# Characteristics of Transgender Women Living with HIV Receiving Medical Care in the United States 

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#### Abstract

Purpose: Little has been reported from population-based surveys on the characteristics of transgender persons living with HIV. Using Medical Monitoring Project (MMP) data, we describe the characteristics of HIV-infected transgender women and examine their care and treatment needs.

Methods: We used combined data from the 2009 to 2011 cycles of MMP, an HIV surveillance system designed to produce nationally representative estimates of the characteristics of HIVinfected adults receiving medical care in the United States, to compare demographic, behavioral, and clinical characteristics, and met and unmet needs for supportive services of transgender women with those of non-transgender persons using Rao-Scott chi-square tests.

Results: An estimated $1.3 \%$ of HIV-infected persons receiving care in the United States selfidentified as transgender women. Transgender women were socioeconomically more marginalized than non-transgender men and women. We found no differences between transgender women and non-transgender men and women in the percentages prescribed antiretroviral therapy (ART). However, a significantly lower percentage of transgender women compared to non-transgender men had $100 \%$ ART dose adherence ( $78.4 \%$ versus $87.4 \%$ ) and durable viral suppression ( $50.8 \%$ versus $61.4 \%$ ). Higher percentages of transgender women needed supportive services. No differences were observed in receipt of most of supportive services, but transgender women had higher unmet needs than non-transgender men for basic services such as food and housing.

Conclusion: We found little difference between transgender women and non-transgender persons in regards to receipt of care, treatment, and most of supportive services. However, the


[^0]noted disparities in durable viral suppression and unmet needs for basic services should be explored further.

## Keywords

HIV; Medical Monitoring Project; transgender women

## Introduction

Transgender persons are at high risk for HIV infection. According to one systematic review, the prevalence of HIV among transgender women was $27.7 \%$ based on four US studies in which the diagnosis was established using HIV testing. ${ }^{1}$ Another systematic review that included international studies found that the pooled HIV prevalence was $19.1 \%$ in transgender women worldwide and their odds of HIV infection compared with all adults of reproductive age was 48.8. ${ }^{2}$ Despite the concern that transgender women living with HIV may not engage in or adhere to HIV care and treatment due to stigma and discrimination or concerns about interaction between antiretroviral therapy (ART) and hormone therapy, ${ }^{3-5}$ Yehia and colleagues ${ }^{6}$ found that rates of retention in care, ART prescription and HIV suppression among transgender persons living with HIV were not significantly different from their non-transgender counterparts in a retrospective cohort study of HIV-infected adults who initiated care at 13 HIV clinics in the HIV Research Network between 2001 and 2011.

Little has been reported on the characteristics of transgender persons living with HIV from population-based surveys. The Medical Monitoring Project (MMP) is a cross-sectional, population-based surveillance system that assesses clinical and behavioral characteristics among adults with HIV infection receiving outpatient medical care in the United States and Puerto Rico. ${ }^{7,8}$ Using data from MMP, we provide nationally representative estimates of the characteristics of HIV-infected transgender women (male-to-female transgender persons) in care and examine whether the findings from Yehia et al can be replicated in a populationbased survey to better inform us of the care and treatment needs of transgender women.

## Methods

We analyzed combined data from the 2009, 2010, and 2011 data collection cycles of MMP. For all data collection cycles, 16 U.S. states and one territory were sampled (California, Delaware, Florida, Georgia, Illinois, Indiana, Michigan, Mississippi, New Jersey, New York, North Carolina, Oregon, Pennsylvania, Puerto Rico, Texas, Virginia, and Washington). Data were collected on adults aged 18 years or older receiving at least one HIV-related medical care visit in participating facilities between January and April of each data collection cycle year. Data were collected through face-to-face interviews and medical record abstractions from June 2009 to May 2012. The data were weighted for probability of selection and nonresponse to be representative of adults receiving outpatient medical care for HIV infection in the United States and Puerto Rico. Prevalence estimates are presented as weighted percentages. The reference period is the 12 months before the patient interview unless otherwise noted. The entire sample includes information on 13,194 participants, who,
after weighting for probability of selection and non-response, are estimated to represent an average population of $447,421 \mathrm{HIV}$-infected adults receiving medical care in the United States between January and April in 2009, 2010, and 2011. MMP methods are described in detail elsewhere. ${ }^{7,8}$

In accordance with the Code of Federal Regulations Title 45 Part 46 Subsections 46.101c and $46.102 \mathrm{~d}^{9}$ and the Guidelines for Distinguishing Public Health Research and Public Health Nonresearch,,$^{10}$ MMP was determined by the Centers for Disease Control and Prevention (CDC) to be a non-research, public health surveillance activity. However, some participating sites obtained local Institutional Review Board (IRB) approval to conduct MMP as required locally.

In a face-to-face interview, respondents were asked to report their sex at birth and their current self-identified gender. Those who self-identified as transgender or had discordant sex at birth and gender were categorized as transgender. Persons whose sex at birth and current gender was male were categorized as non-transgender men and persons whose sex at birth and current gender was female were categorized as non-transgender women. Transgender persons were further categorized into transgender women (male-to-female transgender, i.e., sex at birth equals male and current gender equals transgender or female) and transgender men (female-to-male transgender, i.e., sex at birth equals female and current gender equals transgender or male). Five persons were excluded because information was missing to classify into one of the above categories. Further, because the number of transgender men was too small ( $\mathrm{n}=22$ ) to conduct comparative analyses, we focused on transgender women and compared their demographic, behavioral, and clinical characteristics, as well as needs for and met/unmet needs for supportive services with those of non-transgender men and non-transgender women (analytic sample size $=13,167$ ) using Rao-Scott chi-square tests. ${ }^{11}$ Statistical significance was defined at an alpha level of 0.05.

## Results

In all, $1.3 \%$, or an estimated 5,729 HIV-infected adults receiving medical care in the United States, self-identified as transgender women. Table 1 shows the demographic, behavioral, and clinical characteristics of transgender women compared to non-transgender men and non-transgender women. Mean age among transgender women was 41.9 years (median 42.9 years). More than $80 \%$ of transgender women were of non-white race/ethnicity and had an annual income less than $\$ 20,000$. Moreover, more than $20 \%$ of transgender women reported homelessness and over $30 \%$ did not have any health insurance. About one-third of transgender women reported injection or non-injection drug use, less than $50 \%$ reported being sexually active, and $17.5 \%$ reported having condomless vaginal or anal sex with an HIV-negative or unknown status partner. More than $90 \%$ were prescribed ART in the past 12 months, more than three-quarters reported $100 \%$ adherence to all ART doses in the past 3 days, and almost $70 \%$ had a suppressed viral load (defined as undetectable or <200 copies $/ \mathrm{ml}$ ) at the most recent test, but only about half had a suppressed viral load at all tests during the past year (i.e., durable viral suppression). Almost one-third was screened for gonorrhea and chlamydia respectively, and almost two-thirds were screened for syphilis.

Compared to both non-transgender men and women, significantly higher percentages of transgender women had incomes less $\$ 20,000$ per year, were homeless, and did not have health insurance. Compared to non-transgender men, a significantly higher percentage of transgender women were of non-white race/ethnicity, had less than a high school education, and had income at or below the poverty level. Compared to non-transgender women, a significantly lower percentage of transgender women were of black or African-American race/ethnicity and a higher percentage were Hispanic or Latino.

Compared to non-transgender women, a significantly higher percentage of transgender women reported use of non-injection and injection drugs in the past 12 months. A significantly lower percentage of transgender women reported any sexual activity compared to non-transgender men and women, but no significant differences in the percentage engaging in any condomless sex or condomless sex with an HIV-negative or unknown status partner were noted.

Also no significant differences were observed in time since HIV diagnosis, stage of disease, geometric mean CD4+ T-lymphocyte cell (CD4) count in the past year between transgender women and non-transgender men and women. Moreover, no significant differences were observed between the percentages of transgender women and non-transgender men and women who were prescribed ART and the percentages who achieved viral suppression at their most recent viral load test. However, compared to non-transgender men, a significantly lower percentage of transgender women reported $100 \%$ adherence to all ART doses in the past 3 days. Also, a significantly lower percentage of transgender women, compared to nontransgender men had a suppressed viral load on all viral load tests in the past year (i.e., durable viral load suppression). There were no significant differences in the percentages of transgender women compared to non-transgender men and women receiving gonorrhea and chlamydia testing, but a significantly higher percentage of transgender women than nontransgender women were tested for syphilis. No significant differences were observed in use of emergency room or urgent care and hospital admission between transgender women and non-transgender persons.

Figure 1 compares the percentages of transgender women versus non-transgender men and women who needed supportive services, whose supportive service needs were met, and whose supportive service needs were unmet (Supplemental Table 1). Significantly higher percentages of transgender women, compared to non-transgender men ( $\mathrm{p}<0.05$ ), needed services including HIV case management ( $70.9 \%$ vs. $60.7 \%$ ), ART adherence support ( $28.3 \%$ vs. $20.0 \%$ ), HIV prevention counseling ( $50.1 \%$ vs. $38.9 \%$ ), mental health services ( $45.5 \%$ vs. $31.8 \%$ ), meal services ( $45.8 \%$ vs. $33.0 \%$ ), domestic violence services ( $3.7 \%$ vs. $1.6 \%$ ), transportation services ( $48.2 \%$ vs. $29.8 \%$ ), and housing services ( $40.0 \%$ vs. $21.7 \%$ ). Compared to non-transgender women ( $\mathrm{p}<0.05$ ), transgender women had significantly higher percentages needing medicine through the AIDS Drug Assistance Program [ADAP] (50.7\% vs. $39.6 \%$ ) and needing housing services ( $40.0 \%$ vs. $30.0 \%$ ). No differences were observed in percentages of those whose needs were unmet for most supportive services examined. However, significantly higher percentages of transgender women than non-transgender men ( $\mathrm{p}<0.01$ ) had unmet needs for meal services ( $13.3 \%$ vs. $6.7 \%$ ) and housing services ( $13.4 \%$ vs. 7.3\%).

## Discussion:

In a nationally representative sample of HIV-infected persons receiving medical care, an estimated $1.3 \%$ self-identified as transgender women. Transgender women in care were socioeconomically more marginalized than non-transgender men and women; higher percentages of transgender women had lower income, were homeless, and did not have health insurance. Similar to findings by Yehia et al., ${ }^{6}$ a similar percentage of transgender women compared to non-transgender persons were prescribed ART and achieved viral suppression at their most recent viral load test. However, similar to findings by Sevelius et al., ${ }^{3}$ a lower percentage of transgender women compared to non-transgender men reported adherence to ART regimen, and the equity in ART prescription was not translated into equity in durable viral suppression, the treatment outcome that uses more stringent criteria (i.e., achieving viral suppression in all tests). These findings suggest a need to investigate what happens to transgender women after they are prescribed ART to better understand what might interfere with their medication adherence and long-term viral suppression. One possibility is a residual need for supportive services given that transgender women are more likely to be socioeconomically marginalized. We found that higher percentages of transgender women needed supportive services. Although we observed little difference between transgender women and non-transgender persons in regards to receipt of most supportive services, a higher percentage of transgender women compared to non-transgender men had unmet needs for basic services such as meal and housing. These unmet basic needs could interfere with medication adherence behaviors ${ }^{12,13}$ that might have resulted in the observed disparities in treatment outcomes. Future research might explore the associations among these factors to explain the disparities between transgender and non-transgender persons, which could further inform programs aiming to reduce such disparities

Limitations of our study are as follows. MMP collects data from HIV-infected persons receiving medical care, and just like Yehia et al., our findings cannot be generalized to all persons living with HIV. To the extent that transgender HIV-infected persons avoid accessing healthcare due to stigma and past negative experiences, ${ }^{5}$ there may be significant disparities in how they access HIV care in the first place. We also did not have data on specific needs of transgender women such as hormone therapy and other transgender-specific health care services, thus our findings on met and unmet needs for supportive services need to be interpreted with caution. Finally, relative to transgender women very little is known in the field of HIV prevention about HIV risk and needs of transgender men (female-to-male transgender persons). ${ }^{14}$ Yet, we were not able to investigate the unique characteristics and needs of transgender men due to small sample size.

## Conclusion:

We found few differences between HIV-infected transgender women and non-transgender persons in care with respect to receipt of most care, treatment, and supportive services; however, the noted disparities in durable viral suppression and unmet needs for basic services should be explored further. Because MMP is conducted annually, CDC will monitor progress towards the goal of reducing health disparities among transgender persons living with HIV.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

We thank the participating MMP patients, facilities, and Provider and Community Advisory Board members. We also acknowledge the contributions of the MMP 2009, 2010, and 2011 study group members
http://www.cdc.gov/hiv/pdf/research_mmp_studygroupmembers_2009.pdf.
http://www.cdc.gov/hiv/pdf/2010-Study-Group-Membersacc.pdf
www.cdc.gov/hiv/pdf/MMP_Resources-2011-Study-Group-Membersacc.pdf

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the U.S. Centers for Disease Control and Prevention.

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Figure 1.
Comparison of met and unmet supportive service needs among HIV-infected transgender women (green bars), non-transgender men (blue bars), and non-transgender women (red bars), Medical Monitoring Project, United States, 2009-2011
Abbreviations: ADAP=AIDS Drug Assistance Program
Met supportive service need defined as needing and receiving service. Unmet supportive service need defined as needing, but not receiving service.
Demographic，behavioral and clinical characteristics of HIV－infected adults receiving medical care，by transgender status－Medical Monitoring Project，

| Characteristics $^{1}$ | Transgender women <br> $(\mathbf{n}=166)$ | Non－transgender men <br> $(\mathbf{n}=\mathbf{9 4 8 9})$ | Non－transgender women <br> $(\mathrm{n}=3512)$ |
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| $\text { Characteristics }{ }^{1}$ | Transgender women ( $\mathrm{n}=166$ ) |  | Non-transgender men ( $\mathrm{n}=9489$ ) |  | Non-transgender women ( $\mathrm{n}=3512$ ) |  | $P \text { value }^{2}$ | $P \text { value }^{3}$ |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Had condomless vaginal or anal sex with HIV-negative or unknown status partner ${ }^{6}$ |  |  |  |  |  |  | 0.1343 | 0.2626 |
| No | 131 | 82.5(74.6-90.4) | 8084 | 88.6(87.7-89.5) | 3005 | 87.1(85.7-88.6) |  |  |
| Yes | 28 | 17.5(9.6-25.4) | 1055 | 11.4(10.5-12.3) | 454 | 12.9(11.4-14.3) |  |  |
| Depression in past 2 weeks |  |  |  |  |  |  | 0.1261 | 0.2511 |
| No depression | 120 | 74.4(67.1-81.6) | 7362 | 77.9(76.5-79.4) | 2441 | 70.2(67.9-72.4) |  |  |
| Other depression | 17 | 9.6(4.3-15.0) | 1081 | 11.9(11.1-12.7) | 487 | 14.6(13.3-16.0) |  |  |
| Major depression | 28 | 16.0(10.0-22.0) | 943 | 10.2(9.1-11.3) | 525 | 15.2(13.5-16.9) |  |  |
| Time since HIV diagnosis |  |  |  |  |  |  | 0.0649 | 0.1290 |
| $<5$ years | 39 | 28.6(20.8-36.4) | 2053 | 22.6(21.3-23.9) | 731 | 21.2(19.4-23.0) |  |  |
| 5-9 years | 44 | 25.8(18.0-33.6) | 1973 | 20.5(19.5-21.6) | 874 | 25.5(23.8-27.1) |  |  |
| 10+ years | 83 | 45.6(36.3-54.9) | 5456 | 56.8(55.0-58.6) | 1904 | 53.3(51.2-55.5) |  |  |
| Stage of disease |  |  |  |  |  |  | 0.7647 | 0.3750 |
| AIDS or nadir CD4 0-199 or CD4\%<14 | 113 | 67.8(59.5-76.1) | 6620 | 69.3(68.3-70.3) | 2362 | 66.8(65.0-68.7) |  |  |
| No AIDS and (nadir CD4 200-500 or CD4\% 14-<29) | 43 | 27.2(19.3-35.1) | 2272 | 24.7(23.5-25.8) | 870 | 24.9(23.0-26.7) |  |  |
| No AIDS and (nadir CD4 > 500 or CD4\%>=29) | 10 | 5.0(1.1-8.9) | 561 | 6.0(5.3-6.8) | 269 | 8.3(7.2-9.4) |  |  |
| Geometric mean CD4 count (cells/mm ${ }^{3}$ ) |  |  |  |  |  |  | 0.6670 | 0.3252 |
| 0-199 | 24 | 16.4(9.2-23.6) | 1168 | 12.7(11.8-13.6) | 440 | 12.3(11.0-13.6) |  |  |
| 200-349 | 28 | 17.5(10.9-24.0) | 1637 | 17.8(16.8-18.9) | 516 | 15.2(14.0-16.5) |  |  |
| 350-499 | 40 | 24.1(17.6-30.7) | 2153 | 24.0(23.1-24.9) | 744 | 22.1(20.5-23.7) |  |  |
| $>=500$ | 68 | 42.0(34.0-50.1) | 4121 | 45.5(44.0-47.0) | 1661 | 50.4(48.4-52.4) |  |  |
| Prescribed ART in past 12 months |  |  |  |  |  |  | 0.3412 | 0.0552 |
| No | 13 | 6.9(2.9-10.9) | 818 | 8.9(8.1-9.7) | 395 | 11.2(9.9-12.4) |  |  |
| Yes | 153 | 93.1(89.1-97.1) | 8671 | 91.1(90.3-91.9) | 3117 | 88.8(87.6-90.1) |  |  |
| ART adherence in past $\mathbf{3}$ days |  |  |  |  |  |  | 0.0143 | 0.2813 |
| Not 100\% adherent | 29 | 21.6(14.7-28.6) | 1092 | 12.6(11.8-13.5) | 533 | 17.5(15.8-19.2) |  |  |
| 100\% adherent | 111 | 78.4(71.4-85.3) | 7397 | 87.4(86.5-88.2) | 2451 | 82.5(80.8-84.2) |  |  |
| Most recent HIV viral load suppressed ${ }^{7}$ |  |  |  |  |  |  | 0.0678 | 0.6685 |
| No | 53 | 31.9(24.0-39.7) | 2318 | 24.6(23.0-26.1) | 1075 | 30.2(28.0-32.3) |  |  |
| Yes | 113 | 68.1(60.3-76.0) | 7171 | 75.4(73.9-77.0) | 2437 | 69.8(67.7-72.0) |  |  |


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| $\text { Characteristics } 1$ | Transgender women ( $\mathrm{n}=166$ ) |  | Non-transgender men ( $\mathrm{n}=9489$ ) |  | Non-transgender women ( $\mathrm{n}=3512$ ) |  | $P \text { value }^{2}$ | $P \text { value }{ }^{3}$ |
| All HIV viral loads suppressed ${ }^{7}$ (durable viral suppression) |  |  |  |  |  |  | 0.0127 | 0.1507 |
| No | 79 | 49.2(40.9-57.5) | 3621 | 38.6(37.0-40.3) | 1535 | 43.1(40.7-45.5) |  |  |
| Yes | 87 | 50.8(42.5-59.1) | 5868 | 61.4(59.7-63.0) | 1977 | 56.9(54.5-59.3) |  |  |
| At least one HIV viral load test every 6 months |  |  |  |  |  |  | 0.7568 | 0.6202 |
| No | 40 | 23.0(15.2-30.8) | 2268 | 24.2(22.6-25.7) | 848 | 24.8(22.6-27.1) |  |  |
| Yes | 126 | 77.0(69.2-84.8) | 7158 | 75.8(74.3-77.4) | 2644 | 75.2(72.9-77.4) |  |  |
| Screened for gonorrhea |  |  |  |  |  |  | 0.4213 | 0.7709 |
| No | 119 | 73.0(64.6-81.3) | 6994 | 76.0(72.8-79.2) | 2456 | 71.8(68.2-75.3) |  |  |
| Yes | 47 | 27.0(18.7-35.4) | 2432 | 24.0(20.8-27.2) | 1036 | 28.2(24.7-31.8) |  |  |
| Screened for chlamydia |  |  |  |  |  |  | 0.1879 | 0.8495 |
| No | 115 | 70.5(62.1-78.9) | 6933 | 75.4(72.1-78.6) | 2396 | 69.7(66.4-73.1) |  |  |
| Yes | 51 | 29.5(21.1-37.9) | 2493 | 24.6(21.4-27.9) | 1096 | 30.3(26.9-33.6) |  |  |
| Screened for syphilis |  |  |  |  |  |  | 0.1028 | 0.0023 |
| No | 51 | 36.3(27.3-45.2) | 3831 | 43.5(40.3-46.8) | 1658 | 51.6(47.2-56.0) |  |  |
| Yes | 115 | 63.7(54.8-72.7) | 5595 | 56.5(53.2-59.7) | 1834 | 48.4(44.0-52.8) |  |  |
| Emergency department or urgent care use |  |  |  |  |  |  | 0.1454 | 0.7038 |
| No | 144 | 86.3(79.5-93.0) | 8580 | 91.4(90.3-92.4) | 3043 | 87.6(85.7-89.5) |  |  |
| Yes | 22 | 13.7(7.0-20.5) | 885 | 8.6(7.6-9.7) | 454 | 12.4(10.5-14.3) |  |  |
| Hospital use |  |  |  |  |  |  | 0.3058 | 0.6021 |
| No | 152 | 90.8(85.6-96.1) | 8834 | 93.7(93.0-94.4) | 3216 | 92.3(91.1-93.5) |  |  |
| Yes | 14 | 9.2(3.9-14.4) | 626 | 6.3(5.6-7.0) | 258 | 7.7(6.5-8.9) |  |  |

Abbreviations: ART=antiretroviral therapy; CD4=CD4+ T-lymphocyte cell; AIDS=Acquired immunodeficiency syndrome.
${ }^{1 .}$ Excludes data for characteristics with any missing or unknown values. Totals in the specific characteristics may not sum up to total sample in the column. Reference period is past 12 months unless otherwise noted.
2. P-value for comparison between transgender women and non-transgender men
3. P -value for comparison between transgender women and non-transgender women
4. Drugs including crack, cocaine, or methamphetamine
${ }^{5 .}$ Excludes persons with missing data needed to determine if they had any sex with a condom
${ }^{6}$. Excludes persons whose partner HIV status was unknown or missing


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