

Cancer is Cancer No Matter Who is in Your Bed:
Cervical Cancer Screening by Sexual Orientation in the United States

Josey D. VanOrsdale, M.A. and Jennifer A. Andersen, M.A.

University of Nebraska-Lincoln

Abstract

Background: This paper utilizes the 2016 Behavioral Risk Factor Surveillance Survey (BRFSS) to understand how women who identify as Lesbian, Bisexual, are unsure about, or do not disclose their sexual orientation obtain testing for cancer prevention and detection.

Methods: We evaluate female respondents, ages 18 to 55, in nine states utilizing HPV testing and sexual orientation modules of the 2016 BRFSS. Responses were compared using multivariate models.

Results: Women that identified as bisexual had 21% lower odds and those who identified as ‘other sexual orientation’ had 53% lower odds of having a Pap smear compared to heterosexual women, when accounting for all other factors. Women that refused to disclose their sexual orientation had 28% lower odds of HPV screening compared to heterosexual women.

Conclusions: Women who identify as LGBT, unsure, or refuse to disclose their sexual orientation are less likely to obtain the preventive services necessary to detect HPV.

Introduction

Cervical cancer is a common reproductive cancer among women in the United States (Clifford et al., 2005; Schiffman et al., 2007; Ferlay et al., 2010). In 2018, the estimates are that 13,240 new cases of cervical cancer will be diagnosed, and 4,170 women will die from the condition (American Cancer Society, 2018). Cervical cancer tends to develop in middle age and is most often diagnosed between the ages of 35 and 44, with 15% of cases developing after the age of 65 (American Cancer Society, 2018). Rates have significantly decreased over time with the development of the Papanicolaou (Pap) test. Lesbians are a group that often underutilize Pap testing and have well documented reasons (e.g. stigma from healthcare providers) for doing so (Mayer et al., 2008; Tracy et al., 2013; Ceres et al., 2018). In addition, a Pap test is often done in conjunction with a Human Papillomavirus (HPV) test, the virus that is currently believed to cause cervical cancer in combination with other risk factors such as smoking, socioeconomic status, being overweight or obese, among others (American Cancer Society, 2018). HPVs are a group of over 200 viruses, of which more than 40 types can be spread easily through direct sexual contact, including skin and mucous membranes (American Cancer Society, 2014). Further, HPV has been shown to be transmitted through vaginally inserted sex toys up to 24 hours after cleaning with a commercial cleaning agent (Anderson et al., 2014).

Background and Significance

The known difficulties in health care utilization for the LGBT population and the prevalence rates of HPV and associated cervical cancer in women require further attention. This paper proposes using the 2016 Behavioral Risk Factor Surveillance Survey to better understand how women who identify as Lesbian, Bisexual, or do not disclose or are unsure about their sexual orientation utilize PAP smears or HPV testing for cancer prevention and detection. No

research, to our knowledge, utilizes the categories of ‘refused’ or ‘don’t know’ within statistical analysis of cervical cancer screening. We hypothesize that the utilization of these categories may provide insight into how LGBT populations who do not identify themselves to healthcare providers fare in comparison to self-identifiers and non-LGBT populations in obtaining screenings.

Literature Review

Sexual Orientation and Cervical Cancer Screening in US Women

Screening for cervical cancer prevents the occurrence of cervical cancer by allowing for the detection and treatment of lesions at the premalignant stage before invasive disease develops (Tracy et al., 2013). The 2012 update of the U.S. Preventive Services Task Force screening guidelines recommends cervical cancer screening that: 1) begin at age 21, 2) continue to at least age 65, and 3) occur at regular intervals— every 3 years up to age 30 and at least every 5 years thereafter. The recommendation statement, however, does not apply to women who have been diagnosed with a high-grade precancerous cervical lesion or cancer, women exposed to diethylstilbestrol, or women who are immunocompromised (UPSTF, 2016).

Prevalence of HPV, a main contributor to the development of cervical cancer, among lesbians and bisexual women has not been widely reported. Previous studies posit that anywhere from 13-30% of women who have sex with women test positive for HPV, potentially higher than the 13-15% of HPV infection reported in the United States (Tracy et al., 2013). These numbers suggest that woman-to-woman transmission of the HPV virus is likely and recommendation guidelines should be consistent for all women, regardless of sexual orientation (Mayer et al., 2008; Tracy et al., 2013). Lesbians and bisexual women, however, often face significant barriers to adequate health care, including cervical cancer screening.

Fears of discrimination reinforce the stress the LGBT population faces daily due to their minority status, increasing the risk of sub-optimal health outcomes. Meyer (2003) described the stress process in the LGBT community using the minority stress model which theorizes: (1) minority status leads to increased distal stressors (e.g. prejudice events), (2) minority status leads to increased proximal stressors (e.g. expectations of rejection and stigma, concealment, internalized homophobia), (3) the increase in stressors, in combination with the environment, general chronic stressors, life events, coping and social support, socialization, and the characteristics of the minority identity (in this case, LGBT) affect the mental health outcomes of the minority person in negative and/or positive ways (Meyer, 2003). The minority stress model helps to explain the increase in physical and mental health disorders among those who identify as LGBT, by explaining how stigma, prejudice, and discrimination increase the amount of stress felt by this population (Meyer, 2003; Lick et al., 2013). A person who identifies as LGBT may suffer differential health outcomes than their heterosexual counterparts for several reasons. Sexual minorities may face structural discrimination, causing them to live in poor environmental conditions, fearing for their job if they are identified as LGBT, and living in poverty. They may experience and or/perceive discrimination and stigma from physicians, which may delay medical help-seeking, increasing the individual's stress level, and further exacerbating the individual's physical and mental health concerns (Meyer, 2003; Lick et al., 2013). The individual may turn to drugs and/or alcohol or other unhealthy behaviors as a coping mechanism, or to self-medicate for mental conditions such as depression or anxiety. The individual may choose not to disclose their sexual identity, which could lead to social isolation and a lack of a social support system. They may experience harassment and/or violence due to their sexual identity. The fear and experience

of stigma related to their sexual identity, heighten stress for the LGBT individual, which in and of itself leads to poor health outcomes (Meyer, 2003; Lick et al., 2013).

While research on cervical cancer in women who identify as lesbians or bisexual is increasing, it is not yet well studied. Research shows that lesbian and bisexual women may think they are at lower risk of contracting HPV than their heterosexual counterparts (Mayer et al., 2008; Tracy et al., 2013; Ceres et al., 2018). Further, research has shown that the LGBT population often face discrimination and homophobia in the healthcare setting (Mayer et al., 2008; Tracy et al., 2013; Ceres et al., 2018). Tracy et al. (2013) found that lesbians who did not get cervical cancer screenings on schedule were less likely to be knowledgeable about HPV risk and less likely to disclose their sexual orientation to their providers. Moreover, LGBT people often are under or uninsured, and have fewer cues to access gynecological care (Tracy et al., 2013). Physicians may also not be as knowledgeable of the risk of HPV in the LGBT population and may not consider their sexual histories when taking a medical history (Mayer et al., 2008; Tracy et al., 2013; Ceres et al., 2018). LGBT populations, due to the risk of discrimination, may not disclose their sexual orientation or sexual history to physicians because of fears of rejection or differential treatment (Tracy et al., 2013). The inability to feel comfortable with disclosing sexual orientation may lead to lesbians and bisexual women to seek out cancer screening less often than heterosexual women (Mayer et al., 2008; Tracy et al., 2013; Ceres et al., 2018). Further, as postulated by Meyer (2003) the coping behaviors used by lesbian and bisexual women may predispose them to cancer. The 2015 National Health Interview Survey data found that lesbians and bisexual are more likely to smoke and have a higher risk of past-year heavy drinking (Ceres et al., 2018). Moreover, women who identify as lesbian or bisexual have a higher risk of obesity (Ceres et al., 2018). Smoking, drinking and obesity are known risk behaviors

related to cervical cancer, and are more prevalent in bisexual women than lesbian women (Durso & Meyer, 2013; Ceres et al., 2018)

Even with these known issues, professional schools and continuing education programs have not developed the training needed to improve the attitudes, knowledge, and skills of physicians and other health care professionals in caring for LGBT people, leading to a shortage of providers for the LGBT community (Mayer et al., 2008; Ceres et al., 2018). The lack of training may compound the issues of non-disclosure of sexual orientation.

Sexual Orientation Disclosure to Physicians

Non-disclosure of sexual orientation, while common in the physician's office, is detrimental to the health of LGBT populations. Research has shown disclosure may be more common among bisexual individuals (Durso & Meyer, 2013). The population of people who identify as bisexual may present additional challenges to healthcare providers (Durso & Meyer, 2013). In addition, Meckler et al. (2006) found that among LGBT youth, the strongest predictor of disclosure of sexual orientation was having a conversation about sex or sexual health. In addition, LGBT youth express that disclosure is needed to provide adequate healthcare, and would welcome such a conversation (Meckler et al., 2006). The youth, when asked how a provider could encourage higher rates of disclosure, 64% of LGBT youth stated to just ask them (Meckler et al., 2006). While asking for sexual orientation could increase disclosure, physicians report training in medical school can contribute to feelings of discomfort and lead physicians ill-prepared to do so (Fallin-Bennett, 2015). Studies evaluating LGBT curriculum in medical schools show a median of two hours of training in the clinical years, and it is often rated as poor or very poor (Fallin-Bennett, 2015). In addition, medical students enter medical school with explicit and implicit bias regarding LGBT people (Fallin-Bennett, 2015). Medical students who

enter medical school with few or no LGBT friends have stronger negative bias towards LGBT people (Fallin-Bennett, 2015). Studies have shown that up to 82% of first year medical students hold some degree of implicit bias towards gay and lesbian individuals (Fallin-Bennett, 2015).

The Healthy People 2020 guidelines specifically state that increasing access to quality healthcare for LGBT populations as a priority (Whitehead et al., 2016). The LGBT populations are less likely to report having a primary care provider than their heterosexual counterparts (Whitehead et al., 2016). Further, despite the Affordable Care Act, LGBT people are also more likely to report being uninsured and unable to afford health services which is confounded by the lack of training on LGBT concerns the providers they do come in contact with (Whitehead et al., 2016). Ensuring providers have training on LGBT health concerns and communication of LGBT friendliness may increase patient disclosure of sexual orientation and aid in patient-provider communication (Whitehead et al., 2016).

Research Methods and Design

The proposed study will utilize the 2016 Behavioral Risk Factor Surveillance System Survey (BRFSS). Consisting of behavioral risk factors, including cancer screening frequency and sexual orientation information, the BRFSS provides behavioral health risk data from roughly 400,000 participants yearly throughout the United States (BRFSS, 2014). The telephone-based BRFSS coordinated by the Centers for Disease Control (CDC) is completed by health departments in all fifty states, and includes Puerto Rico, D.C., and Guam. This survey collects information from adults 18 years of age and older utilizing both core and optional supplemental survey modules to fit a specific state's needs. In 2016, twenty-six states included the sexual orientation module, and nine included the module on HPV testing. Thus, the BRFSS provides

important and powerful tools in order to target and building health promotion activities (BRFSS, 2014).

The analysis will be performed on female respondents aged 18 to 55 ($N = 34,856$). The 55-year-old threshold is optimal for this analysis since the HPV screening was not available until the year 1999. Women in this sample over the age of 55 were most likely into menopause by this time and are less likely to have continued standard reproductive screenings in the same capacity as their younger counterparts (NCHS, 2017). For the preliminary analysis although there were only 36% complete cases, listwise deletion was performed. Individuals that did not have definitive responses on any of the variables of interest were removed from the sample. In the proposed study, the missing values will instead be evaluated incorporating the sample design features (weights, stratum, and primary sampling units) as well as imputations, as computed using MI ICE in Stata. The proposed analyses (and preliminary analyses) will be estimated using logistic regression models for both HPV screening, and the Pap smear, controlling for sociodemographic and healthcare covariates. These analyses are completed using STATA 15.0.

Variables of Interest

HPV testing and Pap smear. During the BRFSS interview respondents were asked “An HPV test is sometimes given with the Pap test for cervical cancer screening. Have you ever had an HPV test?” This response was coded as a binomial indicator variable and used as the primary dependent variable. Additionally, we analyzed in a separate analysis whether the respondent had a PAP smear. This question was worded “A Pap test is a test for cancer of the cervix. Have you ever had a Pap test?” This screening was also considered in a separate model for comparison, but also serves as a sensitivity test since many women may receive the HPV test unknowingly as part

of the standard annual test. However, this measure should only be analyzed as a proxy that poses limitations.

Sexual orientation and gender identity. In the BRFSS the female respondents were asked if they considered themselves to be straight, lesbian, or bisexual. They were also able to select other, don't know or to all together refuse to answer the question. In this analysis this variable is used as a categorical variable where each value represents one of these options (in the logistic model each category becomes a binomial 0/1 indicator). We did not collapse or delete responses based on the non definitive responses of "other", "don't know" or "refused" responses as we are particularly interested in who these individuals may be, and how the stigma of being in a LGB category, or not knowing your appropriate social label, may influence one's access to the necessary screenings.

Healthcare controls. In an effort to isolate the health disparities that may be occurring based on sexual orientation in the screening for cervical cancer and HPV, we included some basic healthcare controls. All of these variables were dichotomized variables where 0 represents a negative response, and a 1 is an affirmation.. First, if the woman had ever received the HPV immunization, where 0 is no, and 1 is yes they have received the HPV vaccination. This immunization could influence whether a respondent is getting a screening and was therefore considered an important factor to consider. Second, we controlled for if the respondent had a doctor checkup in the last 12 months, where 0 is no and 1 indicates they had seen a doctor. Third, we included in the model if in the last 12 months the respondent had ever needed a doctor but was unable to go due to money. Fourth, it was also important to consider if the respondent had a regular doctor, 0 equals no and 1 is yes the respondent has a primary physician. The last

healthcare control included was whether the respondent had healthcare insurance, where 0 is no and 1 indicates they do have health insurance.

Sociodemographic controls. As this analysis seeks to evaluate the minority health disparities that may be influencing the screening of women for a potentially deadly cancer, we included many sociodemographic controls. We included in the model the women's marital status, where 1 indicated that she was married. The woman's race and ethnicity were also included. Although traditionally this variable would be condensed down into a three or four category variable, in order to highlight the health disparities occurring this variable was left an 8 category variable. In the analysis each category would be transformed as a dichotomous 0/1 indicator that allowed the results to show the particular race and ethnicities that may be advantaged or disadvantaged. These categories included white, black, Asian, Hawaiian and Pacific Islander, American Indian or Alaskan Native, Other race, Multiracial, or Hispanic. The respondents age was also included, but was divided by individuals that were less than 44 years old (equal to 0), and those that were 45 years and older for the preliminary analysis to follow the Center for Disease Control and Prevention statistical design (NCHS, 2016). Lastly, in multiple category ordinal variables we accounted for both the respondent's education and income.

Results

In a preliminary analysis of the data, Table 1 shows 89.5% of the women in the sample had indicated receiving a Pap smear in their lifetime, while only 55% of the sample had indicating receiving the HPV screening. The sample also includes nearly 8% of the respondents have a sexual orientation other than heterosexual. Collectively these numbers provided significant results in both the logistic regression of Pap smear screenings, as well as in the HPV screening.

In Table 2, a logistic regression analysis indicates that lesbian, bisexual and those of other sexual orientation all had significantly lower odds of receiving a Pap smear compared to those of heterosexual women, when holding all other factors constant (Model C). Lesbian women, compared to heterosexual women had 49% lower odds of having had a Pap smear, controlling for other factors ($p < .001$). Women that identified as bisexual had 21% lower odds of having had a Pap smear compared to heterosexual women ($p < .01$), and women that identified as being of 'other sexual orientation' had 53% lower compared to heterosexual women, when accounting for all other factors ($p < .001$). Interestingly, when including race and ethnicity in the model we also see that Hawaiian Pacific Islander women, Native American women, and both other and multiracial women all saw significantly lower odds of having a Pap smear, when accounting for all other factors. These results suggest there are significant disparities in the rates that women are getting or being given Pap smears based on sexual orientation as well as their race.

In Table 3, we analyze the odds of receiving the HPV screening, specifically. Similar to the previous model of the Pap smear the sexual orientation women had significantly lower odds of having the HPV screening. However, in this model bisexual women, after controlling for all other factors, has 28% higher odds of having their HPV screening compared to heterosexual women ($p < .001$). Additionally, in this model the women that refused to answer the question regarding their sexual orientation had 28% lower odds of having their HPV screening compared to the heterosexual women ($p < .001$). Consistent with the previous table, the women that identified racially as being Hawaiian Pacific Islander, or American Indian also had significantly lower odds of getting an HPV screening test.

Preliminary Discussion and Implications

The preliminary findings presented here demonstrate that there are still disparities in healthcare for the LGBT community, even though the Healthy People 2020 guidelines specifically states access to quality healthcare for LGBT populations is a priority (Whitehead et al., 2016). Women who identify as Lesbian and Bisexual, or who are unsure about or wish not to disclose their sexual orientation are less likely to obtain the preventive services necessary to detect HPV and cell abnormalities, leaving them at greater risk of developing cervical cancer. Additionally, the preliminary analysis illustrates that the social construct of race places an additional burden on women.

While this study provides important information about the relationship of the LGBT population, their decision to disclose sexuality preferences, and the stigma related to HPV testing, this study is not without its limitations. First, while we attempt to hone in on both the HPV screening as well as the Pap smear, it is difficult to conceptualize whether the issue is with the practitioners not giving sufficient information to sexual minority women, or if it is the women themselves. While one could argue that a women's lack of knowledge of the importance of maintaining these screenings, the onus for ensuring proper treatment falls ultimately falls on the provider and their ability to communicate with their patient. A second limitation of this study, is that the lack of universality in the questions presented in the BRFSS. The HPV module used to ask these questions had significant missingness, and while the proposed study can use imputation to estimate responses, the analysis would be more robust with actual participant responses.

This study has several potential implications for healthcare providers. First, understanding the impact of non-disclosure on healthcare outcomes may help to justify the need

for additional funding within medical schools to address the impacts of implicit bias on LGBT health. Moreover, it may encourage pre-medical programs to include curriculum that address implicit and explicit bias prior to students entering medical training. These training programs may encourage LGBT individuals to trust their health care providers opening them up to disclose their sexual orientation, which will allow for their medical needs to be addressed fully.

Additionally, providing culturally competent training for medical professionals must include education on the intersection of race and sexuality. The double burden of dual minority status may mean that women of color, who also identify as a sexual minority, may be of greatest risk of not receiving appropriate screenings. While this study highlights the importance of implementing these policies with haste, they also highlight the importance of continuing to evaluate these health disparities in individuals of any and all minority status.

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Table 1. Descriptive Statistics (n= 34, 856)

| | Percent |
|---|---------|
| <u>Dependent Variables</u> | |
| Has had a PAP smear | 89.53 |
| Has had HPV screening | 54.79 |
| <u>Sexual Identity</u> | |
| Heterosexual | 91.91 |
| Lesbian | 1.55 |
| Bisexual | 3.86 |
| Other | .51 |
| Not sure | .99 |
| Refused | 1.17 |
| <u>Demographic Variables</u> | |
| Married | 51.17 |
| <i>Race/Ethnicity</i> | |
| White | 68.46 |
| Black | 9.73 |
| Asian | .84 |
| Hawaiian/ Pacific Islander | 4.06 |
| American Indian or Alaskan | .86 |
| Other Race | .39 |
| Multi Race | 3.26 |
| Hispanic | 12.40 |
| <i>Age</i> | |
| Age 18 to 44 | 61.41 |
| Age 45 to 55 | 38.59 |
| <i>Income</i> | |
| Less than \$10,000 | 5.38 |
| \$10,000 - \$14,999 | 4.43 |
| \$15,000 - \$19,999 | 6.77 |
| \$20,000 - \$24,999 | 7.46 |
| \$25,000 - \$34,999 | 8.31 |
| \$35,000 - \$49,999 | 11.05 |
| \$50,000 - \$74,999 | 13.59 |
| Over \$75,000 | 32.45 |
| <i>Education</i> | |
| No education | .11 |
| Elementary School | 2.17 |
| Some High School | 4.87 |
| High School Degree | 22.91 |
| Some College | 28.69 |
| College Degree | 41.13 |
| <u>Healthcare Variables</u> | |
| Has had an HPV Immunization | 1.79 |
| Had a doctor checkup ¹ | 72.31 |
| Could not go to doctor because of cost ² | 14.79 |
| Has a regular doctor | 83.21 |
| Has health insurance | 90.61 |

Notes: Source: BRFSS, Behavioral Risk Factor Surveillance System Survey, 2015

¹ in the past 12 months

² in the past 12 months

Table 2. Logistic Regression¹ of Sexual Identity on Having PAP smear (*n*= 34, 856)

| | Model A | Model B | Model C |
|---|----------------|------------|----------|
| <u>Sexual Identity</u> | | | |
| Lesbian | .411*** | .523*** | .509*** |
| Bisexual | .445*** | .781** | .806** |
| Other | .261*** | .436*** | .467*** |
| Not sure | .444*** | .840 | .932 |
| Refused | .609*** | .919 | .952 |
| <u>Demographic Variables</u> | | | |
| Married | | 4.19*** | 4.095*** |
| <u>Race/Ethnicity</u> | | | |
| Black | | 1.092 | 1.045 |
| Asian | | 1.246 | 1.267 |
| Hawaiian/ Pacific Islander | | .210*** | .217*** |
| American Indian or Alaskan | | .318*** | .332*** |
| Other Race | | .457** | .484** |
| Multi Race | | .740** | .750** |
| Hispanic | | .977 | 1.046 |
| Age | | 4.543*** | 4.197*** |
| Income | | .990*** | .990*** |
| Education | | 1.373*** | 1.360*** |
| <u>Healthcare Variables</u> | | | |
| Has had an HPV Immunization | | .909 | .886 |
| Had a doctor checkup ² | | | 1.377*** |
| Could not go to doctor because of cost ³ | | | 1.372*** |
| Has a regular doctor | | | 1.657*** |
| Has health insurance | | | 1.102 |
| | Log Likelihood | -11566.108 | -9673.04 |
| | | | -9539.17 |

Notes: Source: BRFSS, Behavioral Risk Factor Surveillance System Survey, 2015

p* < .05, *p* < .01, ****p* < .001

¹ Odds Ratios

² in the past 12 months

³ in the past 12 months

| Table 3. Logistic Regression¹ of Sexual Identity on Having HPV Screening (n= 34, 856) | | | |
|---|----------------|------------|------------|
| | Model A | Model B | Model C |
| <u>Sexual Identity</u> | | | |
| Lesbian | .667*** | .640*** | .634*** |
| Bisexual | 1.379*** | 1.258*** | 1.282*** |
| Other | .453*** | .494*** | .519*** |
| Not sure | .517*** | .753* | .836 |
| Refused | .520*** | .694** | .721** |
| <u>Demographic Variables</u> | | | |
| Married | | .969*** | .958 |
| <u>Race/Ethnicity</u> | | | |
| Black | | 1.054 | 1.022 |
| Asian | | 1.206 | 1.179 |
| Hawaiian/ Pacific Islander | | .382*** | .387*** |
| American Indian or Alaskan | | .499*** | .509*** |
| Other Race | | 1.280 | 1.320 |
| Multi Race | | .965 | .973 |
| Hispanic | | .954 | 1.002 |
| Age | | .606*** | .577*** |
| Income | | .994*** | .994*** |
| Education | | 1.242*** | 1.225*** |
| <u>Healthcare Variables</u> | | | |
| Has had an HPV Immunization | | 2.097*** | 2.085*** |
| Had a doctor checkup ² | | | 1.315*** |
| Could not go to doctor because of cost ³ | | | 1.257*** |
| Has a regular doctor | | | 1.252*** |
| Has health insurance | | | 1.324*** |
| | Log Likelihood | -23919.653 | -23220.016 |
| | | | -23064.673 |

Notes: Source: BRFSS, Behavioral Risk Factor Surveillance System Survey, 2015

* $p < .05$, ** $p < .01$, *** $p < .001$

¹ Odds Ratios

² in the past 12 months

³ in the past 12 months