Improving HIV Surveillance Among Transgender Populations in Tennessee

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Abstract

Purpose: HIV prevalence and outcome disparities among sexual and gender minorities are profound in the United States. Tennessee HIV surveillance practices have not been uniform for transgender status, although data collection capabilities exist. We, therefore, describe current reporting of data on transgender individuals in Tennessee to identify targets for improvement.

Methods: Data for all HIV-diagnosed individuals living in Tennessee as of December 31, 2013, were extracted from the Enhanced HIV/AIDS Reporting System (eHARS). The *birth_sex* (“Male” or “Female”) and *current_gender* (“Male,” “Female,” “Male-to-Female,” “Female-to-Male,” or “Additional Gender Identity”) variables were examined, and proportion missing *current_gender* data by region was ascertained. Transgender individuals were defined as having different *birth_sex* and *current_gender* values. To ensure the protection of health information, data were cleaned, deidentified, and aggregated using Statistical Analysis Software (SAS) Version 9.3 (SAS Institute, Inc., Cary, NC).

Results: Among 16,063 HIV-diagnosed individuals in Tennessee, 27 were transgender: 52% ($n=14$) with “Male-to-Female,” 26% ($n=7$) with “Female,” and 22% ($n=6$) with “Male” as their *current_gender* values. Proportions missing *current_gender* differed significantly by region across Tennessee (global, $P<0.01$).

Conclusion: While HIV-positive transgender individuals should be recognized as integral members of the LGBT community, they should also be acknowledged as a separate subgroup when appropriate. Collecting information about current self-identified gender identity should no longer be optional in Tennessee HIV surveillance. Although making efforts to collect both *birth_sex* and *current_gender* mandatory with each interview will improve surveillance, it is critical to train all staff properly on the correct way to inquire about gender identity in a culturally sensitive manner. Revamping data collection methods will not only improve inconsistent methods currently in place but will also allow staff to become more competent in asking the relevant questions and serving transgender individuals.

Key words: HIV, LGBT health, sexual and gender minority, sexual health, transgender.

Introduction

OVER THE PAST 10 YEARS, HIV prevalence in the United States has grown steadily, and the incidence has remained constant at around 50,000 new infections per year, yet some populations remain disproportionately affected.¹

The 2020 National HIV/AIDS Strategy for the United States released in July 2015 prioritized the same four goals as the 2010 strategy: reducing new infections, increasing access to care/improving health outcomes for people living with HIV, reducing HIV-related health disparities and health inequalities, and achieving a more coordinated national response to the HIV epidemic.² The first goal emphasizes re-

ducing new infections among “key populations and geographic areas,” particularly (black) transgender women and the Southern United States.² The third goal reinforces the importance of reducing the disparate impact among sexual and gender minorities.²

A transgender person is an “individual who has a different biological sex, gender identity, and/or gender expression than the one assigned to them at birth.”³ Transgender communities include individuals who self-identify as transgender women (Male-to-Female), transgender men (Female-to-Male), “Male,” “Female,” or as an Additional Gender Identity. It is important to consider that anatomical sex, self-identified gender identity, and gender expression are

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independent of a person's sexual orientation, particularly pertinent in the context of behavioral risks for persons living with HIV/AIDS.⁴

Unfortunately, HIV-related disparities among sexual and gender minorities persist. Men who have sex with men (MSM) and transgender women represent the populations most severely affected by HIV.¹ In 2013, the Centers for Disease Control and Prevention (CDC) estimated that the HIV prevalence for transgender women of reproductive age was nearly 50 times higher compared to that for cisgender (i.e., nontransgender) adults of reproductive age and that transgender women had among the highest prevalence of all groups at risk for infection.⁵ Studies have identified very high percentages ($\geq 60\%$) of transgender sex workers with HIV, previous syphilis infection, or prior hepatitis B virus and HIV infection rates that were 10 times higher in transgender women sex workers than in nontransgender female sex workers.⁶

Coupled with higher risk for HIV infection, inequalities experienced by transgender people include, but are not limited to, increased risk for homelessness, harassment, violence, murder, mental health, physical health, sexual health, lower income, discrimination, lack of employment/workplace or housing protections, difficulty obtaining identity documents matching one's gender identity, lack of public accommodation protections, and adverse healthcare experiences.⁷ In addition, Sevelius' Model of Gender Affirmation outlines risk contexts faced by transgender women of color, such as sex (including sex work) to obtain gender affirmation, condomless sex, and heavy substance abuse among others.⁸

An often ostracized and vulnerable group, violence is reported more often among transgender populations than in the general population. Nationally, at least one transgender individual is murdered each month.⁹ While occurrences of national hate crimes occur at an alarming rate, the Southern United States appears to be disproportionately affected by both HIV and incidents of transgender violence.^{10–12} Numerous recent high-profile murders in the region emphasize the challenges presented in the integration of transgender persons into the mainstream community and potentially negative sociocultural impacts.

Also relevant to this population in Tennessee, the HIV case fatality rate in the Southern United States is twice as high as the state with the smallest case fatality rate.¹³ In 2011, the Southern United States reflected 37% of the total U.S. population but nearly 50% of new HIV diagnoses.¹⁴ The South has unique challenges, such as transphobia, large rural populations, a shortage of HIV specialty providers, distrust of the healthcare system, homophobia, HIV stigma, increased marginalization of individuals identifying as transgender, and lack of social acceptance of these individuals.¹³ With such opposition, employment becomes challenging, and risky behaviors may increase as a means for survival, augmenting the likelihood of HIV acquisition.

National HIV infection estimates among transgender populations vary because surveillance data either do not exist or are not collected consistently. The CDC developed HIV surveillance guidance on transgender data collection for health departments; however, the guidance is currently being revised and does not reflect recent data collection developments.⁵ In future, collecting data on one's current gender

identity can be facilitated and standardized by meaningful use as it was announced in the final recommendations for stage 3 that both sexual orientation and gender identity will be elements that are available within the Certified Electronic Health Record Technology (CEHRT).¹⁵ This provides a platform of opportunity among providers to develop a better understanding of health disparities involving transgender persons.¹⁵

Given the differential impact of HIV/AIDS on transgender individuals, the multiple barriers the transgender population may experience, particularly in the Southern United States, and the potential public health impact of more accurate surveillance as a pathway to earlier diagnosis and treatment, this study sought to identify current transgender data reporting gaps in Tennessee within the Enhanced HIV/AIDS Reporting System (eHARS) database. The eHARS application has been identified by the CDC as "essential to monitor the HIV/AIDS epidemic and evaluate prevention policies and programs" and to target areas for data collection improvement.¹⁶

Methods

Tennessee HIV surveillance activities have collected data on transgender individuals since August 2007; however, there has been no uniform procedure among HIV service providers or disease intervention specialists (DIS) for collecting or reporting these data. Data from the Tennessee eHARS database were aggregated for all individuals living with diagnosed HIV in the state of Tennessee as of December 31, 2013.¹⁷ The variables *birth_sex* and *current_gender* within the eHARS person data set reporting birth sex and self-reported current gender, respectively, were examined to ascertain the frequency and percentage of individuals who had a response for *current_gender*. With the Tennessee eHARS data collection practices currently in place, birth sex is self-reported and may not reflect the actual birth sex. *Birth_sex* is a required variable in eHARS; therefore, *birth_sex* was populated for all individuals with values of either "Male" or "Female."

In contrast, *current_gender* is not a required variable in eHARS; where populated, values of "Male, Female, Male-to-Female, Female-to-Male, and Additional Gender Identity" are available. "Additional Gender Identity" is a category designed within eHARS to represent those who identify as gender nonconforming or a self-identified gender identity outside male-to-female or female-to-male indicators.

Of persons with values for *current_gender*, the frequency and percentage that had a discordant *birth_sex* and *current_gender* were calculated. Prevalence of persons living with HIV and reporting completeness for *current_gender* within each Public Health region of Tennessee (West, Mid-Cumberland, South Central, Upper Cumberland, Southeast, East, and Northeast) and each Metropolitan region (Shelby which includes Memphis, Madison which includes Jackson, Davidson which includes Nashville, Hamilton which includes Chattanooga, Knox which includes Knoxville, and Sullivan which includes Kingsport) were assessed to determine the burden of HIV as well as the frequency and disparity of reporting for the number of transgender individuals by the region in which they resided as of December 31, 2013.

FIG. 1. Prevalence of diagnosed HIV in Tennessee by Metropolitan or Public Health region, as of December 31, 2013.

Data analysis

The chi-squared test for differences in proportions was used to assess differences in HIV prevalence and reporting completeness of *current_gender* by region, and Fisher's exact test was used to assess differences in the number of transgender individuals by reporting category in *current_gender* and by *birth_sex*. To ensure the protection of health information, data were cleaned, deidentified, and aggregated using Statistical Analysis Software (SAS) Version 9.3 (SAS Institute, Inc., Cary, NC). This study received exempt approval by the Tennessee Department of Health Institutional Review Board.

Results

The unadjusted prevalence of diagnosed HIV within the 13 regions of the state of Tennessee, as of December 31, 2013, is depicted in Figure 1.¹⁷

An estimated 23% of the population in Tennessee lives in the nonurban areas.¹⁸ The largest cities are in the Metropolitan areas of Memphis (Shelby), Nashville (Davidson), and Knoxville (Knox).¹⁸ There were statistically significant differences in HIV burden across Public Health regions of Tennessee, with prevalence ranging from 8.6 to 13.6 per 10,000 persons ($P < 0.01$) (Fig. 1).¹⁷ Differences existed between Metropolitan regions as well, with Shelby reporting the highest prevalence (63.9/10,000 persons) and Sullivan reporting the lowest (7.3/10,000 persons) ($P < 0.01$).¹⁷

The 16,063 prevalent HIV-diagnosed individuals in Tennessee as of the end of 2013 are described by the Public Health region or Metropolitan area in Table 1.¹⁷ The final HIV surveillance data set for the entire state contained only 44.0% ($n = 7070$) of individuals with *current_gender* recorded in eHARS as *current_gender* is not a mandatory variable in eHARS.¹⁷

There were significant differences in reporting completeness across all regions, with the Sullivan Metropolitan region having the highest proportion of individuals missing data on

current_gender (82.6%) and the Madison Metropolitan region having the lowest proportion (17.0%) (Fig. 2 and Table 1).¹⁷ There were also differences between regions when specifically compared to Davidson County, the seat of government for the capital of Tennessee. The Shelby, Knox, and Sullivan Metropolitan regions, and the Northeast and Mid-Cumberland Public Health regions, had significantly higher missingness of *current_gender* compared to Davidson County ($P < 0.01$ each, Table 1).¹⁷ The Sullivan and Northeast regions represent the northeast corner of the state, and the Mid-Cumberland region immediately surrounds Davidson County. However, Madison and Hamilton Metropolitan regions and the West and Southeast Public Health regions (the two regions immediately surrounding Madison and Hamilton, respectively) had lower proportions of missing data compared to Davidson ($P < 0.01$ each, Table 1).¹⁷

There were also variations in reporting *current_gender* in the Metropolitan areas ($n = 5290$) and Public Health regions ($n = 1780$) ($P < 0.01$).¹⁷ Shelby ($n = 2474$) and Davidson ($n = 1611$) in the Metropolitan regions and West ($n = 524$) and Mid-Cumberland ($n = 421$) in the Public Health regions exhibited the greatest ascertainment of the *current_gender* variable (35.0%, 22.8%, 7.4%, and 6.0% completeness, respectively).¹⁷

There were 27 individuals identified as having a discordant *birth_sex* and *current_gender* in the final eHARS data set for data as of December 31, 2013, and therefore classified as transgender.¹⁷ Of the 27 individuals identified as transgender, 52% ($n = 14$) had "Male-to-Female," 26% ($n = 7$) had "Female," and 22% ($n = 6$) had "Male" as *current_gender* values (not necessarily indicative of self-identified gender identity).¹⁷ There were no individuals with either "Female-to-Male" or "Additional Gender Identity," whether for those with "Male" or "Female" listed as *birth_sex* values.¹⁷ Those with "Male" value for *birth_sex* were more likely to have their transgender status determined by direct note of transition in *current_gender* ("Male-to-Female") compared to those with *birth_sex* recorded as "Female" ($P < 0.01$).¹⁷

TABLE 1. HIV-DIAGNOSED INDIVIDUALS IN eHARS BY TENNESSEE REGION, VALUE OF *BIRTH_SEX*, AND *CURRENT_GENDER* MISSINGNESS, RECORDED AS OF DECEMBER 31, 2013¹⁷

Tennessee region	Birth_sex	Missing current_gender	p ^a
	No. (column %)	No. (row %)	
Metropolitan regions			<0.01 ^b
Shelby (Memphis)	5999 (37.3)	3525 (58.8)	0.03
Davidson (Nashville)	3703 (23.1)	2092 (56.5)	Reference
Hamilton	939 (5.8)	268 (28.5)	<0.01
Knox	850 (5.3)	521 (61.3)	0.01
Madison	223 (1.4)	38 (17.0)	<0.01
Sullivan	115 (0.7)	95 (82.6)	<0.01
Subtotal, Metropolitan regions	11,829 (73.6)	6539 (55.3)	
Public Health regions			<0.01 ^c
West	725 (4.5)	201 (27.7)	<0.01
Mid-Cumberland	1388 (8.6)	967 (69.7)	<0.01
East	644 (4.0)	381 (59.2)	0.21
Southeast	322 (2.0)	124 (38.5)	<0.01
South Central	429 (2.7)	261 (60.8)	0.09
Upper Cumberland	346 (2.2)	207 (59.8)	0.23
Northeast	380 (2.4)	313 (82.4)	<0.01
Subtotal, Public Health regions	4234 (26.4)	2454 (58.0)	<0.01 ^d
Total	16,063	8993	

^aChi-squared test comparing proportions with missing *current_gender* for each region versus Davidson County (reference group).

^bP-value reported for global test of difference in proportions across all Metropolitan regions.

^cP-value reported for global test of difference in proportions across all Public Health regions.

^dP-value reported for test of difference in proportions comparing Metropolitan to Public Health regions.

eHARS, Enhanced HIV/AIDS Reporting System.

Similar to the results of the *current_gender* variable attainment, 70% ($n=19$) of individuals identified in eHARS as transgender reported their current address within one of the Metropolitan areas.¹⁷

Discussion

There were important reporting, data completeness, and regional differences identified within our surveillance data that may limit identification of transgender individuals.

The small number ($n=27$) of transgender individuals in eHARS may have resulted from *current_gender* not being addressed in interviews with patients and/or the *current_gender* data being entered based solely on assumptions by the interviewer. In addition, we cannot exclude the possibility that the *current_gender* value discrepancies with *birth_sex* values were data entry errors by interviewers in cases with only singular values (as opposed to transition values, as “Male-to-Female” or “Female-to-Male”) for *current_gender*.¹⁷ Furthermore, disparate reporting by region may be

FIG. 2. Percentage of prevalent HIV-diagnosed individuals in Tennessee missing *current_gender* data, among those with *birth_sex* recorded in eHARS, by Metropolitan or Public Health region. eHARS, Enhanced HIV/AIDS Reporting System.

attributed to Metropolitan areas historically carrying a higher burden of HIV disease than the Public Health regions in Tennessee; these differences do not necessarily indicate that self-identified gender identity inquiries are being made more frequently in the Metropolitan areas. The overall volume of HIV cases is higher, and resources and support for transgender individuals are more readily available in these areas.

There are several organizations in the Nashville area, such as the Tennessee Transgender Political Coalition and the Tennessee Transgender Journey Project, working with transgender individuals.^{19,20} A possible confounding with respect to disparate reporting by region might have occurred as HIV-positive individuals identifying as transgender could reside more often in the Metropolitan areas of the state, such as Nashville and Memphis, as opposed to the outlying rural areas to have access to these resources and to feel a greater sense of acceptance in their community.

To help direct resources where they are most needed statewide, the Tennessee Department of Health HIV/STD/Viral Hepatitis Section will implement separate or expanded risk factor ascertainment categories for transgender individuals as their primary risk factors for HIV acquisition may differ from other populations. The adaptation of these expanded risk factor categories could also provide the framework for development of prevention strategies to identify high-risk HIV-negative transgender individuals and prevent further HIV transmission within this population. Above all, HIV testing should be offered within the transgender community, and culturally competent medical staff should be providing care and seeking risk factor ascertainment.

Although some persons may not identify as transgender for fear of discrimination, obtaining voluntary information from an individual during the interview process is critical to building a robust and an accurate transgender HIV surveillance database. Inquiring about both birth sex and current gender is a measure recommended by the Center of Excellence for Transgender Health to collect data on transgender persons.⁴ Two questions are suggested: "What is your sex or current gender?" and "What sex were you assigned at birth?"⁴ It is also recommended that these questions are asked in that particular order, while patients are given answer choices and permitted to check all that apply. Using both sex and gender validates the individual being interviewed and increases the likelihood the individual will disclose their present and past self-identified gender identity information.⁴

The Tennessee Department of Health HIV Section routinely conducts surveillance activities to identify individuals living with HIV and target prevention and care efforts to populations and areas that are most gravely affected. Consequently, if HIV geographic hot spots are unidentifiable due to data sparsity, adequately directing prevention and care efforts becomes challenging. With a paucity of data currently available pertaining to transgender communities, it is highly likely that these individuals are being inadvertently disenfranchised and, therefore, are not being adequately identified, advocated for, or served.

Recognizing the current flawed data collection practices for the HIV-positive transgender population in Tennessee, the Tennessee Department of Health plans to revamp its data collection methods in an effort to define and establish a process to accurately estimate the current transgender population among persons living with HIV in Tennessee. In ad-

dition, we will be able to represent this population in our epidemiology profile data sets as a separate subgroup and distinctive from MSM. From these data, the Tennessee Department of Health can tailor HIV prevention services specifically for these sexual and gender minorities, as well as develop culturally acceptable services for this population.

A significant limitation to this study is that it could not be determined whether an individual was asked about their *current_gender* or if the *current_gender* data were entered based solely on assumptions by the interviewer. For example, if the patient being interviewed has *birth_sex* listed as male and they are wearing clothing typically worn by a female, the interviewer could potentially denote their *current_gender* as female. This becomes problematic if female is not their *current_gender* identity and illustrates the importance of asking both the sex and gender questions and giving the patient the right to disclose. All interviewers are trained with the same curriculum; however, there is no method taught on how to specifically ask the gender identity questions in a structured consistent manner.

As there has been no standardized collection of the variable *current_gender* during the study period, there is a high probability of interobserver variability and low validity greatly influencing these results. It was initially recommended by the CDC in 2007 that the *current_gender* field be completed on every individual entered into eHARS; however, as of 2009, interviewers were asked to only complete this variable for those who identified as transgender, and consequently, data for the variable *current_gender* became discordant during the 3-year period. Currently, *current_gender* data collection varies between one of these two methods throughout the state, and as a result, gender identity questions are likely not addressed, and gender identity is underreported.

The lack of "chooses not to answer" as a *current_gender* option is a further weakness in data collection capabilities and potentially introduces extrapolation and underreporting of data. As a result, the interviewee could incorrectly label themselves in an effort to conform to one of the available answer choices or they may choose not to answer, causing the variable information to be left blank and possibly causing additional underreporting of data.

Conclusion

While HIV-positive transgender individuals should be given the opportunity to be recognized as members of the LGBT community, they should also be acknowledged as a separate subgroup when appropriate. Collecting information about one's current self-identified gender identity should no longer be optional in Tennessee HIV surveillance. Although making efforts to collect both *birth_sex* and *current_gender* mandatory with each interview will improve surveillance, it is critical to train all staff properly on the correct way to inquire about gender identity in a culturally sensitive manner. This must also include an opt-out/decline to state current gender identity. Revamping our data collection methods will not only improve the critically inconsistent methods currently in place but will also allow staff to become more comfortable with asking the questions and serving transgender individuals.

It is hoped that with the additional training of DIS and HIV providers, development of a new Adult Case Report Form (ACRF), and the inclusion of transgender identity in routine

surveillance activities, this data collection will become standardized and easier to obtain. Once this information is collected and the current gender data are more reflective, conclusions with respect to the transgender community will be able to be drawn from the eHARS surveillance data, and transgender-specific data sets will be produced for public consumption. These more accurate surveillance data will enable a more robust public health response designed specifically for the highly vulnerable and high-risk transgender population in Tennessee.

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Disclaimer

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