen F. Morin¹, and NIMH Healthy Living Project Team

¹Center for AIDS Prevention Studies, University of California, San Francisco, San Francisco, CA, USA; ²HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute and Columbia University, New York, NY, USA; ³Center for AIDS Intervention Research, Medical College of Wisconsin, Milwaukee, WI, USA; ⁴Center for Community Health, University of California, Los Angeles, Los Angeles, CA, USA.

BACKGROUND: Disparities in the use of antiretroviral therapy (ART) for HIV disease have been documented across race, gender, and substance use groups.

OBJECTIVE: The current analysis compares self-reported reasons for never taking or stopping ART among a diverse sample of men and women living with HIV.

DESIGN: Cross-sectional interview.

PARTICIPANTS: HIV + (N=3,818) adults, 968 of whom reported discontinuing or never using ART.

MEASUREMENTS: Computerized self-administered and interviewer-administered self-reported demographic and treatment variables, including gender, race, ethnicity, CD4 count, detectable viral load, and reported reasons for not taking antiretroviral therapy.

RESULTS: Despite equivalent use of ART in the current sample, African-American respondents were 1.7 times more likely to report wanting to hide their HIV status and 1.7 times more likely to report a change in doctors/clinics as reasons for stopping ART ($p=.049$, and $p=.042$) and had odds 4.5 times those of non-African Americans of reporting waiting for viral marker counts to worsen ($p<.0001$). There was a lower tendency (OR=0.4) for women to endorse concerns of keeping their HIV status hidden as a reason for stopping ART compared to men ($p=.003$). Although those with an IDU history were less likely to be on ART, no differences in reasons for stopping or never initiating ART were found between those with and without an IDU history.

CONCLUSIONS: A desire to conceal HIV status as well as a change in doctors/clinics as reasons for discontinuing ART were considerably more common among African Americans, suggesting that perceived HIV/AIDS stigma is an obstacle to maintenance of treatment. Findings also indicate differences in reasons for stopping ART by gender and a perceived desire to wait for

counts to worsen as a reason for not taking ART by African Americans, regardless of detectable viral load, CD4 count, age, education, employment, sexual orientation, and site.

KEY WORDS: HIV/AIDS; treatment disparities; gender; race; ethnicity; substance use.

J Gen Intern Med 24(2):247–51

DOI: 10.1007/s11606-008-0854-z

© Society of General Internal Medicine 2008

INTRODUCTION

Throughout the HIV epidemic in the US, women, African Americans, and those with injection drug use histories are less likely to receive antiretroviral therapy (ART) for HIV disease, despite equivalent treatment indications^{1–4}. Although there is evidence that these disparities are narrowing over time^{5–7}, they have not been eliminated. Efforts to reduce disparities have targeted policy and educational approaches⁸, but a greater understanding of personal factors associated with non use of ART is needed. The purpose of the current analysis is to report group differences in self-reported reasons for not taking ART among a diverse sample of HIV-infected men and women. Understanding reasons for not utilizing available treatments from patients' perspectives can inform ongoing efforts to reduce treatment disparities.

METHODS

HIV-positive individuals in four US cities (San Francisco, Los Angeles, Milwaukee, and New York City) were screened between July 2000 and January 2002 for a randomized behavioral prevention trial⁹. Respondents were at least 18 years of age, provided written informed consent and medical documentation of HIV, and did not evidence severe neuropsychological impairment or psychosis. All activities were approved by the sites' Institutional Review Boards (IRB). Procedures involved a combination of Audio Computer-Assisted Self-Interviewing (ACASI) and Computer-Assisted Personal Interviewing (CAPI) using the Questionnaire Development System (QDS), Nova Research Company.

Received February 28, 2008

Revised September 23, 2008

Accepted October 14, 2008

Published online November 18, 2008

Respondents received US\$ 50 for completing the interview; additional details of study procedures are provided elsewhere^{10,11}. The current analyses focus on the baseline screening data of the subsamples of those respondents who indicated that they had previously stopped ART or had never initiated ART.

Measures

Background data included age, race, gender, injection drug use (IDU) in the prior 12 months, self-reported CD4 count, reported detectable HIV viral load, and length of HIV diagnosis. Respondents not on ART were asked if they had ever been on ART. Those not on ART were asked to select all applicable reasons for never taking or for stopping ART from a comprehensive list of reasons (see [Appendix](#)).

Statistical Analysis

The selection of reasons for never taking or stopping ART was guided by efforts to identify the most likely causes of disparities (Table 2). These emphasized the potential impact of lack of access to care and the potential role of stigma. The objective of this analysis was not to determine clinical indications for ART, but rather to analyze differences across groups in the self-reported reasons for ART non-use. In doing so, it was important to account for the likelihood that individuals may be prescribed ART based on disease progression. To partially

control for potential group differences in clinical indication for ART, we entered detectable vs. undetectable viral load and most recent CD4 count into the models. These were included in the absence of nadir CD4 data, which would have been a preferable marker of clinical indication for ART. We controlled for age, education, employment, sexual orientation, and site in all analyses. Initial logistic regressions of each of the outcomes (0 = no; 1 = yes) on single explanatory variables and control variables were conducted. Final multivariate models included all explanatory variables from the initial models and the same control variables (viral load, most recent CD4 count, age, education, employment, sexual orientation, and site). Odds ratios and profile likelihood-based 95% confidence intervals are reported for all single degree-of-freedom effects; for multi-category explanatory variables multiple degree-of-freedom omnibus likelihood ratio tests are reported. Analyses were conducted with SAS v9.1.3.

RESULTS

Sample Description and Treatment Variables

Of the 3,818 individuals interviewed, 399 (10.5%) indicated never having taken ART (Table 1). This subsample was mostly African American (57%), male (75%), and had no history of IDU (86%). In addition, 569 (14.9%) indicated previously taking ART. Those who had stopped ART were mostly African American (53%), male (68%), and had no history of IDU (81%).

Table 1. Sample Characteristics

| Variable | Stopped ART (n=569) | | Never on ART (n=399) | | Currently on ART (n=2,850) | |
|--------------------------|---------------------|---------------|----------------------|---------------|----------------------------|---------------|
| | N (%) | Mean (SD) | N (%) | Mean (SD) | N (%) | Mean (SD) |
| Age (years) | — | 40.6 (7.3) | — | 40.2 (7.9) | — | 42.5 (7.6) |
| Gender | | | | | | |
| Male | 386 (67.8) | — | 299 (75.1) | — | 2,146 (75.3) | — |
| Female | 182 (32.0) | — | 98 (24.6) | — | 701 (24.6) | — |
| Transgender | 1 (0.2) | — | 1 (0.3) | — | 3 (0.1) | — |
| Ethnicity | | | | | | |
| Black/African American | 303 (53.3) | — | 228 (57.3) | — | 1,502 (52.7) | — |
| Hispanic/Latino | 95 (16.7) | — | 58 (14.6) | — | 528 (18.6) | — |
| White | 147 (25.8) | — | 100 (25.1) | — | 755 (26.5) | — |
| Other | 24 (4.2) | — | 12 (3.0) | — | 63 (2.2) | — |
| Employment status | | | | | | |
| Working | 161 (28.3) | — | 155 (38.9) | — | 832 (29.3) | — |
| Not working | 408 (71.7) | — | 244 (61.1) | — | 2,007 (70.7) | — |
| Sexual orientation | | | | | | |
| Heterosexual | 267 (46.9) | — | 168 (42.2) | — | 1,225 (43.1) | — |
| Homosexual | 204 (35.8) | — | 154 (38.7) | — | 1,236 (43.3) | — |
| Bisexual | 80 (14.1) | — | 62 (15.6) | — | 328 (11.5) | — |
| Other/not sure | 18 (3.2) | — | 14 (3.5) | — | 56 (2.1) | — |
| Education | | | | | | |
| <High school | 178 (31.3) | — | 98 (24.6) | — | 724 (25.4) | — |
| High school | 154 (27.1) | — | 110 (27.6) | — | 767 (26.9) | — |
| Some college | 185 (32.5) | — | 140 (35.2) | — | 936 (32.8) | — |
| College graduate | 52 (9.1) | — | 50 (12.6) | — | 423 (14.8) | — |
| CD4 count | — | 421.0 (293.2) | — | 558.1 (324.7) | — | 427.5 (292.2) |
| Viral load | | | | | | |
| Undetectable | 94 (17.6) | — | 87 (24.1) | — | 1,306 (47.3) | — |
| Detectable | 441 (82.4) | — | 274 (75.9) | — | 1,456 (52.7) | — |
| History of IDU | | | | | | |
| Yes | 106 (18.8) | — | 56 (14.1) | — | 227 (8.0) | — |
| No | 458 (81.2) | — | 342 (85.9) | — | 2,619 (92.0) | — |
| Time since HIV diagnosis | — | 9.0 (4.6) | — | 6.5 (5.3) | — | 8.6 (4.5) |

Table 2. Initial and Final Multivariate Logistic Regression Results

| Outcome | Initial OR ^c (95% CI) | Final OR ^d (95% CI) |
|---|-------------------------------------|-----------------------------------|
| Why never used ART (N=399; 10.5%) | — | — |
| Waiting for CD4/VL counts to worsen (N=254; 63.8%) | — | — |
| Black race | 3.5 (1.8, 6.9) | 4.5 (2.0, 10.1)*** |
| Female gender | 1.1 (0.6, 2.0) | 0.9 (0.4, 2.1) |
| Any IDU (past 12 months) | 0.9 (0.5, 2.0) | 1.2 (0.5, 2.9) |
| CD4 ^b | 0.9 (0.8, 1.1) | 0.9 (0.8, 1.0) |
| Detectable viral load | 1.4 (0.6, 3.2) | 1.8 (0.6, 5.5) |
| Site X ² (DF) ^a | 6.6 (3) | 2.5 (3) |
| Los Angeles | — | — |
| Milwaukee | 3.3 (1.3, 8.5) | 2.8 (0.7, 10.2) |
| New York | 1.3 (0.6, 3.2) | 1.2 (0.4, 3.3) |
| San Francisco | 1.4 (0.6, 3.5) | 1.4 (0.5, 3.8) |
| Sexual orientation X ² (DF) ^a | 4.0 (3) | 1.3 (3) |
| Straight | — | — |
| Gay | 0.7 (0.4, 1.3) | 1.1 (0.4, 2.8) |
| Bisexual | 0.9 (0.4, 2.2) | (0.3, 2.8) |
| Other | 2.4 (0.7, 7.9) | 2.4 (0.6, 10.1) |
| Education X ² (DF) ^a | 1.3 (3) | 0.8 (3) |
| <HS graduate | — | — |
| HS graduate | 0.9 (0.5, 1.9) | 1.4 (0.6, 3.3) |
| Some college | 0.7 (0.3, 1.4) | 1.1 (0.5, 2.8) |
| College graduate | 0.7 (0.2, 2.1) | 1.7 (0.4, 6.3) |
| Age | 1.0 (1.0, 1.0) | 0.9 (0.9, 1.0005)* |
| Employment | 0.6 (0.3, 1.2) | 0.5 (0.2, 1.2) |
| Provider did not offer ART (N=100; 25.1%) | — | — |
| Black race | 0.8 (0.5, 1.2) | 0.9 (0.5, 1.5) |
| Female gender | 0.8 (0.5, 1.3) | 1.3 (0.7, 2.4) |
| Any IDU (past 12 months) | 1.3 (0.8, 2.2) | 1.4 (0.8, 2.6) |
| CD4 ^b | 0.8 (0.8, 0.9)*** | 0.8 (0.8, 0.9)*** |
| Detectable viral load | 1.0 (0.5, 1.8) | 0.7 (0.4, 1.3) |
| Site X ² (DF) ^a | 0.8 (3) | 1.1 (3) |
| Los Angeles | — | — |
| Milwaukee | 0.8 (0.4, 1.8) | 0.9 (0.3, 2.4) |
| New York | 0.8 (0.4, 1.4) | 0.9 (0.4, 1.7) |
| San Francisco | 0.9 (0.5, 1.5) | 0.7 (0.4, 1.4) |
| Sexual orientation X ² (DF) ^a | 5.1 (3) | 4.1 (3) |
| Straight | — | — |
| Gay | 1.5 (0.9, 2.4) | 1.6 (0.8, 3.2) |
| Bisexual | 1.3 (0.7, 2.4) | 1.5 (0.7, 3.1) |
| Other | 0.3 (0.04, 2.5) | 0.4 (0.05, 3.1) |
| Education X ² (DF) ^a | 3.7 (3) | 1.7 (3) |
| <HS graduate | — | — |
| HS graduate | 0.9 (0.5, 1.6) | 0.9 (0.4, 1.7) |
| Some college | 0.9 (0.5, 1.5) | 0.7 (0.4, 1.3) |
| College graduate | 1.7 (0.8, 3.6) | (0.4, 2.3) |
| Age | 1.0 (1.0, 1.1) | 1.0 (1.0, 1.1) |
| Employment | 1.2 (0.8, 2.0) | 1.3 (0.8, 2.3) |
| Wanted to hide HIV status (N=37; 9.3%) | — | — |
| Black race | 1.0 (0.7, 1.5) | 0.8 (0.5, 1.3) |
| Female gender | 1.2 (0.9, 1.8) | 1.6 (0.9, 2.7) |
| Any IDU (past 12 months) | 1.1 (0.7, 1.7) | 1.0 (0.5, 1.8) |
| CD4 ^b | 1.0 (1.0, 1.1) | 0.9 (0.8, 1.0) |
| Detectable viral load | 0.9 (0.6, 1.5) | 1.0 (0.5, 1.8) |
| Site X ² (DF) | 11.9 (3) | 6.3 (3) |
| Los Angeles | — | — |
| Milwaukee | 0.3 (0.2, 0.7) | 0.3 (0.1, 0.9) |
| New York | 0.9 (0.6, 1.4) | 0.9 (0.5, 1.5) |
| San Francisco | 0.7 (0.5, 1.2) | 0.7 (0.4, 1.1) |
| Sexual orientation X ² (DF) | 1.6 (3) | 2.6 (3) |
| Straight | — | — |
| Gay | 0.8 (0.5, 1.2) | 0.6 (0.4, 1.1) |
| Bisexual | 0.8 (0.5, 1.4) | 0.8 (0.4, 1.4) |
| Other | 1.0 (0.4, 2.7) | 0.9 (0.3, 2.7) |
| Education X ² (DF) | 8.0 (2)* | 7.0 (3) |
| <HS graduate | — | — |
| HS graduate | 0.6 (0.4, 1.0) | 0.8 (0.5, 1.4) |

Table 2. (continued)

| Outcome | Initial OR ^c (95% CI) | Final OR ^d (95% CI) |
|--|-------------------------------------|-----------------------------------|
| Some college | 1.2 (0.8, 1.8) | 1.4 (0.8, 2.3) |
| College graduate | 1.3 (0.7, 2.4) | 1.9 (0.9, 4.1) |
| Age | 1.0 (1.0, 1.0) | 1.0 (1.0, 1.0) |
| Employment | 1.1 (0.7, 1.6) | 0.9 (0.6, 1.4) |
| Not receiving medical care (N=36; 9.1%) | — | — |
| Black race | 0.8 (0.5, 1.2) | 0.8 (0.5, 1.3) |
| Female gender | 1.2 (0.8, 1.9) | 1.6 (0.9, 2.7) |
| Any IDU (past 12 months) | 0.9 (0.5, 1.4) | 1.0 (0.5, 1.8) |
| CD4 ^b | 0.9 (0.8, 0.98)* | 0.9 (0.8, 0.98)* |
| Detectable viral load | 1.1 (0.6, 1.8) | 1.0 (0.5, 1.8) |
| Site X ² (DF) | 3.5 (3) | 6.3 (3) |
| Los Angeles | — | — |
| Milwaukee | 1.4 (0.7, 2.8) | 1.7 (0.7, 3.9) |
| New York | 0.9 (0.5, 1.6) | (0.6, 1.9) |
| San Francisco | 0.8 (0.4, 1.3) | 0.6 (0.3, 1.1) |
| Sexual orientation X ² (DF) | 0.7 (3) | 1.3 (3) |
| Straight | — | — |
| Gay | 1.1 (0.7, 1.8) | 1.3 (0.7, 2.5) |
| Bisexual | 1.1 (0.6, 1.9) | 1.4 (0.7, 2.9) |
| Other | 0.7 (0.2, 2.6) | 1.0 (0.3, 3.9) |
| Education X ² (DF) | 2.5 (3) | — |
| <HS graduate | — | — |
| HS graduate | 0.8 (0.5, 1.3) | — |
| Some college | (0.6, 1.6) | — |
| College graduate | 1.4 (0.7, 2.8) | — |
| Age | 1.0 (1.0, 1.0) | — |
| Employment | 1.0 (0.7, 1.6) | — |
| Why stopped ART (N=569; 14.9%) | — | — |
| Wanted to avoid side effects (N=316; 55.8%) | — | — |
| Black race | 1.1 (0.7, 1.6) | 1.0 (0.6, 1.7) |
| Female gender | 0.5 (0.3, 0.9)** | 0.6 (0.3, 1.1) |
| Any IDU (past 12 months) | 0.9 (0.5, 1.5) | 0.7 (0.3, 1.6) |
| CD4 ^b | 0.8 (0.8, 0.9)*** | 0.9 (0.8, 0.9)*** |
| Detectable viral load | 3.7 (2.0, 6.6)*** | 2.8 (1.3, 5.6)** |
| Site X ² (DF) | 0.6 (3) | 2.1 (3) |
| Los Angeles | — | — |
| Milwaukee | 0.8 (0.4, 1.7) | 0.6 (0.2, 1.9) |
| New York | (0.6, 1.8) | 1.3 (0.6, 2.4) |
| San Francisco | 1.0 (0.6, 1.7) | 0.9 (0.5, 1.8) |
| Sexual orientation X ² (DF) | 7.1 (3) | 10.9 (3) |
| Straight | — | — |
| Gay | 1.1 (0.7, 1.8) | 0.7 (0.3, 1.4) |
| Bisexual | 1.7 (0.9, 3.1) | 1.7 (0.8, 3.9) |
| Other | 3.4 (1.1, 10.7) | 4.4 (1.0, 20.0) |
| Education X ² (DF) | 4.4 (3) | 0.5 (3) |
| <HS graduate | — | — |
| HS graduate | 1.3 (0.8, 2.4) | 1.3 (0.6, 2.8) |
| Some college | 1.6 (0.9, 2.8) | 1.1 (0.6, 2.3) |
| College graduate | 1.9 (0.9, 3.8) | 1.1 (0.4, 2.8) |
| Age | 1.0 (1.0, 1.0) | 1.0 (1.0, 1.1) |
| Employment | 1.5 (1.0, 2.3)* | 1.6 (0.9, 2.6) |
| Changed provider or clinic (N=89; 15.7%) | — | — |
| Black race | 1.5 (1.0, 2.3)* | 1.7 (1.02, 2.7)* |
| Female gender | 0.8 (0.5, 1.2) | 0.7 (0.4, 1.3) |
| Any IDU (past 12 months) | 0.9 (0.5, 1.5) | 0.9 (0.5, 1.9) |
| CD4 ^b | 0.9 (0.9, 0.99)* | 1.0 (0.9, 1.1) |
| Detectable viral load | 1.8 (1.1, 2.9)* | 2.2 (1.2, 4.0)* |
| Site X ² (DF) | 4.4 (3) | 5.6 (3) |
| Los Angeles | — | — |
| Milwaukee | 0.7 (0.4, 1.5) | 0.5 (0.2, 1.4) |
| New York | 0.9 (0.5, 1.6) | 1.1 (0.6, 2.1) |
| San Francisco | 0.6 (0.4, 1.1) | 0.6 (0.3, 1.2) |
| Sexual orientation X ² (DF) | 3.3 (3) | 5.0 (3) |
| Straight | — | — |
| Gay | 1.1 (0.7, 1.7) | 0.9 (0.4, 1.6) |
| Bisexual | 1.7 (0.9, 3.0) | 1.8 (0.8, 3.9) |
| Other | 1.5 (0.5, 4.6) | 2.1 (0.5, 8.4) |

(continued on next page)

Table 2. (continued)

| Outcome | Initial OR ^c (95% CI) | Final OR ^d (95% CI) |
|---|-------------------------------------|-----------------------------------|
| Education χ^2 (DF) | 4.9 (3) | 4.4 (3) |
| <HS graduate | — | — |
| HS graduate | (0.6, 1.7) | 0.6 (0.3, 1.2) |
| Some college | 1.5 (0.9, 2.6) | 1.1 (0.6, 2.1) |
| College graduate | 1.6 (0.8, 3.2) | 1.0 (0.4, 2.4) |
| Age | 1.0 (1.0, 1.0) | 1.0 (1.0, 1.1) |
| Employment | 1.1 (0.7, 1.6) | 1.1 (0.7, 1.8) |
| Wanted to hide HIV status (N=55; 9.7%) | | |
| Black race | 1.0 (0.7, 1.6) | 1.7 (1.004, 3.0)* |
| Female gender | 0.6 (0.4, 0.99)* | 0.4 (0.2, 0.7)** |
| Any IDU (past 12 months) | 1.1 (0.6, 2.0) | 0.9 (0.4, 2.0) |
| CD4 ^b | 1.1 (1.1, 1.3)*** | 1.2 (1.1, 1.3)*** |
| Detectable viral load | 0.6 (0.3, 0.995)* | 0.7 (0.3, 1.4) |
| Site χ^2 (DF) | 17.6 (3)*** | 9.4 (3)* |
| Los Angeles | — | — |
| Milwaukee | 0.3 (0.2, 0.7) | 0.4 (0.1, 1.3) |
| New York | 0.6 (0.3, 1.1) | 0.6 (0.3, 1.3) |
| San Francisco | 1.2 (0.7, 2.2) | 1.5 (0.7, 3.2) |
| Sexual orientation χ^2 (DF) | 6.1 (3) | 1.4 (3) |
| Straight | — | — |
| Gay | 1.8 (1.1, 2.8) | (0.5, 2.1) |
| Bisexual | 1.3 (0.7, 2.4) | 0.8 (0.3, 1.8) |
| Other | 1.8 (0.6, 6.1) | 2.0 (0.4, 9.2) |
| Education χ^2 (DF) | 9.6 (3)* | 7.6 (3) |
| <HS graduate | — | — |
| HS graduate | 0.9 (0.5, 1.6) | 0.6 (0.3, 1.2) |
| Some college | 1.2 (0.7, 2.0) | 0.7 (0.4, 1.5) |
| College graduate | 2.9 (1.3, 6.7) | 1.9 (0.7, 5.6) |
| Age | 1.0 (1.0, 1.0) | 1.0 (1.0, 1.0) |
| Employment | 1.6 (1.1, 2.5)* | 1.3 (0.8, 2.3) |

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

^aFor multi-category explanatory variables, multi-parameter likelihood ratio chi-square tests, degrees of freedom, and p -values are reported.

^bAll odds ratios reflect a 1-unit change in the explanatory variable, except CD4, which is displayed in units of 100.

^cInitial logistic regression analyses contain the single explanatory variable listed only.

^dFinal multivariate analyses contain all explanatory variables listed

Initial Logistic Regression Model Results

When comparing pairs of ART usage groups (never, current, or past use of ART) along the dimensions of race, gender, and IDU history, we found the following patterns, after considering CD4 count, viral load, age, education, employment, sexual orientation, and study site: Compared to those who had stopped ART, men were more likely than women to have never taken ART (OR=1.5; 95% CI=1.02, 2.21). Compared to those currently on ART, individuals with an IDU history were more likely to have never been on ART than non-IDUs (OR=2.05; 95% CI=1.54, 2.74), and they were less likely than non-IDUs to have stopped prior ART treatment (OR=0.66; 95% CI=0.45, 0.95). There were no differences between the ART groupings of African-American and non-African-American respondents.

Final Logistic Regression Model Results

After considering site, most recent CD4 count, detectable viral load, sexual orientation, education, and age (see Table 2), multivariate logistic regression revealed that African Americans had odds 4.5 times relative to non-African Americans of

reporting that they were waiting for CD4/VL to worsen as a reason for never starting ART (95% CI=2.0, 10.1). African Americans also had higher odds of reporting having changed doctors/clinics (OR=1.7; 95% CI=1.02, 2.7) and a desire to keep their HIV status hidden (OR=1.7; 95% CI=1.004, 3.0) as reasons for stopping ART. Women had lower odds than men of endorsing concerns about keeping their HIV status hidden (OR=0.4; 95% CI=0.2, 0.7) as a reason for stopping ART. No differences were found between those with and without a history of IDU. Forty-three African Americans reported discontinuing ARVs to hide their HIV status. Of these participants (mean age 40.8 years, SD=6.6), most were male (60%), had no history of IDU (91%), and reported heterosexual orientation (56%).

DISCUSSION

Among those respondents who had never taken ART, there was an increased likelihood for African Americans to report that they were waiting for their viral markers (CD4 and viral load) to worsen. While the current data cannot rule out the possibility that ART was not clinically indicated for those who report waiting to initiate treatment, the analysis took into account proxy markers for disease progression: detectable viral load and most recent CD4 count.

Among those who reporting having stopped a previous ART regimen, African Americans were more likely to endorse wanting to hide their HIV status as a reason for discontinuing ART. Such a difference suggests that HIV-related stigma may be a more salient barrier to successful maintenance of care for African Americans than for others living with HIV^{12,13}. It may be that this pattern reflects a larger mistrust about HIV and HIV treatment that has been reported among African Americans in the US. In a recent study with 500 randomly selected African Americans, Bogart and Thorburn found that a substantial proportion endorsed believing that HIV was an artificially made virus (48%), that information and a cure for HIV were being withheld from the poor (59% and 53%, respectively), and that those who take HIV medications are guinea pigs for the government (44%)¹⁴. It is possible that these beliefs may negatively influence decisions to initiate or continue HIV treatment and may therefore partially drive the differences reported in the present sample. Additionally, African Americans had higher odds of reporting a change in doctors/clinics as a cause for stopping ART. This may indicate a lack of continuity of providers and care settings, which has been linked to poorer clinical outcomes over time in other studies^{15,16}.

Women were more likely than men to have previously stopped ART, but did not differ in the stated reasons for initializing treatment. Among those stopping ART, women were less likely than men to report concern over wanting to hide HIV status in their decision-making. This may reflect a different contextual context for women living with HIV, which may vary in terms of level of HIV stigma, isolation, and access to resources and peer support^{17,18}. It is also unknown whether some women in the sample initiated ART use during pregnancy to prevent vertical transmission and subsequently stopped ART.

Limitations of the current data include the use of a convenience sample from several years prior, cross-sectional

design, and self-report data. These factors may give over-estimated rates of ART usage, as many respondents were recruited from clinic settings. Knowing nadir CD4 would have strengthened our analysis of group differences in current ART usage rates. Finally, these data were collected up to early 2002 and therefore may not reflect current rates of ART use or current issues in ART decision-making.

Findings represent a step toward understanding the mechanisms by which disparities in HIV care may result. Of particular significance is that although African Americans did not differ from other groups on rates of ART usage, those who were not currently using ART disproportionately cited barriers related to stigma and continuity of treatment factoring into their decision-making. Gender differences in the factors driving decision-making about treatment also suggest that women and men may have different informational needs when making decisions about care.

Acknowledgments: This study was funded by cooperative agreements between the National Institute of Mental Health and the University of California, Los Angeles (U10MH057615); HIV Center/Research Foundation for Mental Hygiene Inc./New York State Psychiatric Institute (U10MH057636); the Medical College of Wisconsin (U10MH057631); and the University of California, San Francisco (U10MH057616).

Conflict of interest: None disclosed.

Corresponding Author: Mallory O. Johnson; Center for AIDS Prevention Studies, University of California, San Francisco, 50 Beale Street, Suite 1300, San Francisco, CA, USA (e-mail: mallory.johnson@ucsf.edu).

REFERENCES

1. Eisenman D, Bogart LM, Bird CE, et al. Differential diffusion of HIV technologies by gender: the case of highly active antiretroviral therapy. *AIDS Patient Care STDS*. 2007;21:390-399.
2. Gebo KA, Fleishman JA, Conviser R, et al. Racial and gender disparities in receipt of highly active antiretroviral therapy persist in a multistate sample of HIV patients in 2001. *J Acquir Immune Defic Syndr*. 2005;38:96-103.
3. Shapiro MF, Morton SC, McCaffrey DF, et al. Variations in the care of HIV-infected adults in the United States: results from the HIV Cost and Services Utilization Study. *JAMA*. 1999;281:2305-2315.
4. Celentano DD, Vlahov D, Cohn S, Shadle VM, Obasanjo O, Moore RD. Self-reported antiretroviral therapy in injection drug users. *JAMA*. 1998;280:544-546.
5. Cunningham WE, Markson LE, Andersen RM, et al. Prevalence and predictors of highly active antiretroviral therapy use in patients with HIV infection in the United States. HCSUS Consortium. HIV Cost and Services Utilization. *J Acquir Immune Defic Syndr*. 2000;25:115-123.
6. Reif S, Whetten K, Thielman N. Association of race and gender with use of antiretroviral therapy among HIV-infected individuals in the Southeastern United States. *South Med J*. 2007;100:775-781.
7. Celentano DD, Galai N, Sethi AK, Shah NG, Strathdee SA, Vlahov D, Gallant JE. Time to initiating highly active antiretroviral therapy among HIV-infected injection drug users. *AIDS*. 2001;15:1707-1715.
8. Morin SF, Sengupta S, Cozen M, Richards TA, Shriver MD, Palacio H, Kahn JG. Responding to racial and ethnic disparities in use of HIV drugs: analysis of state policies. *Public Health Rep*. 2002;117:263-272. discussion 31-2.
9. Gore-Felton, C, Rotheram-Borus MJ, Weinhardt LS, et al. The Healthy Living Project: an individually tailored, multidimensional intervention for HIV-infected persons. *AIDS Educ Prev*. 2005;17:21-39.
10. Johnson MO, Catz SL, Remien RH, et al. Theory guided, empirically supported avenues for intervention on HIV medication nonadherence: Findings from the Healthy Living Project. *AIDS Patient Care STDS*. 2003;17:645-656.
11. Weinhardt LS, Kelly JA, Brondino MJ, et al. HIV transmission risk behavior among men and women living with HIV in four US cities. *J AIDS Human Retrovirol*. 2004;36:1057-1066.
12. Clark HJ, Lindner G, Armistead L, Austin BJ. Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women Health*. 2003;38:57-71.
13. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003;57:13-24.
14. Bogart LM, Thorburn S. Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J Acquir Immune Defic Syndr*. 2005;38:213-218.
15. Tobias C, Cunningham WE, Cunningham CO, Pounds MB. Making the connection: the importance of engagement and retention in HIV medical care. *AIDS Patient Care STDS*. 2007;21(Suppl 1):S3-S8.
16. Giordano TP, Gifford AL, White AC Jr, et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis*. 2007;44:1493-1499.
17. Kremer H, Sonnenberg-Schwan U. Women living with HIV does sex and gender matter? A current literature review. *Eur J Med Res*. 2003;8:8-16.
18. Gaskins S. Issues for women with heterosexually transmitted HIV disease. *AIDS Patient Care STDS*. 1999;13:89-96.

APPENDIX

Reasons for Stopping or Discontinuing ARV Therapy

1. Doctor told you to stop
2. The drug(s) did not work
3. The drug(s) initially worked, but then stopped working
4. You switched to other drugs
5. You did not want side effects of the drugs
6. Could not afford the drug
7. You were on too many medications
8. Your partner or friends suggested you stop taking them
9. You changed doctors or clinics
10. You prefer alternative treatments
11. You don't want anyone to find out that you are HIV-positive
12. You decided to stop because your CD4 and VL numbers have been good
13. You believe you have been cured of HIV

Reasons for Never Taking ARV Therapy

1. You could not afford the medications
2. Your doctor never offered them to you
3. Your family/friends discouraged you from taking them
4. You are not receiving medical care
5. You did not want the side effects
6. You were concerned about toxicity
7. You don't think the medications work
8. You are worried about becoming resistant to the medications
9. You prefer alternative treatments
10. You don't want anyone to find your pills and figure out that you are HIV-positive
11. You are waiting until your CD4 or VL numbers get worse to take the medications