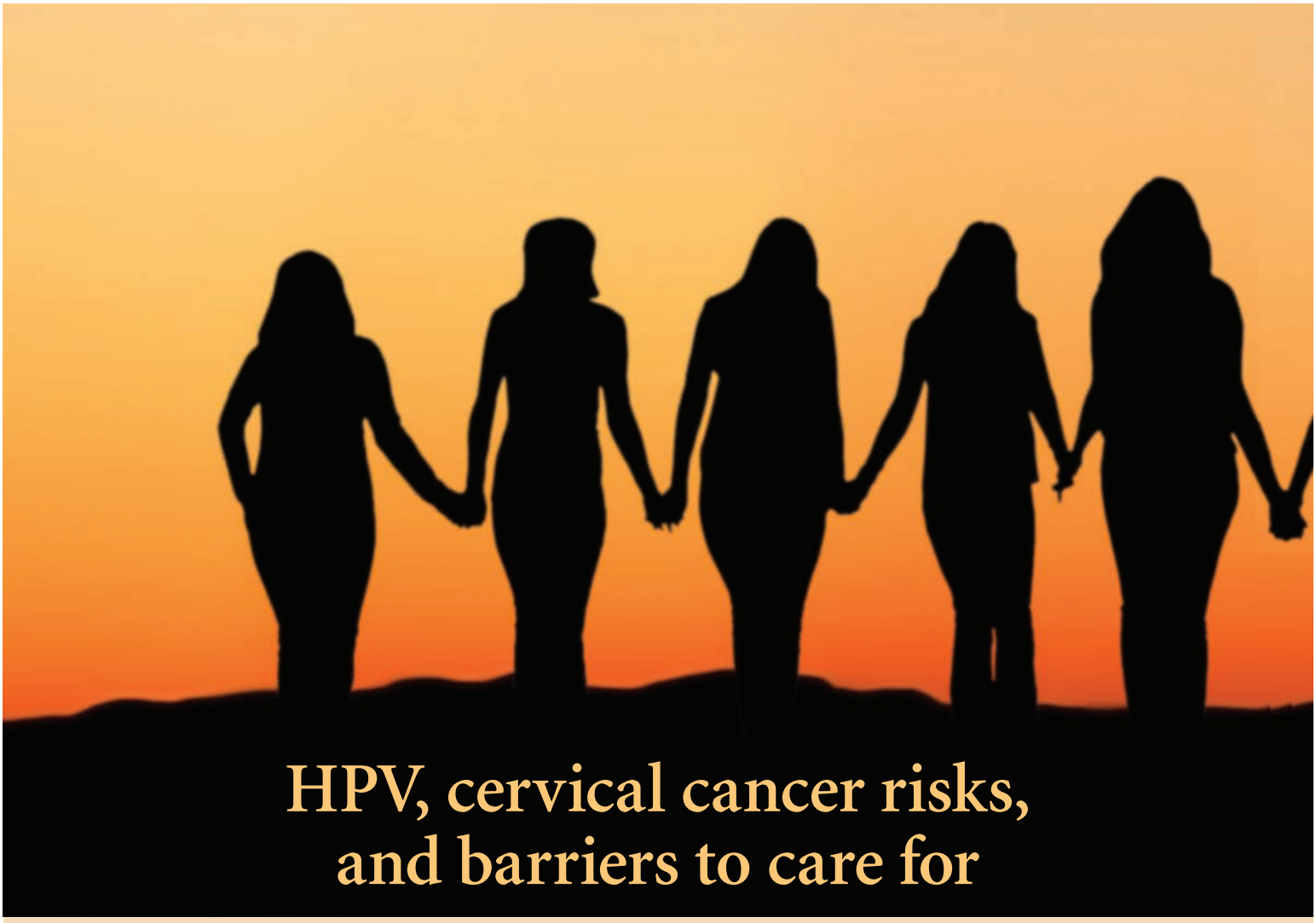

HPV, cervical cancer risks, and barriers to care for lesbian women

By Lindsay Waterman, MN, ARNP and Joachim Voss, PhD, RN, ACRN, FAAN

Lesbian women, a sexual minority in the United States, account for between 3% and 11% of the nation's females.[1] The risk of cervical cancer among lesbians is frequently underestimated and unrecognized by both lesbians and healthcare providers (HCPs).[2-7] In all women ages 21 to 65 years, screening every 3 years can detect abnormal cervical cells and precancerous lesions; however, lesbians are screened at rates 5% to 18% lower than heterosexual women because of the perceived lack of risk exposure.[8-10]

Human papillomavirus (HPV) is contracted by direct skin-to-skin contact, and although the types of HPV that affect the genital tract are commonly contracted by genital-to-genital contact (often associated with heterosexual intercourse), HPV DNA have been detected on fomites.[11-13] More than 99% of cervical cancer cases are associated with the long-term consequences of HPV infection.[14] Because of the perceived or real lack of contact with men, lesbians and their HCPs often do not recognize their potential risk for HPV infection, and HCPs often do not encourage lesbian patients to get regular screenings.[2,4,5,7]

Lesbians are underrepresented in health research. The hesitance of study participants to disclose sexual orientation because of privacy concerns or fear of repercussions, difficulties with recruitment of lesbians for research, and the reluctance of HCPs to ask patients about their sexual orientation are some of the reasons little is known about lesbian health behaviors.[15] Most studies aimed at

Keywords: cervical cancer, human papillomavirus, lesbian women, Pap smear

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Abstract: The purpose of this article is to identify Pap testing rates among lesbians and identify reasons for lack of recognition of cervical cancer risks in lesbians. Articles that reported cervical cancer screening rates among lesbians were searched. Between 48% and 81% of lesbians reported recent Pap smears. The lesbian community requires better education, and healthcare providers should promote regular Pap smears for all women.

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recruiting lesbians use convenience sampling due to challenges collecting meaningful data from a relatively small group of individuals. Recruiting participants at lesbian community events, where women publicly acknowledge their sexual orientation, may affect the generalizability of results toward all lesbians.[2] In addition, many medical record systems do not allow researchers to identify sexual orientation as a searchable demographic criterion.[15] This limits the use of medical record searches to track screening rates.

The purpose of this article is to review current literature and identify Pap testing rates among lesbians. The article will also identify unique barriers to screening lesbians, identify prevalence and perceived risk of HPV, explore how HCP knowledge about risks may be affecting screening rates, identify recommendations for practice, and propose research ideas for future studies.

Cervical cancer incidence and impact of screening

The estimated annual incidence of new diagnoses of cervical cancer in the United States is 7.8 cases per 100,000 women.[16] In 2014, an estimated 12,360 new cases were diagnosed, and approximately 4,020 women died of cervical cancer.[16] With the introduction of Pap testing in the 1950s, the incidence of and death rate from cervical cancer in the United States decreased by more than 60% between 1955 and 1992.[17] Cervical cancer develops slowly and manifests in early signs of precancerous lesions, cervical changes that are detectable

with regular Pap smears. Cervical cancer can take 10 to 20 years to develop after initial HPV exposure; therefore, most cases of advanced cervical cancer occur in women without previous screening.[18]

HPV infection

An estimated 99.7% of cervical cancer cases are associated with HPV infection.[14] There are over 120 types of HPV identified to date, but more than 70% of invasive cervical cancers are associated with one or both types of HPV (HPV 16 and HPV 18).[11,19]

More than 50% of sexually active persons will contract at least one strain of HPV in their lifetime.[20] One study reported that 65% of subjects who initially tested positive for cervical HPV subsequently tested negative after 12 months because most HPV infections are cleared or suppressed by the immune system.[21,22] HPV infections, if not cleared, can be episodic and fluctuate around the threshold level of detectability, making it difficult to estimate the time between initial HPV exposure and the development of high-grade cervical lesions.[23]

Lesbians are at risk for HPV

Until recently, HCPs did not view HPV as a condition that women who have sex with women (WSW) were at risk for contracting.[24] However, several studies and case reports have reported both positive HPV tests and squamous epithelial lesions in WSW exclusively.[24-26] Because HPV is transmitted by skin-to-skin contact, it is likely that WSW contract the virus via female genital-to-genital, oral-genital, or digital-genital contact.[11,25] Furthermore, HPV DNA has been detected on fomites, such as speculums and on nonmucosal skin, such as fingers.[12,13,27] Therefore, women can contract HPV from sexual practices involving fingers or sharing toys.[4]

Many lesbians and their partners have had previous sexual contact with men. In four studies focused on cervical cancer in lesbians, between 63% and 86% (average = 77%) reported that they had sex with men in the past, and between 3% and 24% (average = 17%) reported having sex with men within the previous year.[4,8,9,24,25] When compared with heterosexual women, lesbians reported more overall sexual partners (mean = 10 versus 7.3 partners [male and female]) and higher rates of sexual intercourse before the age of 18 (64% versus 56%), both of which are risk factors for HPV infection and cervical cancer.[10,28]

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Cervical cancer screening guidelines

No cervical cancer screening guidelines currently include language or considerations for lesbians. In 2012, the U.S. Preventive Services Task Force (USPSTF) changed the screening recommendations for cervical cancer to a Pap test every 3 years for all women ages 21 to 65 who have a cervix, regardless of sexual history.[29] This interval can be extended to every 5 years for women ages 30 to 65 if Pap and HPV tests are both conducted. These recommendations mirror that of the American Cancer Society, and both were developed in partnership with the American Congress of Obstetricians and Gynecologists.[30,31]

Defining "lesbian" in health data

There are no universally agreed-upon definitions for sexual identity terms such as "lesbian" when discussing research related to female sexual minorities.[32] Sexual orientation consists of three components: behavior, identity, and desire/attraction.[33] A person's sexual identity may not reflect his or her past or present sexual behaviors or sexual attractions. Therefore, lesbians are women who have a permanent relationship with other women, have women exclusively as sexual partners, or who have self-identified as lesbians. The lack of clarity between role expectations, sexual behaviors, and desires makes it challenging for researchers to design inclusion/exclusion criteria for the recruitment of lesbians. In some cases, this excludes bisexual women from being integrated into the lesbian category, as they have sexual contact with both genders.

Healthcare limitations for lesbians

There are many barriers to healthcare acquisition for lesbian women. Cochran and colleagues reported that lesbian and bisexual women are 6% less likely than heterosexual women to have healthcare insurance coverage.[34] This is possibly related to same-sex partnerships not being recognized as eligible for shared insurance benefits.[34] With implementation of the Affordable Care Act, more insurance options may become available. Women insured under a managed-care plan often do not have a choice in HCPs, thus, limiting access to "lesbian friendly" providers often sought out by lesbians enrolled in fee-for-service plans.[35] Social and cultural biases pose barriers to healthcare for lesbians. Historically, same-sex orientation between men or women has been viewed as a disease, and same-sex sexual acts were

Study breakdown

Study code/ First author	Country[a]	Year published	Sample size[b]	Recruitment method	Data collection tool
1 Bailey[24]	UK	2000	606	Clinic referral	Questionnaire[c], Pelvic Exam with cytology
2 Marrazzo[25]	US	2000	149	Media ad	Questionnaire, Pelvic Exam with cytology
3 Aaron[8]	US	2001	1,010	Mailing list, event, participant referral (snowball sampling)	Questionnaire
4 Marrazzo[4]	US	2001	248	Community ad, Media, Clinic Referral	Questionnaire, Pelvic Exam with cytology
5 Brown[2]	AU	2003	384	Community event	Questionnaire
6 Matthews[10]	US	2004	550	Community ad	Questionnaire
7 Grindel[42]	US	2006	1,139	Community ad	Questionnaire
8 Tracy[39]	US	2010	225	Media	Questionnaire
9 Charlton[9]	US	2011	60	Established cohort	Questionnaire
10 Tracy[7]	US	2013	1,006	Mailing list	Questionnaire

[a] US=United states, UK=United Kingdom, AU=Australia
[b] Does not include any heterosexual or separated bisexual comparison group
[c] Self-report questionnaire

deemed criminal.[15] These views have created a climate of stigma from HCPs, and in some cases, hostility against lesbian patients.[15]

In one study, 77% of lesbian respondents reported that their HCP knew their sexual orientation, and 5% acknowledged a problem with their HCP because of that knowledge.[36] HCP distrust is especially high in the setting of gynecologic care due to extreme emotional and physical vulnerability.[37] Lesbian women may be less likely to pursue preventive or curative care because of prior negative experiences with the healthcare system.[37,38]

Factors putting lesbians at risk for higher rates of cervical cancer

Lesbian women have higher rates of many gynecologic cancer risk indicators and behaviors when compared with heterosexual women in the United States.[34] These include higher percentages of body mass index scores above normal (27.7% versus 18.3%), higher alcohol use (69.6% versus 66.9%), and higher current or past cigarette smoking (55.2% versus 36.2%).[34] When these risks are combined with the current evidence of barriers to healthcare access, it stands to reason that lesbian women, although at risk for HPV and cervical cancer, may not be adequately screened.

Methods

The authors searched relevant literature in PubMed, CINAHL, and dissertations between 2000 and 2013. The authors' search terms included combinations of the words HPV, lesbian, WSW, Pap, cervical cancer, preventive, disparities, and screening. Nineteen manuscripts were identified and reviewed for original quantitative research that included Pap screening rates in lesbians or WSW. The authors eliminated nine articles because they did not contain original research or were qualitative studies focused on barriers rather than screening rates and were left with 10 key studies (see *Study breakdown*). All were cross-sectional, nonexperimental design. The authors extracted the data on current Pap screen rates, condensed it into aligning categories, and built a table to summarize the data, including the

percentages of women who reported never having had a Pap test and the percentages of lesbians who reported being screened at intervals that would meet current guidelines (see *Pap testing frequency rates among lesbians*).

Results

Demographics. These studies reported that the mean age of participants were between 22 and 44 years, all reported predominantly White participants (75% to 93%), most participants had a college education (37% to 74%), and most reported having some type of healthcare coverage (72% to 90%) (see *Study demographics*).

Pap frequency rates among lesbians. Lesbians in the United States reported having a Pap within the previous 3 years at a rate of 48% to 81% (mean = 60.5%), of 57% in the United Kingdom, and 78% in Australia. The mean rate of women among all key studies who had a Pap testing within the previous 3 years was 68.1%. This is lower than the previously published Pap testing rates for heterosexual women, which estimated 3-year rates to be between 78% and 80%.[34]

Pap testing frequency rates among lesbians

Study code/ First author	Never had a Pap test (%)[a]	Annual Pap test or Pap test within previous 2-3 years (%)	>3-5 years since last Pap test (%)
1 Bailey[24]	17	57	NR
2 Marrazzo[25]	NR[b]	85	NR
3 Aaron[8]	6	75	NR
4 Marrazzo[4]	4	NR	NR
5 Brown[2]	12	78	NR
6 Matthews[10]	3	81	NR
7 Grindel[42]	6	53	6
8 Tracy[39]	6	80	13
9 Charlton[9]	25	48	NR
10 Tracy[7]	NR	62	38

[a] Results rounded to nearest whole number
[b] NR=not reported in study results publication

Many lesbians do not seek gynecologic care. Much of the gynecologic care for premenopausal women is focused around contraception and pregnancy services that many lesbians do not seek.[3,34,39] In addition to the lack of regular specialty provider contacts, negative healthcare experiences and misinformation regarding preventive healthcare needs from peers and primary HCPs add to the lack of seeking preventive gynecologic care.[39,40]

Prevalence and perceived risks. WSW perceived themselves at a lower risk of contracting HPV than heterosexual women (mean risk rate = 17.8 and 27.7 for WSW and 101.2 and 107.7 for heterosexual women).[3] Despite the high prevalence of HPV infection, only 25% of WSW felt they were at risk.[6] Few WSW (6% of participants and 30% of participants) believed that HPV is spread by female-to-female sexual contact.[6,40]

There is a tendency to believe that sex between women is inherently safe due to minimal body fluid exchange.[6] Mainstream safer sex campaigns often exclude WSW. This creates confusion about lesbians' risk of sexually transmitted infections (STIs). Dental dams are promoted as a barrier method of safer oral sex for lesbians but are rarely promoted for heterosexual use. This disconnect creates confusion about their efficacy and cynicism about their value.[6]

HCP knowledge and screening practices of WSW. Several articles suggest that HCPs' lack of knowledge surrounding HPV risk in lesbians could be an additional barrier to Pap screening and potentially lead to late detection of cervical cancer.[2,4,5,7] Tracy and colleagues reported that the lack of an HCP referral for testing was the most common reason given by lesbians for not getting screened.[7] Marrazzo and colleagues reported that 10% of participants stated that an HCP had previously told them that they did not need a Pap smear because they were not sexually active with men.[4] Brown and colleagues reported that 9% of study participants had been previously told that they were ineligible for a Pap test and that 89% of the time, this advice came from their HCP.[2] McIntyre and colleagues conducted a qualitative study of seven lesbian women's experiences with Pap testing in which four reported being told by their HCP that they did not need Pap testing because they were lesbians.[5]

Discussion

The authors found that the majority of women who self-identify as lesbian have had previous male sexual partners and that HPV can be transmitted between WSW exclusively. Lesbians have higher rates of known risk factors for cervical cancer and lower rates of cervical cancer screenings than heterosexual women. Their experiences with HCPs were often perceived as negative, and stigma/misinformation

Study demographics

Study code/ First Author	Age range (years)[a]	Mean age (years)	Caucasian ethnicity (%)	College graduate (%)	Has medical insurance (%)
1 Bailey[24]	19-69	31	89	NR	NR
2 Marrazzo[25]	NR	32	92	NR	NR
3 Aaron[8]	NR	40	89	70	NR
4 Marrazzo[4]	NR	31	88	69	72
5 Brown[2]	56% < 40yrs 44% > 40yrs	NR	NR	NR	NR
6 Matthews[10]	20-86	43	76	37	90
7 Grindel[42]	NR	NR	75	74[b]	NR
8 Tracy[37]	18-68	41	87	76	78
9 Charlton[9]	17-25	22	93	NR	NR
10 Tracy[7]	21-70	44	77	45	84

[a] NR=not reported in study results publication
[b] Rounded to nearest whole number

were common occurrences when it came to cancer prevention. This, along with underrepresentation in health research, difficulties accessing healthcare insurance, and lack of access to "lesbian-friendly" providers have contributed to health disparities for lesbians.

Recent healthcare initiatives have aimed to highlight and reduce health disparities among the lesbian, gay, bisexual, and transgender (LGBT) population, such as the Healthy People 2020 goals.[41] New policies, driven by the Affordable Care Act, target improving data collection among the LGBT population (Section 4302).[41] Hopefully, more accurate data will be available to represent this population in healthcare research as these efforts materialize.

The studies examined were limited due to convenience sampling of lesbians willing to disclose their sexual orientation and demographics that are unlikely to mirror the lesbian population as a whole. None of the key studies indicated that they only included women within the age range of current Pap screening guidelines (21 to 65 years). Of note, previous guidelines included younger age initiation of screening and unclear evidence in regards to when Pap screening should be stopped. Previous guidelines also included more frequent Pap testing, as often as annually, so some participants in these studies are noted to be adherent by current standards but were not screening at the proposed guidelines of the time.

Lesbian women should receive Pap and HPV testing at the same intervals as heterosexual women to prevent cervical cancer.

The participants in these studies were primarily White and college-educated women. These demographics typically have higher Pap rates as compared with racial minorities and women with less education.[7,16] Lesbians have lower rates of healthcare insurance, but four key U.S. studies reported that 72% to 90% of participants had insurance coverage.[35] Study participants may have higher Pap rates than lesbians in general because insurance is likely to pay for Pap screening.

Due to inconsistencies in healthcare messages of safer sex and STI risks, unless lesbians are specifically referred to in women's sexual health information, they may assume that when it is promoted that "all women are at risk for HPV and need regular Pap tests," this only refers to heterosexual women.[6] Furthermore, current research on ideal cervical cancer screening intervals and improved accuracy of HPV testing have driven guideline changes and lengthened screening intervals to as long as 5 years.[42] This could downplay the public perception of the need for routine Pap screening and further perpetuate the problem of cervical cancer, especially in lesbians who are already underscreened.

Recommendations for research and practice

Further studies about cervical cancer screening rates are needed to recruit lesbians from diverse racial, socioeconomic, and educational backgrounds that more accurately reflect the general population. The true magnitude of the problem may be greatly underestimated by not being able to include these women. More new cases of cervical cancer are diagnosed in Black and Hispanic women (9.6 and 10.9 new cases per 100,000 persons, respectively) than White women (7.9), yet there is little data about lesbian screening rates in those specific populations.[16] Lesbians need better education that they are at risk for HPV and cervical cancer. Further research is needed, in collaboration with lesbian informants, to develop pamphlets, posters, and advertisements that deliver this information in a culturally sensitive way.

When caring for a lesbian patient, it is most important to be cognizant that there has been a previous culture of mistrust of HCPs. One must be sensitive while collecting a detailed sexual history and to not make assumptions about sexual practices. HCPs must understand that many lesbians and/or their partner(s) have had sexual contact with males and that STIs can be passed via female-to-female contact. HPV is common and is spread by skin-to-skin and genital-to-genital contact and can also be spread by fingers and toys. This is important information to share with lesbian patients, as there are many misconceptions about HPV risks. Practitioners need to know that all women with a cervix, regardless of sexual orientation, are at risk for cervical cancer. It is critical to reinforce to lesbian patients that the Pap screening recommendations apply to them. Lesbian women should receive Pap and HPV testing at the same intervals as heterosexual women to prevent cervical cancer. NP

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