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Medication adherence among transgender women living with HIV

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Abstract

Medication adherence is linked to health outcomes among adults with HIV infection. Transgender women living with HIV (TWLWH) in the U.S. report suboptimal adherence to medications and are found to have difficulty integrating HIV medication into their daily routine, but few studies explore factors associated with medication adherence among transgender women. Thus, the purpose of this paper is to examine demographic and clinical factors related to self-reported medication adherence among transgender women. This secondary analysis is based on data collected from the Symptom and Genetic Study that included a convenience sample of 22 self-identified transgender women, 201 non-transgender men, and 72 non-transgender women recruited in northern California. Self-reported medication adherence was assessed using the AIDS Clinical Trials Group Adherence Questionnaire. Gender differences in demographic and clinical variables were assessed, as were differences between transgender women reporting high and low adherence. Transgender women had lower adherence to medications compared to non-transgender males and non-transgender females (p=.028) and were less likely to achieve viral suppression (p=.039). Within the transgender group, Black/African Americans reported better adherence than participants who were Whites/Caucasian or other races (p=.009). Adherence among transgender women was unrelated to medication count and estrogen therapy, but consistent with other reports on the HIV population as a whole; transgender women with high adherence were more likely to achieve viral suppression compared to the transgender women with low adherence. Despite the high incidence of HIV infection in the transgender population, few studies focus on TWLWH, either in regard to their adherence to antiretroviral therapies or to their healthcare in general. To address ongoing health disparities, more studies are needed focusing on the transgender population's continuum of care in HIV therapies.

Keywords

HIV; transgender; gender identity; medication adherence; health disparities

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Introduction

Transgender women (adults who identify with a different gender than the gender assigned at birth) have a high prevalence of HIV in the United States (Baral et al., 2013; Herbst, Jacobs, Finalayson, & McKleroy, 2008). Furthermore, multiple studies support that *transgender women living with HIV* (TWLWH) were less likely to report higher adherence to anti-retroviral therapy (ART) compared to other adults with HIV (Sevelius, Carrico, & Johnson, 2010; Mizuno, Frazier, Huang & Skarbinski, 2015). In TWLWH, ART adherence has been associated with older age, abstinence from alcohol, positive gender affirmation and adherence to hormones (Sevelius, Saberi, & Johnson, 2014). Similarly, in our previous analysis of adherence and symptom experience among adults living with HIV (Gay et al., 2011), we found that our group of TWLWH reported significantly poorer adherence compared to other adults. The purpose of this secondary analysis is to further explore the findings from our previous study by examining factors related to self-reported medication adherence specifically among our sample of transgender women.

Methods

This secondary analysis is based on data collected from the Symptom and Genetic Study, which focused on biomarkers of symptom experience among people living with HIV (Lee et al., 2009). The Committee on Human Research at the University of California, San Francisco approved this study. Informed consent was obtained prior to participation.

Participants

The study enrolled 350 adults living with HIV in the San Francisco Bay Area between April 2005 and December 2007. Participants were recruited through flyers posted at HIV clinics and community sites. Eligibility criteria included the ability to speak and read English, age ≥ 18 years, and a time since HIV diagnosis of ≥ 30 days. Exclusion criteria included the self-reported use of illicit drugs, a positive urine drug test, working nights, pregnancy within the past 3 months, or self-reported diagnosis of apnea, narcolepsy, bipolar disorder, schizophrenia, or dementia.

Procedures

Paper questionnaires were self-administered at the General Clinical Research Center at UCSF. Anthropometric measures, a urine sample, and a blood sample were also obtained. CD4 and viral load levels were obtained from medical records. The current analysis is based on data collected at the baseline assessment.

Instruments

Demographic and clinical characteristics—A questionnaire developed for this study was used to obtain age, gender, marital status, education, ethnicity, employment, comorbid conditions, AIDS diagnosis, and medication regimen, including current ART status. Gender was measured by use of a single self-report question to identify current

gender identity and was confirmed by genetic testing (Hennessey et al., 2013). Polypharmacy is defined as ≥ 5 medications.

Medication adherence—The AIDS Clinical Trials Group Adherence Questionnaire version used in this study included 9 items from the original 14 derived from a prior analysis (Holzemer et al., 2006). The questionnaire assessed adherence to all medications and was not specific to HIV medications. Respondents were asked to rate how often each of the nine reasons for missing medication applied to them within the previous month on a 4-point scale (never, rarely, sometimes, often). Total scores can range from 9 to 36, with higher scores indicating lower adherence. In addition to reporting total adherence scores, scores were also dichotomized into the two adherence groups defined by Holzemer et al. (2006) as higher adherence (scores 9–20) and lower adherence (scores 21–36). The Cronbach α coefficient for the 9 items was .848 in our total sample and .812 among the TWLWH.

Analysis

SPSS version 22.0 (SPSS, Inc., Chicago, IL) and Stata version 13 (StataCorp, College Station, TX) were used to conduct all analyses. Frequencies, means, and standard deviations were used to summarize the participant characteristics. Viral load and CD4 were analyzed as both continuous values (square root-transformed for CD4 and log-transformed for viral load) and in clinically significant categories (e.g., CD4<200cells/mm^3 and viral suppression ≤ 200 copies/ml). Chi-square tests, Fisher's Exact test (when expected cell frequencies were <5), t-tests and analysis of variance were conducted, and post hoc Z-tests were performed with Bonferroni adjusted *p* values to evaluate pairwise differences. Pearson correlations were employed to analyze the relationships between continuous variables. *P* values < 0.05 were considered statistically significant. Because null findings are not an indication of an absence of effects, especially given the small sample size in Table 3, less emphasis is placed on statistical significance and proportions are emphasized.

Results

Sample Characteristics

The parent study enrolled a convenience sample of 350 participants living with HIV. Non-transgender women (17%; n=16) were more likely than transgender women (0%; n=0) or non-transgender men (7%; n=16) to be excluded due to positive urine screening (*p*=.007). Five non-transgender men and two non-transgender women over 60 years of age were excluded to better match the age range for these two groups with ages of the transgender participants. Given the emphasis on medication adherence, participants who did not complete the adherence questions (non-transgender men=7, non-transgender women=4) or were not taking any medications (non-transgender men=3, non-transgender women=2) were excluded from this secondary analysis. The sample for this analysis consisted of 295 participants: 201 non-transgender men, 72 non-transgender women, and 22 self-identified TWLWH.

Gender differences in demographic and clinical characteristics

Table 1 summarizes the demographic characteristics across TWLWH, non-transgender men, and non-transgender women. No gender differences were found in age, disability status, income, CD4, viral load, AIDS diagnosis, comorbidities, medication count or current ART use. Post hoc Z-tests with Bonferroni corrections indicated the TWLWH (59%) and non-transgender women (64%) were significantly more likely than non-transgender men (28%) to identify as African-American.

Gender differences in medication adherence

ANOVA indicated a significant gender difference in log-transformed adherence scores (Table 2). Bonferroni post hoc tests indicated that TWLWH had significantly lower adherence (i.e. higher scores) than non-transgender men (p=.023), but the comparison between TWLWH and non-transgender women did not reach statistical significance(p=.069). A similar pattern was evident in the analysis of dichotomized adherence scores.

Demographic and clinical characteristics associated with transgender adherence

Table 3 compares TWLWH with lower and higher adherence on demographic and clinical characteristics. The factors associated with adherence among TWLWH were race/ethnicity and viral load. Bonferroni post hoc tests indicated that the 13 TWLWH who identified as Black/African American reported better medication adherence (lower adherence scores) than the 9 TWLWH who identified as White/Caucasian (p=.03) or other race (p=.003). Dichotomized adherence scores also supported this finding. TWLWH with lower adherence had proportionally higher viral loads than TWLWH with higher adherence, although the difference did not reach statistical significance [t(17.4)=2.08 p=.053] in this small sample.

Discussion

TWLWH in this sample were primarily single women of color with low education, and nearly a third (32%) reported low adherence to medications. TWLWH reported lower adherence to medications than non-transgender men, and the difference in adherence between TWLWH and non-transgender women approached statistical significance, supporting past findings (Mizuno et al., 2015; Sevelius et al., 2014; Sevelius et al., 2010). As expected, lower adherence among the TWLWH in this sample was associated with detectable viral loads and failure to achieve viral suppression, further supporting literature that adherence to medications is positively related to virologic outcomes (Cantudo-Cuenca et al., 2014; Mizuno et al., 2015).

Several limitations are noted for this study. Research samples of TWLWH are typically small in numbers, and our findings, also based on a small sample, may have limited generalizability to the larger population of TWLWH in or outside of San Francisco. The study also excluded people who tested positive for an illicit substance, and while none of the transgender women in this study were excluded due to positive urine screening, these findings may not generalize to TWLWH who also use illicit substances. Furthermore, the parent study was not designed to focus on TWLWH and therefore did not address the unique issues of the transgender population that may influence adherence: stigma/discrimination,

patient-provider relationships, or hormone therapy. Moreover, the adherence measure used in this study has not been previously validated with TWLWH and relied on self-report, which is vulnerable to social desirability bias and memory limitations. Also, the adherence questionnaire used in this study was not specific to ART, and thus, the results may be influenced by other medications and their side effects. Although data was collected from 2005–2007, the findings of this study concerning TWLWH, a difficult group to engage in studies, are relevant and current. This study not only provides support for existing literature but also identifies that better adherence was associated with African American race/ethnicity in this small sample, and this finding warrants further exploration in a larger study.

Conclusions

Few studies address HIV care and trans-specific issues among transgender women. Further studies investigating associations between medication adherence, race and trans-specific issues (hormone therapy, gender affirmation and stigma) are necessary. Positive provider-patient clinical relationships and integration of hormone therapy with HIV care can help increase engagement in care for transgender women living with HIV. Additionally, reduction of HIV-related stigma and gender-related stigma (being transgender) and attention to socio-demographic factors (race, occupation, housing, etc.) in health care environments can greatly improve retention in clinical care and the quality of life for this highly impacted group.

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References

Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. The Lancet. 2013; 13:214–222. [PubMed: 23260128]

Cantudo-Cuenca MR, Jimenez-Galan, Almeida-Gonzalez CV, Morillo-Verdugo R. Concurrent use of comedications reduces adherence to antiretroviral therapy among HIV-infected patients. Journal of Managed Care & Specialty Pharmacy. 2014; 20(8):844–850. [PubMed: 25062078]

Gay C, Portillo CJ, Kelly R, Coggins T, Davis H, Aouizerat BE, Lee KA. Self-reported medication adherence and symptom experience in adults with HIV. Journal of the Association of Nurses in AIDS Care. 2011; 22(4):257–268. [PubMed: 21377900]

Hennessy MD, Zak RS, Gay CL, Pullinger CR, Lee KA, Aouizerat BE. Polymorphisms of Interleukin-1 Beta and Interleukin-17Alpha Genes are associated with restless legs syndromes. Biological Research for Nursing. 2013; 16(2):143–151. [PubMed: 23460603]

Herbst JH, Jacobs ED, Finalayson TJ, McKleroy VS. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: A systematic review. AIDS Behavior. 2008; 12:1–17. [PubMed: 17694429]

Holzemer WL, Bakken S, Portillo CJ, Grimes R, Welch J, Wantland D, Mullan JT. Testing a nurse-tailored HIV medication adherence intervention. Nursing Research. 2006; 55(3):189–197. [PubMed: 16708043]

Lee KA, Gay CL, Portillo CJ, Coggins T, Davis H, Pullinger CR, Aourizerat BE. Symptom experience in HIV-infected adults: A function of demographics and clinical characteristics. Journal of Pain and Symptom Management. 2009; 38:882–893. [PubMed: 19811886]

Mizuno Y, Frazier EL, Huang P, Skarbinski J. Characteristics of transgender women living with HIV receiving medical care in the United States. LGBT Health. 2015; 2(3):228–234. [PubMed: 26788671]

Sevelius JM, Carrico A, Johnson MO. Antiretroviral therapy adherence among transgender women living with HIV. Journal of the Association of Nurses in AIDS Care. 2010; 21(3):256–264. [PubMed: 20347342]

Sevelius JM, Saberi P, Johnson MO. Correlates of antiretroviral adherence and viral load among transgender women living with HIV. AIDS Care. 2014; 26(8):976–982. [PubMed: 24646419]

Table 1

Demographic and Clinical Characteristics by Gender

	Transgender (n=22) % (N) or Mean ± SD	Non-transgender Men (n=201) % (N) or Mean ± SD	Non-transgender Women (n=72) % (N) or Mean ± SD	Statistics (reported if p<.10)
DEMOGRAPHICS				
Age, years (range 22–60)	43.0 ± 9.11	44.8 ± 7.64	45.6 ± 7.50	NS
Race/ethnicity				Fisher's exact p<.001[1]
Whites/Caucasian	2.5% (3)	83.1% (98)	14.4% (17)	
Black/African-American	11.2% (13)	49.1% (57)	39.7% (46)	
Other	9.8% (6)	75.4% (46)	14.8% (9)	
Education				Fisher's exact p=.002
≤ High School Diploma	10.9% (14)	55.5% (71)	33.6% (43)	
Some College	4.9% (5)	76.5% (78)	18.6% (19)	
≥ College Degree	4.6% (3)	80.0% (52)	15.4% (10)	
Work Status				NS
Employed	4.8% (2)	78.6% (33)	16.7% (7)	
Not Employed/Student	8.3% (2)	66.7% (16)	25.0% (6)	
Disability	7.9% (18)	66.4% (152)	25.8% (59)	
Monthly Income				NS
< $1,000	8.0% (16)	65.2% (131)	26.9% (54)	
≥ $1,000	6.4% (6)	74.5% (70)	19.1% (18)	
Partner				χ^2 (2)=7.221, p=.027
No	8.4% (16)	72.1% (137)	19.5% (37)	
Yes	5.7% (6)	61.0% (64)	33.3% (35)	
CLINICAL CHARACTERISTICS				
CD4	**(n=22)**	**(n=190)**	**(n=69)**	
Mean ± SD, cells/mm^3	376.23 ± 237.05	460.21 ± 274.17	413.19 ± 237.04	NS[2]
Category				NS
<200 cells/mm^3	11.8% (6)	62.7% (32)	25.5% (13)	
200–499 cells/mm^3	7.3% (9)	65.9% (81)	26.8% (33)	
≥ 500 cells/mm^3	6.5% (7)	72.0% (77)	21.5% (23)	
Viral Load	**(n=21)**	**(n=185)**	**(n=68)**	
Mean ± SD, log(copies/ml)[3]	2.99 ± 1.13	2.55 ± 1.20	2.73 ± 1.28	NS
Viral suppression				χ^2(2)=6.51, p=.039
No (>200 copies/ml)	11.9% (14)	61.0% (72)	27.1% (32)	
Yes (≤200 copies/ml)	4.5% (7)	72.4% (113)	23.1% (36)	
AIDS Diagnosis				χ^2(2)=5.03, p=.081
No	10.4% (14)	62.2% (84)	27.4% (37)	
Yes	5.0% (8)	73.1% (117)	21.9% (35)	

	Transgender (n=22) % (N) or Mean ± SD	Non-transgender Men (n=201) % (N) or Mean ± SD	Non-transgender Women (n=72) % (N) or Mean ± SD	Statistics (reported if p<.10)
Hepatitis C Diagnosis	**(n=21)**	**(n=191)**	**(n=68)**	NS
No	7.6% (14)	68.1% (126)	24.3% (45)	
Yes	7.4% (7)	68.4% (65)	24.2% (23)	
Comorbidities	**(n=21)**	**(n=191)**	**(n=68)**	NS
No	11.0% (12)	67.9% (77)	21.1% (23)	
Yes	5.3% (9)	68.4% (118)	26.3% (45)	
Medication Count	5.5 ± 2.48	6.8 ± 4.39	6.9 ± 3.86	NS[4]
Polypharmacy				NS
No (<5 medications)	6.5% (6)	70.7% (65)	22.8% (21)	
Yes (≥5 medications)	7.9% (16)	67.0% (136)	25.1% (51)	
HIV Drug Class				NS
None	8.9% (7)	59.5% (47)	31.6% (25)	
NRTI only	0.0% (0)	93.8% (15)	6.3% (1)	
NNRTI/NRTI backbone	11.3% (7)	66.1% (41)	22.6% (14)	
PI w/ NRTI backbone	5.5% (7)	71.7% (91)	22.8% (29)	
Other (e.g., triple class)	9.1% (1)	63.6% (7)	27.3% (3)	
Currently on ART				NS
No	8.9% (7)	59.5% (47)	31.6% (25)	
Yes	6.9% (15)	71.3% (154)	21.8% (47)	
Taking Estrogen				Fisher's exact p<.001[5]
No	3.2% (9)	72.3% (201)	24.5% (68)	
Yes	76.5% (13)	0.0% (0)	23.5% (4)	

Notes: NRTI = Nucleoside/Nucleotide Reverse Transcriptase Inhibitors; NNRTI = Non-nucleoside Reverse Transcriptase Inhibitors; PI =Protease Inhibitors

NS = not significant (p > .10)

[1] z-tests with Bonferroni corrections indicated that transgender adults or non-transgender women were more likely to be Black /African American than non-transgender men

[2] Square root of CD4 used in statistical analysis

[3] Undetectable viral loads were assigned a value of 1.69

[4] Square root of med count used in statistical analysis

[5] z-tests with Bonferroni corrections indicated that transgender adults were more likely to be on estrogen than non-transgender women and non-transgender men

Table 2.

Adherence by Gender

	Transgender (n=22) % (N) or Mean ± SD	Non-transgender Men (n=201) % (N) or Mean ± SD	Non-transgender Women (n=72) % (N) or Mean ± SD	Statistics
ADHERENCE MEASURES				
Total score[6]	17.1 ± 5.75	13.9 ± 4.94	14.3 ± 5.67	F(2,292)=3.61,p=.028[7]
Category				Fisher's exact p=.050
Lower adherence (score≥21)	17.1% (7)	58.5% (24)	24.4% (10)	
Higher adherence (score<21)	5.9% (15)	69.7% (177)	24.4% (62)	

[6]Higher adherence scores indicate poorer adherence; log-transformed adherence scores were used for analysis.

[7]Bonferroni post hoc tests indicate that transgender women are less adherent to medications than non-transgender men.

Table 3

Characteristics Associated with Adherence Among Transgender Women (n=22)

	Adherence category		Adherence scores[8]
	Higher adherence (n=15) % (N) or Mean ± SD	**Lower adherence (n=7) % (N) or Mean ± SD**	**Mean ± SD**
Age, years (range 22–60)			r=−.182
Mean ± SD, 42.95 ± 9.11	45.3 ± 9.11	37.9 ± 7.20	
Race/ethnicity	*9*		*10*
Whites/Caucasian	33.3% (1)	66.7% (2)	21.7 ± 3.21
Black/African American	92.3% (12)	7.7% (1)	13.7 ± 3.99
Other	33.3% (2)	66.7% (4)	22.3 ± 4.65
Education			
≤ High School Diploma	71.4% (10)	28.6% (4)	17.0 ± 5.51
Some College	60.0% (3)	40.0% (2)	17.0 ± 6.36
≥ College Degree	66.7% (2)	33.3% (1)	18.0 ± 8.19
Work			
Employed	100% (2)	0.0% (0)	11.5 ± 3.54
Not Employed/Student	50.0% (1)	50.0% (1)	16.0 ± 8.49
Disability	66.7% (12)	33.3% (6)	17.9 ± 5.60
Monthly Income			
< $1,000	62.5% (10)	37.5% (6)	17.6 ± 6.12
≥ $1,000	83.3% (5)	16.7% (1)	15.8 ± 4.88
Partner			
No	68.8% (11)	31.3% (5)	17.2 ± 5.72
Yes	66.7% (4)	33.3% (2)	16.8 ± 6.37
CD4			
Mean ± SD,[11] cells/mm^3	410.4 ± 251.66	303.0 ± 199.30	r=−.137
Category			
<200 cells/mm^3	50.0% (3)	50.0% (3)	18.9 ± 5.66
200–499 cells/mm^3	77.8% (7)	22.2% (2)	16.2 ± 5.52
≥500 cells/mm^3	71.4% (5)	28.6% (2)	16.7 ± 6.60
Viral Load (n=21)			r=.256
Mean ± SD, log(copies/ml)	2.70 ± 1.18	3.59 ± 0.77	
Viral suppression	*12*		
No (>200 copies/ml)	50.0% (7)	50.0% (7)	18.4 ± 6.51
Yes (≤200 copies/ml)	100% (7)	0% (0)	14.4 ± 3.36
AIDS Diagnosis			
No	71.4% (10)	28.6% (4)	16.4 ± 6.23
Yes	62.5% (5)	37.5% (3)	18.5 ± 4.87
Hepatitis C Diagnosis (n=21)			
No	78.6% (11)	21.4% (3)	16.1 ± 4.67

	Adherence category		Adherence scores[8]
	Higher adherence (n=15) % (N) or Mean ± SD	Lower adherence (n=7) % (N) or Mean ± SD	Mean ± SD
Yes	42.9% (3)	57.1% (4)	20.3 ± 6.58
Comorbidities (n=21)			
No	75.0% (9)	25.0% (3)	16.2 ± 5.07
Yes	55.6% (5)	44.4% (4)	19.2 ± 6.08
Medication Count	5.4 ± 2.77	5.7 ± 1.89	r=.326
Polypharmacy			
No (<5 medications)	83.3% (5)	16.7% (1)	14.0 ± 5.10
Yes (≥5 medications)	62.5% (10)	37.5% (6)	18.3 ± 5.68
Currently on ART			
No	57.1% (4)	42.9% (3)	18.7 ± 6.63
Yes	73.3% (11)	26.7% (4)	16.4 ± 5.37
Taking Estrogen			
No	66.7% (6)	33.3% (3)	16.9 ± 6.33
Yes	69.2% (9)	30.8% (4)	17.3 ± 5.57

All results non-significant except as otherwise indicated in footnotes.

[8] Higher adherence scores indicate non-adherence; log-transformed adherence scores were used for analysis.

[9] Fisher's Exact p=.009

[10] Blacks had significantly better adherences scores than either Whites or Other races; F(2,19)=9.56, p=.001

[11] Comparisons are based on square root transformed scores of CD4; n=22

[12] Fisher's Exact p=.047