# HIV TESTING BEHAVIORS AND DISCRIMINATION IN A MEDICAL SETTING AMONG TRANSGENDER WOMEN (TGW) OF COLOR IN THE UNITED STATES: UNDERSTANDING THE EFFECT ON HIV TESTING FREQUENCY

by

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## ABSTRACT

**Public Health Significance:** HIV testing is an integral part of reducing new HIV infections in the United States, and needs to be increased among high-risk populations. A significant portion of transgender women (TGW) of color may not be aware of their HIV positive status, indicating a need to increase HIV testing. This is difficult because TGW of color are poorly represented in research and are often not targeted specifically by interventions.

**Methods:** Data for this analysis came from *Promoting Our Worth, Equality, and Resilience* (POWER). In 2014 and 2015, POWER recruited Black men who have sex with men as well as TGW of color at Black Pride events in Philadelphia, PA; Houston, TX; Washington, D.C.; Detroit, MI; Memphis, TN; and Atlanta; GA. This analysis includes data from 304 transgender women.

**Results:** Of TGW of color who did not self-report being HIV positive and had received a HIV test in their lifetime, 80.11% had received a HIV test in the previous six months, while 19.89% had not received a HIV test in the previous six months. Out of the entire sample, 30 individuals had never received a HIV test in their lifetime. Age was found to be negatively associated with receiving a HIV test in the previous six months (AOR=0.93; 95% CI 0.88, 0.99).

**Conclusion:** Understanding the complex social and structural factors that influence decisions regarding HIV testing behaviors among TGW of color will be critical to developing effective interventions targeted for TGW of color. Overall, more research is needed to better understand the factors, barriers, and facilitators of HIV testing, and how the interactions between all three influence HIV testing decisions among TGW of color in the United States.

# TABLE OF CONTENTS

# LIST OF TABLES

# PREFACE

## ACKNOWLEDGEMENTS

# 1.0    BACKGROUND

Transgender women (TGW) experience some of the highest rates of HIV infection in the United States, but relatively little is known about the specific risk behaviors and lived experiences that contribute to the high prevalence and incidence rates. In 2011, the Williams Institute at the University of California, Los Angeles estimated the number of adult transgender males and females in the United States to be around 700,000, or 0.3% of the adult population in the United States [1]. In 2016, the Williams Institute published an updated report that analyzed data from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS collects data from adults in the United States, and while it does ask respondents about their gender identity, it is not targeted specifically for transgender individuals. The updated report estimated that the actual number of transgender adults in the United States could be as high as 1.4 million, or 0.6% of the total adult population of the United States [1]. As a specific population, transgender individuals are often neglected in terms of research and public health interventions [2]. Among the already underrepresented LGBT related research studies funded by the National Institutes of Health between 1989 and 2011, only 6.8% focused on transgender populations [3]. The CDC does not uniformly collect data on transgender populations, and as a result transgender women are typically included in the same category as men who have sex with men (MSM) for research purposes [3,4]. This is problematic because TGW in the United States do not experience the same HIV infection risks as MSM, and can also face markedly different barriers to accessing healthcare services. While the need for more targeted HIV prevention services has been recognized by researchers, little evidence exists to inform the development of targeted services for TGW of color [5,6].

HIV testing plays a significant role in preventing future cases of HIV and is a critical component in the effort to end the HIV epidemic in the United States. Earlier diagnosis of HIV leads to earlier initiative of treatment, which ultimately results in improved clinical outcomes [7].

Early diagnosis of HIV is also instrumental in achieving viral suppression, which is critical for reducing the spread of sexually-transmitted HIV [7]. HIV positive individuals who are unaware of their HIV positive status account for almost one third of HIV transmission in the United States. In 2011, it was estimated that 14% of the 1.2 million individuals living with HIV in the United States were unaware of their HIV positive status [8]. The CDC currently recommends that sexually active MSM get tested on an annual basis if they do not have multiple/anonymous sexual partners, and every 3-6 months if they have multiple and/or anonymous sexual partners [8]. Because the CDC does not collect data on transgender individuals as a distinct epidemiologic population, TGW are included in the recommendations for MSM regarding HIV testing. This has the potential to be problematic because much less is known about the specific sexual behaviors and risk factors related to HIV for TGW compared to MSM. The CDC has also recommended that healthcare providers offer HIV testing on an opt-out basis, meaning that all individuals would be routinely tested unless they requested that the test not be run [9]. In addition, the lack of national surveillance of HIV incidence and prevalence rates among transgender individuals significantly limits the amount of evidence that can be used to advocate for increased funding of targeted interventions.

In 2010, the National Center for Transgender Equality and the National Gay and Lesbian Task Force conducted a national survey among transgender individuals in the United States regarding discrimination, health, and access to healthcare. The National Transgender Discrimination Survey (NTDS) was answered by over 7,000 individuals, and found that transgender individuals, and particularly transgender women in the United States experience high rates of discrimination and substandard medical care due to gender identity/expression in their lifetimes [10]. The survey found that transgender individuals (male to female and female to male) in the United States experience HIV prevalence rates that are four times higher than the national average, at 2.64% compared to 0.6% for the general population [10]. Rates of discrimination in a medical setting and refusal of medical care were particularly high: 28% of respondents reported verbal harassment in a medical setting and 19% of respondents reported being denied medical care because of their gender identity/expression [10]. In particular, TGW experienced the highest amount of treatment denial in the entire sample, 22% of TGW in the survey reported being denied care based on their gender identity/expression [10]. Discrimination in a medical setting can have detrimental effects on healthcare access, and can have a strong

influence on individuals' decisions about whether or not to access healthcare when needed. Postponement of accessing needed medical services due to discrimination by providers was reported by 22% of TGW in the survey, and postponement of accessing preventative services, such as HIV testing, was reported by 25% of TGW [10]. This is significant due to the high prevalence rates of HIV experienced by TGW, which are potentially being driven by high rates of previously unaware HIV positive individuals in the population.

TGW of color experience poorer health outcomes than the general population, due to a variety of complex social and structural factors. A widely-cited meta-analysis estimated HIV prevalence among all transgender women in the United States to be 28%, although the lack of research focusing specifically on transgender health in the United States is a significant barrier in determining a more precise estimate [11]. The same meta-analysis found that African American transgender women experienced higher HIV prevalence rates: 56.3% based on test results, and 30.8% based on self-reported data [11]. The intersection of racial and gender-identity for TGW of color can lead to health disparities due to the structural and social barriers that society has created and reinforced. In particular, it can contribute to disproportionately high rates of HIV which can then be exacerbated by limited access to competent healthcare among TGW of color in the United States. TGW also face a large number of unique structural barriers regarding employment, housing, and food security that contribute to increased risk for contracting HIV and poorer overall health outcomes [11,12]. In particular, experiences of employment-based discrimination have been found to be prevalent among TGW of color, and can often lead to detrimental health outcomes. Structural barriers for TGW have been associated with increased frequency of unprotected anal intercourse (UAI), increased victimization, and decreased readiness to change risky behavior [11,13,14].

In addition, stigma and discrimination have been associated with increased risk for depression, suicide, and HIV in TGW [15]. Stigma and discrimination can lead to depression and low self-esteem among transgender women, which can influence substance use and rates of UAI [16]. Anticipated HIV stigma, or fear of discrimination based upon a positive diagnosis, has been shown to have negative effects on HIV testing frequency in MSM and TGW. One study found that anticipated HIV stigma was associated with a 60% decrease in the odds of HIV testing in the past 6 months, and that every standard deviation increase in anticipated stigma was associated with a 54% decrease in odds of having a HIV test in the past 6 months [17].

There are several frameworks that can be used to better understand the complexity of social and structural factors that influence HIV testing behaviors among TGW of color. Syndemics is a term used to explain a set of mutually reinforcing interactions between a disease and various social factors. Due to the complexity of social and structural factors associated with HIV testing among TGW of color, using a syndemic framework to analyze the interactions could prove useful. Instead of social factors having a one-to-one relationship with a health outcome, there are reciprocal interactions that cumulatively result in the amplification of the disease and the factors that negatively affect health outcomes and/or increase risk for the disease [18,19]. Stall et al. first applied syndemics to HIV among MSM in the United States after recognizing that psychosocial issues among MSM seemed to be related [19]. Syndemics focuses on the additive effects that multiple factors can have on a health outcome, and has been successfully applied to both MSM and transgender women populations in the United States [19,20]. In addition to syndemics, Meyer's Minority Stress Model is another useful framework that can potentially be applied to HIV testing among TGW of color. The model operates on the notion that chronic exposure to stress from stigma and discrimination can lead to psychological internalization and negative health outcomes [21]. The model was originally created to explain the effects of stigma and discrimination among sexual minorities, but has since been successfully applied to gender minority populations [20,21].

The purpose of this analysis is to characterize HIV testing frequency, test site type, and reasons for postponing or not initiating HIV testing among TGW of color. In addition, this analysis will explore the association between discrimination in a medical setting and regularity of HIV testing as recommended by the CDC for high risk individuals. Specifically, we hypothesize that:

Transgender women of color who have experienced medical-based discrimination within the previous year will be less likely to have received an HIV test in the last 6 months than transgender women of color who have not experienced medical-based discrimination within the previous year.

## 2.0    METHODS

## 2.1    STUDY DESIGN AND POPULATION

Data for this analysis came from the Promoting Our Worth, Equality, and Resilience (POWER) study. POWER used time-location sampling to recruit men who have sex with men (MSM) and transgender women (TGW) at Black Pride events in six cities across the United States during the summers of 2014, 2015, and 2016. This analysis was conducted using the data from 2014 and 2015 as data collection for 2016 was still ongoing at time of analysis. The study visited the following cities: Philadelphia, PA; Houston, TX; Washington, DC; Memphis, TN; Detroit, MI; and Atlanta; GA. Participants were sampled using time-location sampling, and survey weights were calculated. Recruited individuals were eligible to participate in the study if they: (1) were assigned male sex at birth, (2) self-reported having a male sexual partner in their lifetime, and (3) were 18 years or older. This analysis focused on transgender women of color and was restricted to individuals who: (1) identified as transgender, or reported having transitioned from male to female, and (2) self-identified as "Black" or "African American;" "Asian;" "Native Hawaiian/Pacific Islander;" and/or "Hispanic/Latino". For gender identity, participants were asked to choose one of the following: (1) male; (2) female; or (3) transgender. This analysis included all participants who answered "transgender" to the following question. In addition, participants were asked "Do you identify as transgender OR have you transitioned from male to female or female to male gender?" Answers were dichotomous (yes/no), and individuals who answered "Yes" were eligible to be included in the analysis.

Participants answered an anonymous self-administered, computer-assisted, behavioral health survey on electronic tablets. The survey was formulated to take approximately 20 minutes to complete, and participants were compensated with $10 upon completion. Participants were

assigned a unique identifier code, created by using a series of questions. Duplicate participants had only their first response included in the current analysis.

Following completion of the survey, all participants were offered onsite, confidential HIV testing with a local community based organization (CBO). The CBOs utilized rapid HIV-testing protocols of their choice, including OraQuick (OraSure Technologies, Inc., Bethlehem, PA), Clearview STAT-PAK (Alere Inc., Waltham, MA), and INSTI (bioLythical Laboratories, Richmond, BC) tests. Preliminary positive test results were confirmed using the existing confirmatory testing protocol of the given jurisdiction at an offsite location at a future date. POWER also offered anonymous HIV testing for individuals that declined confidential testing with the CBO. POWER staff utilized OraQuick for oral fluid, and did not report test results to participants. Participants who received a HIV test from either POWER or the CBO were compensated an additional $10.

Unique subject ID numbers were used to link participant survey files to HIV test results. Participants that completed the survey, and a HIV test were compensated a total of $20. All study procedures were approved by the Institutional Review Board at the University of Pittsburgh.

## 2.2    MEASURES

*Demographics*

Participants were asked to self-report age, highest education level, income before taxes, race, and ethnicity. For race, participants were initially asked if they identified as Black/African American. Participants that answered "yes" to the dichotomous question were considered to self-identify as Black or African American for the purposes of this analysis. In addition, participants were also asked a separate question regarding identifying as Hispanic or Latino/a. This was a dichotomous question (yes/no), and participants that answered "Yes" were considered to self-identify as Latino/a for the purposes of this analysis. Participants were also asked to identify the ethnic group/groups that they considered themselves to be in, and were instructed to check all groups that applied. Participants were given the following choices: (1) Caucasian or White, (2) Asian, (3) Native Hawaiian or Pacific Islander, and (4) Other. Race and ethnicity were collapsed

into two dummy variables, one representing identifying as Black/not identifying as Black and the other representing identifying as Latino/not identifying as Latino. For highest education level, participants were asked to choose from the following choices: (1) Never attended school; (2) Grades 1 through 8; (3) Grades 9 through 12; (4) Grade 12 or GED; (5) Some college, Associate's degree, or technical degree; (6) Bachelor's degree; or (7) Any post graduate studies. For analysis, education level answers were recoded to create the following categories: (A) Never attended high school; (B) At least some high school; (C) Some college; (D) College diploma or more. Category A was created by combining choices 1 and 2, Category B by combining choices 3 and 4, Category C was comprised solely of choice 5, and Category D was comprised of choices 6 and 7. Participants were also asked to report their annual income before taxes in the past year. Participants were instructed to choose from the following categories: (1) <$9,999; (2) $10,000-$29,999; (3) $30,000-$49,999; (4) $50,000-$69,999; (5) $70,000-$89,999; and (6) $90,000 and up.

*HIV Status*

HIV status was determined through the combination of self-report data from the survey and biological data. Individuals were considered to be HIV-positive if they: (1) had a preliminary HIV-positive test result, or (2) answered "HIV-positive" to "What was the result of you most recent HIV test?" Individuals were only considered to be HIV-negative if self-report data was confirmed via HIV test result. HIV status was coded as missing for individuals who either did not receive HIV testing or received an indeterminate test result from either POWER or the community partner, unless the individual had self-identified as HIV-positive.

*Knowledge of HIV-Positive Status*

Knowledge of HIV-positive status was determined using self-report and biological data. Individuals were considered to be previously diagnosed if they self-reported HIV-positive status in the survey. Individuals were considered to be previously unaware of their HIV-positive status if they received a HIV-positive test result and answered "HIV-negative," "Indeterminate," or "I don't know," when questioned about their most recent HIV test result. Using both HIV test results and survey answers, HIV-positive participants were classified as either: (1) previously unaware HIV-positives, or (2) previously aware HIV-positives.

7

*HIV Testing: Lifetime and Within the Past Six Months*

Participants were asked if they had received a HIV test in the six months prior to the assessment date. Participants were also asked if they had ever been tested for HIV in their lifetime. Answers for both questions were dichotomous (Yes/No). Individuals who refused to answer were removed from the analytic sample.

*Location of Most Recent HIV Test*

Participants were asked to self-report the location of their most recent HIV test. Participants could choose from the following choices: (1) HIV counseling and test site, (2) HIV/AIDS street outreach program/mobile Unit, (3) drug treatment program, (4) needle exchange program, (5) correctional facility (jail or prison), (6) family planning or obstetrics clinic, (7) public health clinic/community health center, (8) private doctor's office, (9) emergency room, (10) hospital, (11) at home, and (12) other location. Testing location was recoded to form the following categories which were used for the analysis: (A) counseling and testing site or mobile unit, (B) drug treatment or needle exchange facility, (C) jail or prison, (D) family planning or public health clinic, (E) doctor's office or hospital, (F) at home, or (G) other location. Choices 1 and 2 were combined to make category A, 3 and 4 were combined to make category B, choice 5 became category C, choices 6 and 7 became category D, choices 8, 9, and 10 became category E, choice 11 became category F, and choice 12 became category G. Frequency of each location category was calculated for all individuals in the analysis that had received a HIV test in their lifetime.

*Most Important Reason for Not Receiving a HIV Test: Lifetime and Past Six Months*

Participants who had never received a HIV test in their lifetime were asked to report the most important reason that described why they had not been tested for HIV. In addition, participants that had not received a HIV test in the six months prior to assessment date were asked to report the most important reason for not testing. For both questions participants could choose from the following choices: (1) you think you are at low risk for HIV infection, (2) you were afraid of finding out you had HIV, (3) you didn't have time, (4) you were afraid of others finding out (confidentiality), (5) you were afraid others would judge you (stigma), (6) you didn't trust the test to be accurate, (7) some other reason, and (8) no particular reason.

*Medical-Based Discrimination*

Assessment of discrimination in a medical setting was based off of multiple survey questions. In Year 1 (2014) of the survey, participants answered a dichotomous question (yes/no) if they had experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior due to race, being gay/having sex with men, HIV status, gender identity/expression, income or social class, or some other reason within the past year. Participants were also asked about the location of discrimination for each reason for discrimination, and were able to indicate multiple locations per reason. Individuals who answered "Yes" to the initial question and indicated "getting medical care" as a location of discrimination were considered to have experienced discrimination in a medical setting for the purposes of this analysis. In Year 2 (2015) of the survey, participants were first asked whether they had experienced discrimination, been prevented from doing something, or been hassled or made inferior in a particular location within the past year. Individuals who answered "Yes" to the initial question about location of discrimination were then asked about their self-perceived reasons for discrimination in the particular setting. Individuals were instructed to select all reasons that applied, and were able to choose from race, being gay/having sex with men, HIV status, income/socioeconomic status, and other reason(s). Individuals who answered "Yes" to the initial question regarding discrimination when trying to get medical care were considered to have experienced discrimination in a medical setting for the purposes of this analysis. Overall rates of medical-based discrimination in the previous year were analyzed by first concatenating variables representing reason for discrimination and a medical setting being the specific location of the discrimination for Year 1. This created five new variables which were grouped, excluding data points from Year 2, to form a new variable that represented all medical-based discrimination for Year 1. A variable representing the combined medical-based discrimination from both years was then generated by taking the row totals from both variables, producing a dichotomous variable that encompassed Year 1 and Year 2. For all discrimination variables, experiencing discrimination was coded as 1 and not experiencing discrimination was coded as 0.

## 2.3    ANALYSIS

The analytic sample was restricted to individuals who either reported themselves to be HIV negative or were unaware of their HIV status. Descriptive statistics and demographic data were used to characterize the analytical sample of TGW of color. Frequencies in the following tables represent raw counts while percentages were calculated taking survey weights into consideration. Analysis was completed using version 14 of STATA (StataCorp, College Station, Texas) and all significance was set at alpha=0.05. Survey weights were incorporated as a separate variable, and were applied using the "svy" command prior to running analyses. The tabulation function was used to calculate both raw frequencies and weighted percentages for all demographic data, HIV status, knowledge of HIV status, HIV testing in the past six months or lifetime, HIV test location, and reasons for not receiving a HIV test.

The frequency and weighted percentage of previously unaware HIV-positive infections were calculated for the sample.  Raw frequencies and weighted percentages were calculated for all demographic categories, HIV testing frequency, type of testing location, and reasons for not seeking HIV testing for individuals that had not received a HIV test in the previous six months or in their lifetime.

Bivariate analysis was used to compare the demographics of individuals who had tested in the previous six months to individuals who had not tested in the previous six months. Individuals who either reported that they were already aware of their HIV positive status or tested positive were removed from bivariate analysis. Race, ethnicity, medical-based discrimination, and highest education level were all compared across testers and non-testers using Pearson's Chi Square test. Individuals with missing data were removed using listwise deletion per STATA default.

A logistic regression model was used to test the effects of medical-based discrimination, age, annual income before taxes, and race/ethnicity on whether or not an individual had received a HIV test in the previous six months. Age was incorporated as a continuous variable. Individuals who reported that they were already aware of their HIV positive status were removed from the model. Study weights were incorporated into the model and city of assessment was controlled for. Individuals who had received a HIV test in the six months prior to the assessment date were compared to individuals who had not received a HIV test in the previous six months

but had at some point in their lifetime. In the logistic regression model, annual income was used to represent socioeconomic status (SES). Individuals who had never received a HIV test in their lifetime were excluded from the model due to the potential for significantly different structural factors that influence their decisions to not receive HIV testing than individuals who have a history of HIV testing but didn't test recently. In particular, individuals who have never received a HIV test in their lifetime could have difficulties accessing medical care.

# 3.0    RESULTS

Table 1 shows the demographic characteristics of the 304 TGW of color in the sample. The mean age of the sample was 28.74, and while 23.37% had not attended high school, 26% had a college degree or higher, which illustrates the high level of diversity in the analytic sample. For race and ethnicity, 90.80% identified as Black, 9.08% identified as Caucasian or White, and 18.26% identified as Latino, with individuals being able to identify with multiple races/ethnicities. For annual income before taxes, 33.30% made less than $9,999; 22.26% made between $10,000 and $29,999; 11.52% made between $30,000 and $49,999; 12.92% made between $50,000 and $69,999; 16.11% made between $70,000 and $89,999; and 3.90% made over $90,000.

Table 2 shows HIV testing behaviors and discrimination in a medical setting among TGW of color. Among TGW of color who had received a HIV test at some point in their lifetime, 19.89% had not received a HIV test in the previous six months. The majority of the sample had received a HIV test in the previous six months, indicating that most individuals were following the CDC guidelines for testing frequency. Out of the entire analytic sample of 304 TGW of color, 30 had never received a HIV test in their lifetime.

Participants reported the most important reason for not receiving a HIV test for either the six months prior to the assessment date, or ever, depending on their HIV testing history. In both cases, low perceptions of risk for contracting HIV was a frequently reported reason participants delayed or avoided HIV testing, with 38.46% of individuals who had never received a HIV test and 22.71% of individuals who had not received a test in the previous six months reporting it as the most important reason. Stigma, or the fear of others judging them, was not reported as a reason for avoiding or delaying HIV testing, only 3.68% of individuals who had never been tested in their lifetime and 7.49% of individuals who had not tested in the previous six months reported it as the most important reason.

Participants who had received a HIV test in their lifetime were asked to report the location of their most recent HIV test; 38.65% had tested at either a HIV counseling and testing site or mobile unit, 16.77% at a family planning or public health clinic, and 27.15% at a doctor's office or hospital. Table 2 also shows the rate of discrimination in a medical setting as experienced by individuals in the sample. Out of the 202 individuals in the sample that identified as HIV negative or tested negative, 29.81% had experienced medical-based discrimination. HIV positivity, which was determined by correlating survey responses and HIV tests, was 37.89% (n=102) for the sample, and 53.11% (n=49) of individuals that tested positive for HIV were previously unaware of their HIV status.

Table 3 shows the results of the bivariate analysis that was used to compare characteristics of TGW of color that had received a HIV test in the previous six months to TGW of color that had not received a HIV test in the previous six months. Race, ethnicity, education level and medical-based discrimination did not differ significantly between the two groups.

Table 4 shows the results of the logistic regression model. The model ultimately did not find medical-based discrimination, annual income, ethnicity, or race to be significantly associated with odds of receiving a HIV test in the previous six months. However, age was found to be negatively associated with HIV testing within the previous six months with an adjusted odds ratio of 0.92 (95% CI 0.88-0.98). TGW of color were less likely to have received a HIV test within the previous six months as their age increased.

**Table 3-1. Characteristics of transgender women of color: United States, 2014-2015**

|  | n=304<br>n (%) |
|---|---|
| **Demographics** | |
| Education (n=301) | |
|   Never attended high school | 63 (23.37) |
|   At least some high school | 110 (30.17) |
|   Some college | 65 (20.47) |
|   College diploma or more | 63 (26.00) |
| City of data collection* (n=304) | |
|   Philadelphia, PA | 40 (13.16) |
|   Houston, TX | 68 (22.37) |
|   Washington, D.C. | 59 (19.41) |
|   Detroit, MI | 68 (22.37) |
|   Atlanta, GA | 61 (20.07) |
|   Memphis, TN | 8 (2.63) |
| Age mean (SD) | 28.74 (9.49) |

**Table 3-1 Continued**

Race (n=304)

| | |
|---|---|
| Black | 283 (90.80) |
| Not Black | 21 (9.20) |

Ethnicity (n=304)

| | |
|---|---|
| Latino | 38 (18.26) |
| Not Latino | 266 (81.74) |

Annual income

| | |
|---|---|
| <$9,999 | 125 (33.30) |
| $10,000-$29,999 | 65 (22.26) |
| $30,000-$49,999 | 32 (11.52) |
| $50,000-$69,999 | 28 (12.92) |
| $70,000-$89,999 | 35 (16.11) |
| $90,000 and up | 11 (3.90) |

Note: Numbers are unweighted counts, percentages reflect weighted proportions
*City of data collection is unweighted

**Table 3-2. HIV testing and discrimination among transgender women of color: United States, 2014-2015**

| | n (%) |
|---|---|
| **Location of most recent HIV test (n=201)** | |
| Counseling and testing or mobile unit | 102 (38.65) |
| Drug treatment and needle exchange facilities | 6 (2.10) |
| Jail or prison | 15 (6.22) |
| Family planning/OB/public health clinic | 44 (16.77) |
| Doctor's office or hospital | 81 (27.15) |
| At home | 7 (3.79) |
| Other | 13 (5.33) |
| **Testing frequency (n=218)** | |
| Tested in the past 6 months | 178 (80.11) |
| Not tested in the past 6 months | 40 (19.89) |
| **Most important reason for not getting a HIV test (lifetime; n=30)** | |
| Low perceived risk for HIV infection | 8 (38.46) |
| Afraid of finding out you had HIV | 3 (18.32) |
| Didn't have time | 3 (20.49) |
| Afraid of others judging you (stigma) | 1 (5.68) |
| Didn't trust the test to be accurate | 1 (2.24) |
| Other reason | 2 (10.91) |
| No particular reason | 2 (3.91) |
| **Most important reason for not getting a HIV test (past 6 months; n=39)** | |
| Low perceived risk for HIV infection | 7 (21.19) |
| Afraid of finding out you had HIV | 3 (3.42) |
| Didn't have time | 10 (21.28) |
| Afraid of others judging you (stigma) | 3 (9.02) |
| Didn't trust the test to be accurate | 1 (8.00) |
| Other reason | 9 (25.84) |
| No particular reason | 6 (11.25) |
| **HIV positivity (n=304) [95% CI]** | 102 (37.89) [32.44, 43.34] |
| Previously unaware HIV positive | 49 (53.11) |

14

**Table 3-2 Continued**
Medical-based discrimination (n=251)

| | |
|---|---|
| Experienced | 62 (27.80) |
| Did not experience | 189 (72.20) |

Note: Numbers are unweighted counts, percentages reflect weighted proportions

**Table 3-3. Comparison of transgender women of color who have received a HIV test in the previous six months to transgender women of color who have not received a HIV test in the previous six months: United States, 2014-2015**

| | Tested in past 6 mo. n=178 | Didn't test in in past 6 mo. n=40 | p |
|---|---|---|---|
| **Demographics** | | | |
| Education | | | 0.500 |
| Never attended high school | 43 | 7 | |
| At least some high school | 61 | 13 | |
| Some college | 42 | 8 | |
| College diploma or more | 32 | 11 | |
| Annual income | | | 0.826 |
| Under $9,999 | 74 | 14 | |
| $10,000-$29,999 | 42 | 6 | |
| $30,000-$49,999 | 22 | 5 | |
| $50,000-$69,999 | 16 | 4 | |
| $70,000-$89,999 | 16 | 3 | |
| $90,000 and up | 7 | 3 | |
| Identify as Black | 165 | 38 | 0.603 |
| Do not identify as Black | 13 | 2 | |
| Identify as Latino | 26 | 4 | 0.445 |
| Do not identify as Latino | 152 | 36 | |
| **Medical-Based Discrimination (n=218)** | | | 0.182 |
| Experienced | 40 | 13 | |
| Did not experience | 138 | 27 | |

**Table 3-4. Logistic regression of predictors for receiving a HIV test in the previous six months among transgender women of color: United States 2014-2015**

| (n=212) | OR | 95% CI | p |
|---|---|---|---|
| Age | 0.93 | 0.88, 0.99 | 0.020* |
| Annual Income | 0.75 | 0.53, 1.06 | 0.101 |
| Identifying as Latino | 1.37 | 0.22, 8.59 | 0.737 |
| Identifying as Black | 0.98 | 0.08, 11.43 | 0.986 |
| Medical-based discrimination | 0.32 | 0.08, 1.35 | 0.121 |

*denotes p<0.05

# 4.0    DISCUSSION

## 4.1    DISCUSSION AND RECOMMENDATIONS

This analysis compared TGW of color who had received a HIV test in the past six months to TGW of color who had not received a HIV test in the past six months. Individuals in these groups did not differ significantly in terms of race, ethnicity, experiencing medical-based discrimination, or education level. Age was found to be negatively associated with receiving a HIV test in the previous six months, with odds of receiving a test within the previous six months decreasing with increasing age. Because many TGW of color believed themselves to be at low risk for HIV, HIV awareness and testing campaigns should be tailored specifically to TGW of color. Target age of TGW of color needs to be considered during the development of future interventions, and future research is needed to determine if risk factors change with age in TGW of color. Location of HIV testing also needs to be considered when planning future public health interventions targeting HIV testing and TGW of color. TGW of color do utilize traditional healthcare venues such as doctors' offices and clinics for HIV testing, but 38.65% of HIV negative individuals in the sample listed either a counseling and testing center or mobile HIV testing unit as the location of their most recent HIV test. While educating providers on how to provide competent care for transgender individuals should be a priority, future HIV testing interventions for TGW of color should also utilize non-traditional testing venues.

This study demonstrates the discordance between the high prevalence rate of HIV and relatively high uptake of consistent testing among TGW of color in the United States. HIV positivity was almost 38% for our sample, which exceeds the estimate of 28% for all TGW in the United States and indicates that TGW of color are at an increased risk for contracting HIV. More importantly, over half of the TGW of color in this sample that tested positive for HIV were previously unaware of their HIV positive status. Late diagnosis of HIV can have disastrous

consequences for both the individual and their sexual partners. Individuals that are unaware of their HIV positive status are unable to enter the care continuum and are more likely to transmit HIV to other individuals. In addition, individuals who are diagnosed during later stages of the disease progression are at a higher risk for mortality and are less likely to respond to antiretroviral treatment [7].

TGW of color are disproportionately burdened with both HIV and unknown HIV positivity. The Medical Monitoring Project estimates that 18.1% of individuals living with HIV in the United States are unaware of their HIV positive status, which is in stark contrast to the 53% of the HIV positive individuals in this analysis who were previously unaware of their HIV positive status [22]. While there are many structural barriers that affect TGW of colors' ability to access healthcare services, stigma and discrimination from healthcare providers or other patients could play a role in decisions regarding HIV testing, namely how frequently individuals decide to get tested. In addition, this analysis found that many TGW of color delayed or avoided HIV testing because they believed that they were at low risk for infection. Of TGW of color that had not received a HIV test ever, almost 40% did not get tested because they believed themselves to be at low risk for HIV. Of individuals that had not received a HIV test in the previous six months, only 22.71% reported low perception of risk as the most important reason for delaying testing. Lack of time and fear of others finding out about their HIV status were also major reasons individuals avoided HIV testing. Self-perception of risk is a powerful driver of decisions regarding HIV testing, and while a relatively small portion of this sample had not received a HIV test in their lifetime it is important to consider the ramifications in the broader scope of the HIV epidemic in this country.

Stigma and discrimination have the potential to play large roles in the decisions that TGW make regarding accessing both preventative and necessary healthcare services in the United States. Transgender adults frequently experience barriers to accessing competent healthcare services in the United States. The NTDS found that transgender adults in the United States were more likely to experience medical-based discrimination if their provider was aware of their transgender status [10]. While the TGW of color that participated in this study may have experiences that differ from the general population of transgender adults or even the general population of TGW of color in the United States, this analysis highlights the need for a more thorough examination of the structural and social barriers associated with HIV testing decisions

among TGW of color. Few studies have focused on the specific role that experiences of discrimination play with regards to HIV testing behaviors among TGW of color in the United States. The NTDS found that 25% of TGW had postponed receiving preventative medical care due to discrimination by providers, although the survey only asked about refusal of care and verbal/physical harassment in terms of discrimination [10]. It is important to consider discrimination in a broader scope, as the cumulative effect of microaggressions over time can also have a dramatic effect on the health outcomes of TGW of color. Operario et al discussed the importance of microaggressions and cumulative discrimination as they relate to syndemics and health outcomes for TGW [20]. The study also found that the association between stigma and health outcomes in TGW followed the predictions of Meyer's Minority Stress Model. Meyer's model focuses on sexual minority populations, although the constructs can be applied to other minority populations that experience high levels of stress due to stigma and discrimination [21]. While Meyer conceptualized his model based off of sexual minority populations like MSM, Operario et al also found that Meyer's model could be successfully applied to TGW, indicating that the principles of the model hold true for gender minorities as well as sexual minorities [20,21].

Both syndemics and Meyer's Minority Stress Model should be considered as theoretical frameworks for future studies looking at HIV testing among TGW of color. Stall et al first applied syndemics to HIV among MSM in the United States, and found that the interaction of psychosocial factors interacted with HIV risk behaviors to put individuals at increased risk for HIV infection. Operario et al examined interactions between unprotected anal intercourse, alcohol intoxication and illicit drug use among TGW in the United States, and found evidence of a syndemic among HIV-related behaviors [20]. It is possible that rather than a straightforward one-to-one relationship between structural and social factors effecting HIV testing decisions among TGW of color, there is an interplay that causes negative amplification on both sides. Essentially, TGW of color who face significant structural barriers that increase their risk for HIV are also prevented from accessing HIV testing due to those same barriers, although more research is needed to better understand if a syndemic is present.

Despite high rates of consistent HIV testing among TGW of color, over half of the individuals that tested positive for HIV were previously unaware of their status. Access to healthcare and health insurance were not examined in this analysis, and it is possible that the

ability to access healthcare services may play a role in shaping decisions around HIV testing for TGW of color in the United States. Among all transgender adults surveyed by the NTDS, overall 19% lacked health insurance and 31% of Black/African American respondents were uninsured [10]. While the number of individuals that were unaware of their status was small relative to the entire sample, the effect that those individuals have on community transmission rates and viral load has the potential to be significant. Furthermore, it would be worthwhile to examine the sexual networks and sexual behaviors of these individuals. In general, more in-depth qualitative research focusing specifically on previously undiagnosed HIV positives and their decisions regarding HIV testing would shed light on this disconnect between testing frequency and the high rate of previously undiagnosed HIV positive TGW of color.

## 4.2    LIMITATIONS

It is important to note that there are several limitations with this study that must be considered. Data regarding testing frequency, location type, and reason for delaying or avoiding testing were all self-reported, and individuals were limited to a number of choices. There are many factors that influence individuals' decisions about where and when to get tested, and why. Participants were only able to select the most important reason for delaying or avoiding HIV testing, while in reality the decision could be influenced by multiple reasons. Individual decisions regarding HIV testing are often complex, and the quantitative nature of this study may limit our ability to fully understand the interactions between participants' beliefs about their own risk, stigma, and other structural factors that shape their decisions.

The findings of this study are not necessarily generalizable to all TGW of color in the United States. TGW of color who attend Black Pride events may differ significantly from TGW of color who do not attend these events. Attending Black Pride events can require significant investments of time and money from the participants, so it is possible that factors like income, employment, and ability to travel influence attendance of Black Pride events. Transgender adults in the United States experience high rates of housing and employment instability. It is also

important to note that the majority of the participants of the POWER study are BMSM, and that the questions in the survey are more applicable to the experiences of BMSM than TGW of color.

There are also limitations with the analysis of medical-discrimination rates and its effect on HIV testing frequency. It is possible that individuals who have tested in the previous six months experienced more medical-based discrimination simply because they were accessing healthcare services more frequently than individuals who had not tested in the previous six months. TGW of color that access healthcare more frequently might experience an increase in their chances of experiencing medical-based discrimination because they have more chances for medical-based discrimination to occur. It is also important to note that medical-based discrimination was not categorized by reason for discrimination for the purposes of this analysis. The survey did ask participants to report the reasons for discrimination, although for this analysis reason for discrimination was determined to be inconsequential as the overall effect of medical-based discrimination was of interest. The purpose of this study was to look at the overall effect that discrimination has on HIV testing frequency, and location of discrimination was determined to be more representative of TGW of colors' experiences as they related to HIV testing frequency. The survey only asked about experiences of discrimination within the previous year, which might not fully illustrate TGW of colors' experiences of discrimination. Other studies have also highlighted the potential for discrimination to have a cumulative effect, which would make it a difficult measure to capture in a cross-sectional study. The study also refers to discrimination as discrete events, while in reality more nuanced forms of discrimination such as microaggressions could have the potential to have the same effects as larger, singular events, particularly if taken cumulatively.

For the logistic regression model, TGW of color who had never received a HIV test in their lifetime were excluded from the model. While this does decrease the size of the analytic sample, non-testers made up approximately 10% of the entire sample of 304 TGW of color. While this is an important group to look in regards to discrimination and decisions regarding HIV testing, the lived experiences of non-testers have the potential to differ significantly from TGW of color who have been tested in their lifetimes, and it is likely that the model used would not be applicable. Annual income before taxes was used instead of education level in the logistic regression model because of the unique employment bias that TGW of color experience in this country. Transgender individuals in the United States experience high rates of employment

discrimination, and thus education level has the potential to inaccurately characterize socioeconomic status. In 2011, a survey of transgender individuals found that 78% had experienced at least one form of harassment or mistreatment in the workplace [23]. In addition, the unemployment rate for transgender individuals of color in the United States is over four times the national unemployment rate [23]. For this analytic sample over half of the participants made less than $30,000 annually before taxes, but 26% had a Bachelor's degree or higher. This discrepancy along highlights the potential problems with using highest education level, as it does not accurately reflect the true SES of the sample.

# 5.0    CONCLUSION


While the majority of TGW of color in this analysis had been tested for HIV within the previous six months, the high prevalence rate of HIV combined with the large proportion of HIV positives that were previously unaware of their status is troubling. It is very clear that interventions targeting HIV testing and status awareness among TGW of color are needed within the United States. Currently, the development of such interventions is hindered by how little is known about TGW of color due to the lack of representation in research in this country [3]. More research exploring the interactions between discrimination, stigma, socioeconomic status, and HIV testing decisions in TGW of color is ultimately needed, as it is likely that TGW of color face unique structural and social barriers resulting in equally unique lived experiences. In particular, both quantitative and qualitative methods need to be utilized in order to fully understand the influence that stigma and discrimination have on HIV-related health disparities among TGW of color.

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