Cancers Disproportionately Affecting the New York State Transgender Population, 1979–2016

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Objectives. To summarize what is known about cancer among the transgender population in New York State.

Methods. We identified transgender patients diagnosed between 1979 and 2016 in the New York State Cancer Registry using reported sex, text search of the case abstract, and linkage to statewide hospitalization records.

Results. We identified 230 transgender patients, including 125 natal males, 48 natal females, and 57 with unknown natal sex. Median age at diagnosis was 47.4 years, compared with 66.0 years for all patients. Transgender patients were more than 2.5 times more likely to use cigarettes than were other cancer patients. Kaposi sarcoma had the highest proportional incidence ratio (71.7).

Conclusions. In New York State, HIV- and human papillomavirus–related cancers disproportionately affect the transgender population.

Public Health Implications. To our knowledge, this is the first report of cancer among the transgender population that incorporates more detailed codes that took effect in 2015. Awareness of the differences in transgender cancer incidence from the general population is vital to ensure that necessary preventive care and screenings are accessible and offered appropriately to this population. (*Am J Public Health.* Published online ahead of print July 19, 2018: e1–e3. doi:10.2105/AJPH.2018.304560)

An estimated 1.4 million people in the United States identify as transgender.[1] This population experiences higher rates of substance abuse, HIV infection, unemployment, mental health issues,[2] and discrimination[3] and lower rates of cancer screenings[4] than does the general population. Transgender persons also face myriad actual and perceived barriers to accessing health care.[3–5] The degree to which these health disadvantages extend to cancer incidence is not well known. Most cancer surveillance reports do not provide transgender-specific information.[4] A recent review by Braun et al.[6] is the most comprehensive examination of the topic to date, reviewing Surveillance, Epidemiology, and End Results (SEER; https://seer.cancer.gov) Program data through 2013. They identified 354 transgender patients but lacked natal sex information. By contrast, this study includes cases diagnosed through 2016 and incorporates text searches of every abstract (standardized data items completed using patient medical records submitted by facilities diagnosing or treating cancer) submitted to the New York State Cancer Registry (NYSCR; https://www.health.ny.gov/statistics/cancer/registry) since 1996, when unstructured text began to be collected. This allowed the identification of miscoded cases and additional cases from earlier years when gender coding was inadequate.

METHODS

We included all transgender cases in the NYSCR diagnosed between 1979 and 2016. We used SAS version 9.3 (SAS Institute, Cary, NC) for all analysis. A nationally standardized code for "transsexual" was first introduced in 1979, and in 2015, 2 additional sex codes were created to identify "transsexual, natal male" and "transsexual, natal female," with instructions to retroactively apply these codes to earlier cases where possible. Because of lags in reporting, at the time of writing, the NYSCR data were complete through 2014, nearly complete for cases diagnosed in 2015, but only partially complete for 2016 cases.

We identified transgender cancer patients in the NYSCR database using reported transgender sex codes and text searches for terms commonly associated with transgender codes (transition, transgender, transsexual, gender, and born). We manually reviewed all selected cases for accuracy. We excluded cases with only a single report containing a transgender code but no supporting text. We modified sex codes stored in the registry where appropriate on the basis of the text or where it could be inferred by a sex organ primary site or mention of an explicit hormone regimen the patient was receiving for transition. We identified 160 transgender patients on the basis of registry information. We identified an additional 70 transgender cases from statewide hospitalization records[7] linked to the NYSCR data through 2013 by searching for *ICD* codes related to conditions for which gender identity did not match natal sex (*ICD-9* 302.50–302.53, 302.6, 302.85 and *ICD-10* F64.0-F64.9, Z87.890, codes modified from Braun et al.)[6] The 230 transgender patients had a total of 260 reportable cancers.

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We calculated the proportional incidence ratio (PIR) for each anatomic site as the ratio of the proportion of cases for the site among the transgender cases divided by the proportion of cases for the site among nontransgender cancer cases in NYSCR diagnosed between 2010 and 2014. We calculated PIRs rather than incidence rates because neither the overall transgender case counts nor counts of the NYS transgender populations were sufficiently reliable. We determined tobacco use on the basis of all cases diagnosed between 2010 and 2014 in the NYSCR with a known tobacco history.

RESULTS

Cancer diagnoses among the transgender population were heavily skewed toward recent years. The earliest was diagnosed in 1989; 2013 was the single year with the most diagnoses (n = 28). Of transgender cancer cases, 54.3% were coded as natal male (n = 125), followed by unknown natal sex (n = 57; 24.8%) and natal female (n = 48; 20.9%). The median age at diagnosis was 47.4 years, compared with 66.0 years in the NYSCR as a whole. The 5-year age group with the most diagnoses was 50–54 years (n = 42). Among the 221 patients with known tobacco status, 42.1% reported cigarette use at diagnosis compared with 16.4% in the NYSCR. We found that 60.5% of the transgender cancer patients (n = 155) living in NYS resided in New York City, versus 36.2% of the NYSCR as a whole. The counties containing the upstate cities of Albany, Buffalo, and Rochester accounted for another 10.0% of cases (11.5% NYSCR), and the counties comprising Long Island accounted for 6.9% (16.5% NYSCR).

Kaposi sarcoma had the highest PIR, followed by anal cancers (Table 1). Anal cancers had the highest case count, followed by non-Hodgkin lymphoma and Kaposi sarcoma. Of those with known human papillomavirus (HPV) status, 7 of 8 anal and 3 of 4 oral cavity and pharynx cases were HPV positive. Of Kaposi sarcoma patients, all 16 with a known HIV/AIDS status were HIV positive (68.6% NYSCR). HIV was present in 76% (n = 19) of lymphoma patients with known HIV status (n = 25; 6.1% NYSCR).

TABLE 1—Cancers Disproportionately Affecting the New York State Transgender Population: 1979–2016

SEER Site Group	PIR (95% CI)	Transgender, No. (%)	NYSCR, No. (%)
Kaposi sarcoma	71.7 (47.8, 107.6)	22 (8.5)	836 (0.1)
Anus, anal canal, and anorectum	29.7 (22.4, 39.4)	41 (15.8)	3 767 (0.5)
Hodgkin lymphoma	6.2 (3.2, 11.7)	9 (3.5)	3 972 (0.6)
Other endocrine including thymus	4.0 (2.2, 7.1)	11 (4.2)[a]	7 582 (1.1)
Testis	3.0 (1.1, 7.9)	4 (1.5)	3 633 (0.5)
Larynx	2.9 (1.2, 6.9)	5 (1.9)	4 729 (0.7)
Non-Hodgkin lymphoma	2.6 (1.8, 3.7)	26 (10.0)	27 640 (3.9)
Oral cavity and pharynx	1.4 (0.7, 2.8)	8 (3.1)	15 202 (2.2)

Note. CI = confidence interval; NYSCR = New York State Cancer Registry; PIR = proportional incidence ratio; SEER = Surveillance, Epidemiology, and End Results. Limited to sites with 4 or more counts and a PIR >1. NYSCR counts and percentage of total nontransgender cases in the NYSCR, 2010–2014 (n = 708 606).

[a]All arising in the pituitary.

DISCUSSION

Although the transgender sex designation has existed in NYSCR since 1979, there has been a large increase in transgender-coded cases since the mid-2000s. More than half of the transgender cancer patients identified as transgender, natal male, although it is unclear whether this is because of higher risk, larger numbers, or better coding. The cohort was disproportionately higher in urban versus rural areas. Although 60.5% of cases had an address at diagnosis in New York City, upstate counties with a major city did report multiple transgender cancer cases.

The incidence of lymphoma in patients with HIV is much higher than in the general population,[8] with Kaposi sarcoma patients typically being HIV positive,[9] and NYSCR is not an exception. The higher PIRs for these cancers were in line with the transgender population's higher rates of HIV infection. Kaposi sarcoma diagnosis in NYS peaked in 1995; by contrast, 86.4% of transgender diagnoses occurred after this year. Although 80% (81.7% NYSCR) of the transgender anal cases had an unknown HPV status, 87.5% (67.2% NYSCR) of anal and 75% (49.8% NYSCR) of oral cavity and pharynx cases with a known HPV status were HPV positive. HPV is a known risk factor for anal, cervical, and head and neck cancers.[10] All laryngeal cancers had an unknown HPV status. Prevalent tobacco use, a known carcinogen, may contribute to increased cancer risk for multiple cancers in this population. Although long-term case–control studies have not found differences in cancer rates in transgender patients receiving hormone therapy, there is not enough evidence to determine whether their cancer risk is different from that of cisgender controls.[11]

PUBLIC HEALTH IMPLICATIONS

Our findings indicate that the NYS transgender cancer population differs considerably from the nontransgender NYS cancer population. It is imperative that health care providers be aware of the cancers that the transgender population are experiencing. Knowing that certain cancers occur disproportionately in transgender patients and that the age of diagnosis is much lower among transgender patients than among the general NYSCR population could help health care providers improve screening and prevention strategies for their transgender patients, providing the best chance of survival. Because many of these cancers can be attributed to viral infections (HIV, HPV), focusing on their prevention should be key. Recent research has found that patients are generally willing to disclose natal sex when asked[12]; provider education in transgender health is needed to present the most effective screening options. The lack of demographic data characterizing the transgender population from the US

Census restricts and precludes the ability to calculate cancer rates among this population, thereby limiting successful interventions, outreach, and policy. AJPH

CONTRIBUTORS

L. M. Hutchison was the lead analyst and author. F. P. Boscoe and B. J. Feingold contributed to the analysis, writing, and editing of the brief. All authors conceptualized the study and approved the final text of the brief.

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HUMAN PARTICIPANT PROTECTION

Institutional review board approval was not needed, as the study used previously collected cancer data and no human participants were involved.

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