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## Correlates of Antiretroviral Adherence and Viral Load among Transgender Women Living with HIV

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### Abstract

Transgender women are 49 times more likely to become HIV infected than other groups, yet they are drastically underserved by current treatment efforts and report lower rates of treatment adherence than other groups. The objective of this study was to explore correlates of antiretroviral (ART) adherence and viral load among HIV-positive transgender women on ART utilizing a cross-sectional survey of a convenience sample of 59 transgender women. In multivariate models of ART adherence, correlates were age, stress appraisal of transphobic experiences, importance of gender affirmation, and adherence to hormone therapy. In multivariate models of self-reported viral load, correlates were stress appraisal of transphobic experiences and being in a relationship. This study provides preliminary evidence of transgender-relevant correlates of ART adherence and viral load.

### Keywords

Transgender Persons; HIV; Medication Adherence; Viral Load; Health Disparities

### Introduction

Transgender women (assigned male but identify as female or transgender) experience disproportionate rates of HIV compared to all other risk groups (Herbst et al., 2008). Transgender women have 49 times higher likelihood of being HIV positive compared to all adults of reproductive age (Baral et al., 2013), and in San Francisco, they have a three-fold higher community viral load and disproportionately higher rates of mortality than MSM and intravenous drug users (Das et al., 2010; San Francisco Department of Public Health, 2008). In addition to high rates of HIV, transgender women are less likely to be on antiretroviral therapy (ART), and those who are on ART report worse adherence and lower self-efficacy to integrate ART into their lives (Melendez et al., 2005; Sevelius, Carrico, & Johnson, 2010). Transgender women likely encounter similar barriers to ART adherence as other marginalized groups (Grant et al., 2011) in addition to barriers that are unique to being

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transgender, such as prioritization of gender-affirming medical care and experiences of transphobic violence (Bockting & Coleman, 2007; Nuttbrock et al., 2009; Sevelius, 2012).

No research to date has examined correlates of adherence and viral load among transgender women specifically. Preliminary evidence suggests transgender-relevant predictors of adherence and viral load, including hormone use, experiences of transphobia, sex work, and the importance of gender affirmation (Sevelius & Johnson, 2013; Sevelius, Patouhas, Keatley, & Johnson, 2013). ‘Gender affirmation’ is an interpersonal process in which a person receives validation of their gender identity and expression (Nuttbrock et al., 2009; Sevelius, 2012). The Model of Gender Affirmation predicts that transgender women who place a high level of importance on gender affirmation but do not receive or internalize this affirmation will choose behaviors that increase their access to gender affirmation, whether those behaviors are healthy or risky (Sevelius, 2012). This study sought to explore demographic/psychosocial and transgender-relevant correlates of ART adherence and viral load among transgender women living with HIV.

## Methods

### Design

We conducted a cross-sectional survey with a convenience sample of HIV-positive transgender women on ART to investigate correlates of HIV clinical outcomes (ART adherence and viral load). This study was approved by University of California, San Francisco Committee on Human Research on August 23, 2010.

### Eligibility and recruitment

Participants were a convenience sample of transgender women in the San Francisco Bay Area recruited using a combination of street outreach, venue-based sampling, and snowball sampling. A peer outreach worker conducted all outreach and survey activities. Eligible individuals were those assigned male sex at birth but who identified as female, transgender, or a gender identity other than male, 18 years or older, English-speaking, and able to provide informed consent. Approximately 6% of those screened were not eligible for the study, and a total of 150 participants were included in the larger dataset. Data from those who reported HIV+ serostatus and currently taking ART (n=59, 39%) were included in the current analyses.

### Data collection

Data were collected from June 2011 to June 2013 on tablet computers using handheld computer-assisted self interviewing, which can increase reports of sensitive behaviors (Bernhardt et al., 2001; Morrison-Beedy, Carey, & Tu, 2006) and is easy to use by respondents with low literacy (Al-Tayyib, Rogers, Gribble, Villarroel, & Turner, 2002; Edwards et al., 2007). The peer outreach worker provided assistance as participants completed the survey. Participants spent approximately 45 minutes completing the survey and were reimbursed US\$30.

**HIV clinical outcomes**—ART adherence over the previous 30 days was assessed using a single rating item, which in previous research produced adherence reports most closely associated with medication electronic event monitors (Lu et al., 2008): “Rate your ability to take all your medications as prescribed” with six response categories ranging from excellent (100% adherent) to very poor (0% adherent). Participants self-reported their most recent CD4+ cell count and whether their HIV viral load was detectable or undetectable at their last laboratory assessment. CD4+ count has been shown to be reliably and validly collected through self-report, and self-reported HIV viral load is most reliable when dichotomized into detectable/undetectable categories (Kalichman, Rompa, & Cage, 2000).

### **Transgender-relevant variables**

**Experiences of transphobia and stress appraisal:** The Experiences of Transphobia scale was adapted from a measure of experiences of racism (Landrine & Klonoff, 1996). Eleven items assess experiences of violence, harassment, and discrimination attributable to participants’ gender identity or expression. A sample item is, “As an adult, how often were you hit or beaten up for being transgender or effeminate?” The range of scores observed was 12 to 63 (summed), with higher scores reflecting more frequent experiences of violence, harassment, and discrimination due to transphobia. Stress appraisal was assessed by asking participants “how stressful was this for you?” after each reported experience (yielding eleven additional items). Participants were asked to rate their stress appraisal of each experience on a 5-point scale from ‘not at all stressful’ to ‘extremely stressful’. The range of scores observed was 12 to 59 (summed), with higher scores reflecting a greater level of stress associated with each experience of transphobia as reported by the participant. Cronbach’s alpha was .96 for the Experiences of Transphobia scale, and .91 for the stress appraisal items.

**Gender affirmation:** ‘Importance of gender affirmation’ pertains to transgender women’s desire for validation of their gender identity and/or expression (Sevelius, 2012). ‘Satisfaction with gender expression’ reflects transgender women’s level of contentment with their current gender expression. Because no measures of gender affirmation currently exist in the literature, a 10-item measure of gender affirmation was developed based on previous research, including qualitative data and cognitive interviewing. The final scale included two 5-item subscales, importance of gender affirmation and satisfaction with current gender expression. A sample item from the importance subscale is “How important is it that strangers call you ‘she’ when talking about you?” The range of scores observed was 1 to 5, and higher scores on the importance scale reflect higher levels of desire for validation of one’s gender identity. A sample item from the satisfaction subscale is “How satisfied are you with your current level of femininity?” Participants responded by rating these items on 5-point scales, ranging from ‘extremely’ to ‘not at all’. The range of scores observed was 1.4 to 5, with higher scores on the satisfaction subscale reflect higher levels of contentment with one’s current gender expression. Cronbach’s alpha was .86 for the importance subscale and .91 for the satisfaction subscale.

**Hormone adherence:** Parallel to ART adherence, 30-day self-reported adherence to hormone therapy was assessed using a single rating item: “Rate your ability to take your

hormones as prescribed,” with six response categories ranging from excellent (100% adherent) to very poor (0% adherent).

**Sex work:** Sex work in the past three months was assessed by asking participants: “In the past 3 months, did you engage in sex work or prostitution, where someone paid you money or gave you something like drugs, food, clothes, or housing in return for sex?”

**Demographic/psychosocial variables—**We collected demographic data, such as age, race/ethnicity, education, and income, as well as ever being homeless, ever being arrested, and stimulant use (crack, cocaine, and methamphetamines). Alcohol use was assessed using the Alcohol Use Disorders Identification Test (AUDIT) (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993), with a score of zero indicating ‘alcohol abstainers’, 1-7 indicating ‘non-hazardous alcohol drinkers’, and 8 indicating ‘hazardous alcohol drinkers’. Post-Traumatic Stress Disorder (PTSD) was assessed using the 17-item Post-Traumatic Stress Disorder Checklist - Civilian Version (PCL-C) (Weathers, Huska, & Keane, 1991). Beck Depression Inventory-Short Form (BDI-SF) assessed depression (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993). Suicidality was assessed with one item that asked if participants had ever thought about or attempted suicide.

**Health care empowerment:** The Health Care Empowerment (HCE) model describes the process and state of being engaged, informed, collaborative, committed, and tolerant of uncertainty regarding health care (M. Johnson, Sevelius, Dilworth, Saberi, & Neilands, 2012; Mallory O. Johnson, 2011). The Health Care Empowerment Inventory includes two subscales: 1) tolerance for uncertainty (TOL) and 2) informed, collaborative, committed, and engaged (ICCE), both of which have been linked to ART adherence and clinical outcomes in prior research (M. Johnson et al., 2012; M.O. Johnson, Dawson Rose, Dilworth, & Neilands, 2012).

## Analysis

We examined transgender-relevant and demographic/psychosocial correlates of two outcome variables: ART adherence (excellent versus less than excellent) and HIV viral load (undetectable versus detectable). We used descriptive statistics to characterize the sample and conducted two parallel analyses for each of the outcome variables: 1) we examined the association between each outcome and each predictor variable in bivariate models and 2) we conducted two multivariate logistic regression analyses per outcome: a) one to examine associations between outcome variables and all transgender-relevant variables, and b) one to examine associations between outcome variables and variables with a bivariate  $p$ -value $<0.1$ . In all multivariate models, using backward elimination, predictor variables were removed until all remaining variables had a  $p$ -value $<0.05$ . Robust standard errors protected against violations of any model assumptions. A two-sided  $p$ -value $<0.05$  was considered statistically significant. All analyses were conducted using Stata 12.1 (StataCorp, College Station, TX).

## Results

Our sample included 59 HIV-positive transgender women who were on ART, predominantly African American with a mean age of 43 years (Table 1). Over one-third

reported excellent ART adherence, 78.6% reported an undetectable viral load, and mean self-reported CD4+ cell count was 556 cell/mm<sup>3</sup>. Over 75% were on hormone therapy and many had used non-prescribed hormones and/or street hormones (49% and 28.8%, respectively).

### **ART adherence**

In bivariate models (Table 2), having excellent ART adherence was associated with age, AUDIT category, higher satisfaction with current gender expression, higher importance of gender affirmation, and excellent adherence to hormone therapy. Both HCE subscales were associated with reporting excellent ART adherence.

In the multivariate model examining transgender-relevant variables, lower stress appraisal of transphobic experiences (OR=0.81, 95% CI=0.71-0.93, p=0.002), excellent adherence to hormone therapy (OR=454.00, 95% CI=14.41-14299.40, p=0.001), and higher importance of gender affirmation (OR=6.03, 95% CI=1.05-34.71, p=0.044) were associated with excellent ART adherence. In multivariate model including all variables with a bivariate p-value<0.1, age (OR=1.15, 95% CI=1.01-1.31, p=0.040), importance of gender affirmation (OR=2.46, 95% CI=1.06-5.73, p=0.037), and excellent hormone therapy adherence (OR=50.34, 95% CI=5.84-433.97, p<0.001) were associated with excellent ART adherence.

### **HIV viral load**

In bivariate models (Table 2), being in a relationship and lower stress appraisal of transphobic experiences were associated with undetectable viral load.

In the multivariate model examining transgender-relevant variables, lower stress appraisal of transphobic experiences was the only variable associated with reporting an undetectable viral load (OR=0.94, 95% CI=0.89-1.00, p=0.044). In the multivariate model with all variables with a bivariate p-value<0.1, being in a relationship was the only variable associated with an undetectable viral load (OR=10.35, 95% CI=1.20-88.95, p=0.033).

## **Discussion**

Among the transgender women who participated in our study, we found multiple correlates of ART adherence and viral load. About a third reported excellent adherence to ART and over 20% reported having a detectable viral load at last assessment, despite the fact that all participants in our sample were currently on ART.

### **Demographic/psychosocial correlates of ART adherence and viral load**

Reporting excellent ART adherence was positively associated with age and abstinence from alcohol. This is consistent with literature reporting associations between older age and better adherence among HIV-positive adults (Barclay et al., 2007). Current literature is mixed on the impact of alcohol use on ART adherence (Samet, Horton, Meli, Freedberg, & Palepu, 2004; Sharma et al., 2013). This study provides preliminary evidence that this association may be worth exploring further among transgender women. As expected, tolerance for

uncertainty and the ICCE subscales of the Health Care Empowerment measure were also associated with high self-reported adherence to ART.

Being in a relationship was associated with reporting an undetectable viral load, which corroborates findings among other populations (Wrubel, Stumbo, & Johnson, 2010), and may be related to social support received in the context of intimate partnerships. Future research should explore how relationship status might support positive clinical outcomes for transgender women living with HIV.

### **Transgender-relevant correlates of ART adherence and viral load**

Experiences that are uniquely relevant to the context of transgender women's lives are important in understanding ART adherence and viral load among those living with HIV, given their disproportionately poor clinical outcomes. Gender affirmation has been identified as an important dimension of transgender women's experiences and may be related to health outcomes (Sevelius, 2012). ART adherence was associated with satisfaction with one's current gender expression and importance of gender affirmation. In multivariate models examining transgender-relevant correlates of ART adherence, adherence to hormone therapy and importance of gender affirmation were associated with adherence to ART.

Excellent adherence to hormones was reported more frequently than excellent adherence to ART. In our sample, gender affirmation was rated as extremely important and thus participants may be particularly motivated to adhere to their hormone regimens. Adherence to hormones was positively associated with ART adherence, which is logical given that medication adherence requires a commitment to self-care and a willingness and ability to structure one's life to accommodate a demanding treatment regimen. The relationship between the importance of gender affirmation and adherence to ART may be mediated by motivation and commitment to self-care. The perception of healthy behaviors such as hormone therapy and ART adherence as affirming of one's gender may predict behavior. Future research should assess the perceived effects of HIV treatment on the body and/or physical appearance among transgender women. In addition, future research should examine the clinical integration of hormone therapy and ART as a potential facilitator of ART adherence and increased treatment engagement (Sevelius & Johnson, 2013).

In the multivariate model looking at transgender-relevant correlates of ART adherence and viral load, stress appraisal of transphobic experiences was negatively associated with ART adherence and having an undetectable viral load. This corroborates findings that stress is associated with nonadherence (French, Tesoriero, & Agins, 2011), and trauma is associated with treatment failure among women, including transgender women (Machtiger, Haberer, Wilson, & Weiss, 2012). Future research should examine the role of coping in the improvement of health outcomes for transgender women living with HIV.

### **Limitations**

This study was cross-sectional and utilized a convenience sample of transgender women living with HIV in the San Francisco Bay Area. The findings drawn here may not generalize to transgender women living in areas with poorer access to culturally competent resources. In addition, all data were collected via self-report. Thus, only participants who were aware

of their HIV-status and were willing to report a positive status were included in the current study. While blood draws and chart abstraction would likely yield the most accurate clinical data regarding current viral load and CD4+ counts, we opted to use self-report measures that have been clinically validated and have demonstrated reliability to reduce costs and minimize barriers to participation. Data gathered via HIV testing and lab results could yield different results. Furthermore, wide confidence intervals were observed for some variables and this is likely due to small cell sizes.

## Conclusion

This study provides preliminary evidence of transgender-relevant correlates of ART adherence and viral load among HIV-positive transgender women. Due to the disproportionate burden of HIV and HIV-related morbidity and mortality among transgender women, it is imperative that future research continues to explore the unique correlates and predictors of clinical outcomes in this population. Interventions are urgently needed to target barriers and bolster facilitators of adherence among transgender women living with HIV.

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**Table 1**

## Characteristics of participants

		N= 59
Age, mean (SD)		43.3 (9.6)
Race/Ethnicity, n (%)		
	Black/African American	37 (62.7)
	White/Caucasian	4 (6.8)
	Hispanic	6 (10.2)
	Other	12 (20.3)
Education, n (%)		
	< High school degree	20 (33.9)
	High school degree	10 (17.0)
	> High school degree	29 (49.2)
Income, per month, n (%)		
	\$1000	35 (59.3)
	>\$1000	24 (40.7)
In relationship, n (%)		25 (44.6)
Homeless, ever, n (%)		49 (83.1)
Arrested, ever, n (%)		46 (78.0)
Stimulant use, past 3 months, n (%) <sup>1</sup>		10 (17.0)
AUDIT categories, n (%)		
	Abstainer	19 (33.9)
	Non-hazardous alcohol drinker	23 (41.1)
	Hazardous alcohol drinker	14 (25.0)
Suicidal ideation, ever, n (%)		28 (47.5)
Sex work, past 3 months, n (%)		17 (34.7)
Experiences of transphobia score, mean (SD)		32.9 (11.7) <sup>3</sup>
Stress appraisal of transphobic experiences, mean (SD)		33.6 (13.6) <sup>4</sup>
Importance of gender affirmation, mean (SD)		3.4 (1.2) <sup>7</sup>
Satisfaction with gender expression, mean (SD)		3.5 (0.9) <sup>3</sup>
Post-traumatic stress disorder score, mean (SD)		40.2 (15.4)
Depression score, mean (SD)		17.5 (11.9)
Tolerance for uncertainty HCE score, mean (SD)		16.3 (3.3)
ICCE HCE score, mean (SD)		17.8 (2.8)
Hormone use, current, n (%)		39 (76.5)
Use of hormones without a prescription, ever, n (%)		25 (49.0)
Excellent adherence to hormones <sup>2</sup> , n (%)		26 (66.7)
Excellent ART adherence <sup>2</sup> , n (%)		20 (33.9)

		N= 59
Undetectable HIV viral load <sup>2</sup> , n (%)		44 (78.6)
Absolute CD4+ cell count (SD) <sup>2</sup> , mean, cells/mm <sup>3</sup>		556.4 (274.7) <sup>6</sup>

ART: antiretroviral therapy; AUDIT: Alcohol Use Disorders Identification Test; HCE: Health Care Empowerment; ICCE: Informed, Committed, Collaborative, Engaged; SD: standard deviation

<sup>1</sup> Stimulant use: crack, cocaine, or methamphetamines

<sup>2</sup> Self-report

<sup>3</sup> N= 57

<sup>4</sup> N= 54

<sup>6</sup> N= 56

<sup>7</sup> N= 52

Table 2

## Bivariate analyses

	Excellent ART Adherence		Undetectable HIV Viral Load	
	OR (95% CI)	p-value	OR (95% CI)	p-value
<b>Transgender-relevant variables</b>				
Hormone use, current	1.88 (0.43-8.17)	0.40	0.81 (0.14-4.58)	0.81
Use of hormones without a prescription, ever	1.33 (0.41-4.26)	0.63	2.88 (0.64-13.07)	0.17
Excellent adherence to hormones	34.50 (3.52-338.09)	0.002	0.95 (0.15-5.99)	0.96
Experiences of transphobia score	0.98 (0.93-1.03)	0.44	0.95 (0.90-1.01)	0.10
Stress appraisal of transphobic experiences	1.00 (0.96-1.05)	0.94	0.94 (0.89-1.00)	0.04
Importance of gender affirmation	2.47 (1.25-4.86)	0.009	0.89 (0.45-1.74)	0.73
Satisfaction with current gender expression	2.56 (1.09-6.05)	0.03	1.21 (0.46-3.18)	0.70
Sex work, past 3 months	0.31 (0.07-1.33)	0.12	0.88 (0.21-3.64)	0.85
<b>Demographic/psychosocial variables</b>				
Age	1.08 (1.01-1.16)	0.03	1.03 (0.96-1.10)	0.46
Race/Ethnicity		0.84*		0.08*
Black/African-American	Reference		Reference	
White/Caucasian	0.69 (0.64-7.55)	0.77	0.39 (0.03-4.79)	0.46
Latina	2.08 (0.36-12.07)	0.41	0.52 (0.04-5.97)	0.60
Other	1.04 (0.26-4.21)	0.95	0.13 (0.03-0.61)	0.01
Education		0.17*		0.22*
< High school degree	Reference		Reference	
High school degree	4.50 (0.88-23.06)	0.07	0.82 (0.06-10.87)	0.88
> High school degree	1.35 (0.37-4.92)	0.65	0.26 (0.05-1.40)	0.12
Income per month > \$1000	0.70 (0.23-2.15)	0.53	1.52 (0.39-5.88)	0.54
Homeless, ever	0.73 (0.18-3.0)	0.66	0.35 (0.04-3.17)	0.35
Arrested, ever	0.77 (0.21-2.80)	0.70	1.13 (0.25-5.07)	0.87
Stimulant use, past 3 months	0.18 (0.02-1.53)	0.12	0.79 (0.14-4.60)	0.79
Suicidal ideation, ever	0.63 (0.21-1.91)	0.42	0.35 (0.09-1.34)	0.13
AUDIT categories		0.03*		0.35*
Abstainer	Reference		Reference	
Non-hazardous alcohol drinker	0.26 (0.07-0.96)	0.04	0.35 (0.06-2.05)	0.25
Hazardous alcohol drinker	0.12 (0.02-0.71)	0.02	0.25 (0.04-1.70)	0.16
In relationship	0.54 (0.17-1.68)	0.29	10.35 (1.18-90.80)	0.04
Health Care Empowerment				
Informed, Collaborative, Committed, Engaged	1.31 (1.02-1.68)	0.03	0.92 (0.74-1.14)	0.45
Tolerant of Uncertainty	1.22 (1.02-1.47)	0.03	0.96 (0.81-1.15)	0.69
Post-traumatic stress disorder score	0.97 (0.93-1.01)	0.11	0.97 (0.92-1.02)	0.26
Depression score	0.96 (0.92-1.01)	0.11	0.96 (0.91-1.01)	0.11

\* Wald test p-value