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See page E197 for details about a podcast interview with the authors of this article.

Lesbian Women and Knowledge About Human Papillomavirus

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Research on lesbian health care is scarce, and a paucity of data exists regarding lesbians' increased health risks. Lesbians and their heterosexual counterparts have health differences, but how they influence risk for subsequent disease is not known. The general public perceives that some sexually transmitted diseases do not affect the lesbian community, that such diseases affect only heterosexual and gay sexual contacts. The purpose of this pilot study was twofold: to explore the association between lesbians' knowledge of human papillomavirus (HPV) cancer risk with age, education, and openness with a woman's healthcare provider; and to explore the relationship between lesbians' knowledge of female-to-female HPV transmission with age, education, and openness with one's physician.

Although a general consensus in recent research on lesbians' health acknowledges that no illnesses are unique to the population, their health concerns and needs may not be addressed in what can often be described as a homophobic and heterosexist environment (Mathieson, Bailey, & Gurevich, 2002; McNair, 2003b). Quantifying how hostile an environment is or how perceptions of homophobia affect women's health-related communications is difficult. Health disparities in this vulnerable population are alarming, and this study tested two of the potential sources (patient knowledge and reluctance to share health information) of negative health outcomes for lesbians.

Literature Review

Many reasons exist for the lack of research on lesbian health. One reason is that homosexuality is stigmatized; therefore, identifying this subpopulation of women to survey them about their healthcare practices is difficult. In the 2000 U.S. census, the most comprehensive sample of same-sex couples was collected, reflecting a change

Purpose/Objectives: To explore the association between lesbians' knowledge of human papillomavirus (HPV) cancer risk with age, education, and openness with a woman's healthcare provider; and to explore the relationship between lesbians' knowledge of female-to-female HPV transmission with age, education, and openness with one's physician.

Design: A descriptive correlational survey.

Setting: Surveys were distributed at lesbian and gay community events such as Bingo A-Go-Go; Rainbow Support Group meetings; Lesbian, Gay, and Bisexual Student Union of the University of Delaware meetings; and the Second Annual Women's Conference of the Women's Project of CAMP (Create a More Positive) Rehoboth.

Sample: 96 women who self-identified as lesbian, bisexual, or transgender and lived in the state of Delaware.

Methods: A 35-question survey, modified from an existing survey from the Delaware Breast Cancer Coalition and Centers for Disease Control and Prevention National Health Interview Survey.

Main Research Variables: Knowledge of HPV transmission, age, education, openness about sexual preference with physician, sexual preference, and knowledge of the relationship between HPV and development of cancer.

Findings: Twenty-nine women (30%) either did not know or did not believe that HPV could be spread by female-to-female sexual contact. Similarly, 29 (30%) of the women did not identify HPV as a cancer risk.

Conclusions: Lack of HPV knowledge was prevalent in this population of women.

Implications for Nursing: Cultural awareness by nurses is essential when discussing cancer prevention and early detection for this vulnerable population. Every woman, regardless of sexual orientation, needs to be informed about routine health screenings, vaccinations, and relative risk for the development of diseases. Culturally competent interventions are essential and are a priority for health professionals who screen and educate women about their healthcare needs.

in polling questions allowing gay and lesbian couples to identify themselves clearly to demographers (Simmons & O'Connell, 2003). The census queried gender

and relationship to the “main householder” (Fields & Clark, 1999). Although the information was asked, calculating or even trying to approximate the number of lesbians living in the United States is difficult. A methodologic problem of defining what constitutes lesbian sexual orientation exists because some lesbians do not identify themselves as such. Not all women whose primary sexual relationships are with women identify themselves as lesbians (McGregor, Carver, Antoni, Yount, & Ironson, 2001). Scientific research recognizes three components of sexuality used to delineate sexual orientation: identity, behavior, and attraction or desire (Dibble, Roberts, & Nussey, 2004). The term “women who have sex with women” describes sexual behavior, whereas lesbian is a term that describes sexual identity (Fethers, Marks, Mindel, & Estcourt, 2000). For purposes of this article, lesbian is the term used to describe both groups.

One of the largest research studies addressing health-related behaviors of the lesbian population came from the Boston Lesbian Health Project (Roberts, Patsdaughter, Grindel, & Tarmina, 2004; Roberts & Sorensen, 1999). The national survey, conducted in 1987 and again in 1997, reported on the health-related behaviors and cancer screenings of lesbians. It included 1,139 lesbian women representing 44 states. Roberts et al. (2004) reported that although the 1997 rates for screenings were improved in lesbians compared to the original 1987 study, the rates still were lower than for women in general. The percentage of lesbians never having a Pap smear changed from 10% (1987) to 6% (1997), and lesbians 40–49 years old having had mammograms changed from 58% (1987) to 87% (1997). The data also revealed that smoking rates increased by 21% (53% compared to 32%) across the same period in younger lesbians.

Lesbians differ from heterosexual women in a number of diseases. Lesbian women have an above-average prevalence of breast and gynecologic cancers, according to aggregate data from several lesbian health surveys (Cochran et al., 2001). Subsequent research has reported that lesbians, as a group, have a higher incidence of certain behavioral and lifestyle-related factors that are known to be linked to the development of breast and cervical cancers (Case et al., 2004; Valanis et al., 2000).

Known risk factors for developing breast cancer among all women are having children after the age of 30 years, having fewer or no prior pregnancies, commencing menstruation at an early age, experiencing menopause at a late age, being obese, and consuming more alcohol (American Cancer Society, 2007). According to the Institute of Medicine’s landmark report “Lesbian Health: Current Assessment and Directions for the Future,” lesbians are less likely to have ever been pregnant or to have given birth to a child (Institute of

Medicine, 1999; Rosenberg, 2001). Fewer pregnancies mean uninterrupted estrogen levels over longer periods of time, which increases risk for ovarian, uterine, and breast cancers (Stine, 2005). Lesbians have been shown to have an increased risk for developing ovarian cancer in a retrospective medical record review (Dibble, Roberts, Robertson, & Paul, 2002).

Heterosexual women’s primary contact with the healthcare system is through reproductive health; young women in general receive much of their health care through childbirth or because of birth-control needs. Lesbians are less likely to receive gynecologic services and are significantly less likely to use contraceptives (Cochran et al., 2001). Preventive health services are structured around contraceptives, which results in lesbians being an “invisible” population (Spinks, Andrews, & Boyle, 2000).

A study comparing breast cancer risks between lesbians and their matched heterosexual counterparts found that lesbians had a significantly higher risk for developing breast cancer (Dibble et al., 2004). The lesbian portion of the sample was acquired with a large convenience snowball method, and each woman recruited was asked to mail the survey to her sister closest in age. The survey method resulted in a matched sample of 324 lesbian women with a biologic, heterosexual sister counterpart, for a total of 648 participants. Breast cancer risk potential was examined with a 90-question survey developed to identify risks for developing breast cancer validated in a prior study. Dibble et al. (2004) demonstrated a complex pattern of demographic and behavioral differences between lesbians and their closest-aged sisters. The researchers concluded that differences in cancer risk were attributable to heterosexual women’s higher scores on all pregnancy-related variables and higher number of breast biopsies.

The risks of developing breast and gynecologic cancers appear to have their origins in physiologic mechanisms related to child bearing, but the cancers also are influenced by a number of perceptions and environmental and lifestyle choices that may occur more in the lesbian community (Dibble et al., 2004; Rosenberg, 2001; Stine, 2005).

In a qualitative study investigating cancer screening experiences of 28 lesbian women, Clark, Bonacore, Wright, Armstrong, and Rakowski (2003) identified several barriers that were unique to women who partner with women. The women identified concerns about acknowledging their sexual orientation for fear of discrimination. In addition, they found that avoidance of healthcare facilities was more prevalent in women who defined themselves androgynously (Clark et al., 2003).

To compare the use of preventive healthcare services by lesbian, bisexual, and heterosexual women, Koh (2000) conducted a survey of 1,304 women at 33 sites in 13 states. A variety of practice settings were used,

including physicians' offices, community clinics, chiropractic offices, and a naturopath's office. Koh's (2000) findings suggest significant differences in preventive health measures depending on self-defined sexual orientation. Preventive health measures used by Koh (2000) were derived from the definitions listed in *Healthy People 2000* (U.S. Department of Health and Human Services, 1991). The measures included risk behaviors (e.g., using illicit drugs in the prior 30 days) and recommended health screening (e.g., having had a cervical screening within the previous two years) (U.S. Department of Health and Human Services, 1991). The findings indicated differences: (a) Illicit drug use was higher in lesbian and bisexual women, (b) lesbian women practiced safer sex less often and had lower incidence of HPV infection compared to heterosexual women, and (c) bisexual and lesbian women were less likely to have had a mammogram than heterosexual women.

Lauver et al. (1999) identified barriers that lesbians face when undergoing mammograms. Telephone interviews were conducted with 107 women and open-ended questions asked about their mammography experience. Some barriers were shared among women of all sexual orientations, but unique barriers for the lesbian population were systems barriers, including poor relationships with practitioners and mistrust of others in the healthcare community.

Risky Behaviors in Lesbians

Aaron, Markovic, Danielson, Honnold, Janosky, and Schmidt (2001), studying a convenience sample of 1,010 self-identified lesbians, found that compared with the general population, the lesbian group was more likely to report cigarette use, alcohol use, and heavy alcohol use. Smoking rates are higher among lesbians and bisexuals than in the general population (Ryan, Wortley, Easton, Pederson, & Greenwood, 2001). In addition, a higher percentage of lesbian respondents had a higher body mass index. Yancey, Cochran, Corliss, and Mays (2003), in their survey of 1,209 lesbian and bisexual women, reported that most lesbian women were overweight or obese.

Research also has reported that lesbians can contract sexually transmitted diseases from other women and are at risk for contracting HPV, a virus that causes cervical cancer (Marrazzo, Stine, & Koutsky, 2000; Stine, 2005). According to Hughes and Evans (2003), high-risk types of genital HPV are associated with high-grade cervical cancers. A misconception exists that lesbians do not need Pap tests because HPV is transmitted only when a woman has sex with a man. The misconception is that lesbians have never had sex with men; however, a very large percentage of lesbians have had previous heterosexual experiences (Bailey, Farquhar, Owen, & Whittaker, 2003; Cochran et al., 2001).

Healthcare Providers' Impact on Disparities

Healthcare providers may perceive lesbians to be less susceptible to cervical cancer compared to women in general and, therefore, may be less likely to recommend them for screening. Research has suggested that lesbians often abstain from or underutilize health care because of real or perceived homophobia, so they display reduced health-seeking behaviors (McNair, 2003a; O'Hanlan, Dibble, Hagan, & Davids, 2004). Consequently, routine screenings may not be performed and cancers may be detected at later, less treatable stages. Valanis et al. (2000) found 4%–5% lower rates of recommended screening services in lesbian women compared with heterosexual women. Although Roberts et al.'s (2004) replication study of the Boston Health Project suggests that lesbians have increased their use of primary care, the rates continue to be lower than in women in general. Therefore, lesbians may miss early cancer for which women who regularly visit a doctor routinely get screened.

Despite the occurrence of genital HPV, women who have sex with women did not receive adequate Pap screening in a study conducted by Marrazzo et al. (2000). The research included 248 women who had sex with women in the preceding year. Their findings suggest that women who have never had sex with men were less likely to have undergone pelvic examinations and had fewer recent Pap tests. Barriers to screening included lack of insurance, previous adverse experiences with healthcare providers, and a belief that Pap tests were unnecessary.

Economic and Social Risks for Disparities

Lesbian and bisexual women also were less likely to have adequate health insurance, were more likely to have been uninsured during the preceding year, and often were unable to benefit from a partner's health insurance plan (Diamant, Wold, Spritzer, & Gelberg, 2000; National Lesbian Health Organization, 2005; National Women's Health Information Center, 2005). In addition, lesbians' sexual activities are illegal in some states, which makes disclosing their sexual orientation or identity to healthcare providers difficult for them (Purnell, 2003).

Methods

Data Source and Methodology

The Delaware Breast Cancer Coalition, Inc., and Screening for Life, a program of Delaware's Division of Public Health, collaborated to survey the lesbian community in the state of Delaware to obtain information to guide public policy. Convenience sampling was used to recruit participants at various locations throughout the state. The sampling sites were selected by expert

advisors from the lesbian community. Surveys were distributed at lesbian and gay community events, such as Bingo A-Go-Go; Rainbow Support Group meetings; Lesbian, Gay, and Bisexual Student Union of the University of Delaware meetings; and the Second Annual Women's Conference of the Women's Project of CAMP (Create a More Positive) Rehoboth. Respondents were self-identified lesbian, bisexual, and transgender women. Only completed surveys from women residing in the state of Delaware were included in the analyses, for a total of 96 usable surveys. The researchers obtained university institutional review board approval.

Instrument

The survey instrument was developed by Rankow and Tessaro (1998b) and is a modification of an expanded tool used previously by Rankow and Tessaro (1998a) to survey the lesbian community. The developers noted that some of the questions in the survey originally were developed, tested, and used in the Centers for Disease Control and Prevention's 1992 National Health Interview Survey (U.S. Department of Health and Human Services, 1991). To the authors' knowledge, the modified survey has no published validity and reliability data. As such, face validity was established by expert review. The survey contains 35 questions, a mixture of multiple-choice questions, fill-in-the-blank questions, and Likert scales (see Figure 1 for sample questions).

Analysis

Graphic analysis and exploratory procedures were completed to assess the distribution of the variables and missing data. The assessment guided the selection of further analyses. Two models were developed to address the purposes of the study. The two study purposes were tested with logistic regression (backward selection). Logistic regressions are used when there is a yes-or-no outcome (in this case, knows or does not know) that was tested for its association with predictor variables that can be factors (e.g., gender) or continuous (e.g., blood pressure). The backward selection places all potential predictors into the model and then removes them one at a time in an attempt to find a model that best fits the data tested. The goal is to remove predictors that do not provide information about the outcome.

Results

Sample Demographics

The sample included 96 women. Most of the women were Caucasian (80, 83%), 7 were African Americans (7%), 1 was Asian (1%), 2 indicated "other" (2%), and 6 (6%) did not report an ethnic affiliation. Thirty-five (37%) were aged 18–39 years, 25 (26%) were 40–49 years, 20 (21%) were 50–59 years, 10 (10%) were 60 years or older,

1. Please circle the letter that best describes how you think of yourself.
 - a. Lesbian only
 - b. Bisexual
 - c. Heterosexual only
2. Please circle the letter that best describes how you think of yourself.
 - a. Feminine (femme)
 - b. Androgynous
 - c. Masculine (butch)
3. Have you told your healthcare provider (the one you see most often) about your sexual orientation?
 - a. Yes, I volunteered the information without being asked.
 - b. Yes, but only after he or she asked me.
 - c. No, but I would tell if he or she asked.
 - d. No, but I assume he or she knows.
 - e. No, I would not tell even if he or she asked.
4. Have you experienced discrimination in health care because of your sexual orientation?
☐ Yes
☐ No

Figure 1. Selected Survey Questions

Note. Based on information from Rankow & Tessaro, 1998b; U.S. Department of Health and Human Services, 1991.

and 6 (6%) did not report an age range. Twenty-one (22%) had a high school degree or less, 32 (33%) were college graduates, 37 (39%) had graduate degrees, and 6 (6%) did not report educational level. When asked whether they had shared their sexual orientation with their healthcare providers, 50 reported that they shared, 6 shared after being asked, and 26 had not shared the information.

Knowledge and Attitudes

The final models included self-reports from 81 (83%) women in the study. Health information often is targeted based on risk factors. The sharing of sexual orientation may influence the types of data shared with patients. Fifty (52%) of the women in the sample volunteered their lesbian status to their healthcare providers, 6 (6%) shared their lesbian status after being asked by their healthcare providers, 25 (26%) would share their status if asked, 1 (1%) would not share her status if asked, and 14 (15%) of the subjects did not respond to the question. In the analysis, women who shared and those who shared after being asked were combined, and those who would share if asked but had not and women who would not share were combined.

Twenty-nine women (30%) either did not know or did not believe that HPV could be spread by female-to-female sexual contact. Similarly, 29 (30%) of the women did not identify HPV as a cancer risk.

When considering the relationships between knowledge of female-to-female HPV transmission and age, education, and openness with one's healthcare provider, openness was the only statistically significant ($p < 0.05$) variable. Interestingly, age and education were not significant contributors to explain a woman's odds

of knowing or not knowing about HPV transmission ($p > 0.05$). Compared to women who had not shared their sexual preference, women who had shared their status as lesbian had increased risks of not knowing about woman-to-woman transmission of HPV. Women who shared their status after being asked about their sexual preference were 4.9 (490%) times ($p = 0.021$) more likely not to know, and women who had declared their sexual status were 7.3 (730%) times ($p = 0.051$ approaching significance) more likely not to know. The Nagelkerke R square was 0.13, indicating that 13% of the variance was explained by the model tested.

The analysis of the relationship between knowledge of HPV risk in developing cancer and age, education, and openness with a woman's physician differed from the finding regarding transmission. In knowledge, the specific levels of education and age were significantly associated ($p < 0.05$) with different odds of not knowing about the link between HPV and cancer risk. As compared to those with less than or only a high school education, those with college education but not graduate degrees were 81.5% ($p = 0.015$) less likely to know about the link between HPV and cancer. The Nagelkerke R square was 0.1, indicating that 10% of the variance was explained by the model tested.

Discussion

In this study, 73% of the women had shared their sexual preference with their healthcare providers, which was associated with increased odds (86%) of not knowing about the woman-to-woman transmission of HPV. On the surface, the finding is counterintuitive because it suggests that the group of women most likely to benefit from HPV education had informed their healthcare providers of their lesbian status but had the least knowledge. This study does not provide a data-driven explanation for the finding, but perhaps physician inexperience or discomfort as noted by Khan, Plummer, Hussain, and Minichiello (2008) may have a chilling effect on the provider-patient relationship that, in turn, has an effect on knowledge. The findings support prior notions of biased care, which remains a rich area for future research (Khan et al., 2008).

Similarly counterintuitive, women with less than a college education were better informed than those with a college degree but did not differ from those with graduate degrees. Initially, the researchers suspected that an interaction between age and educational level might have driven this finding. To test this, a Spearman correlation was completed that suggested only a weak relationship between age and education in this sample ($r = 0.293$, $p < 0.001$). Although this study does not demonstrate a causal link between not knowing a woman's sexual preference and increased health risk, it is pragmatic to assume that women sharing their sexual

orientation may not be receiving targeted health education or that the information is not being communicated in a manner that promotes retention (Polek, Hardie, & Crowley, 2008). Interestingly, sharing or not sharing sexual preference was not significant ($p > 0.05$) in association with awareness that HPV can increase risk for cervical cancer. This study was underpowered and, thus, cannot state with any certainty that the sharing of sexual status does not also affect risk teaching in cancer prevention. One potential explanation for future testing is that providers may be making incorrect assumptions about women's prior knowledge to target their teaching. Thus, those with less education would more likely receive prevention education, leaving college graduates without exposure to critical knowledge. These findings parallel the work of others and suggest that more intensive work is needed to inform lesbians and to encourage all healthcare providers to assess the sexual orientation of their patients (Marrazzo et al., 2000; Stine, 2005).

Implications for Nursing

Preventive counseling is essential to risk reduction and is best received when it is relevant to a patient's lifestyle or unique risks. In this study, 25% of lesbians did not share their sexual orientation with their healthcare providers, which relates, in part, to their lack of knowledge about HPV. The Gay and Lesbian Medical Association (2002) lists 10 topics lesbians should discuss with their healthcare providers to counter cultural incompetence: breast cancer, depression and anxiety, gynecologic cancer, fitness, substance abuse, tobacco, alcohol, domestic violence, osteoporosis, and heart health. Healthcare providers can help reduce barriers that women may encounter by assessing their offices for approachability, attitudes, accountability, and awareness (Purnell & Paulanka, 2003). In 2006, a vaccine protecting females from four types of HPV that cause most cervical cancers was licensed by the U.S. Food and Drug Administration (American Cancer Society, 2008). The American Cancer Society (2008) recommended that all females be routinely vaccinated against HPV starting at age 11 years to prevent cervical cancer. It also recommended that women through age 26 who have not yet been vaccinated or completed the vaccine series receive the vaccine. The vaccine is given in a series of three injections over a six-month period (National Center for Immunization and Respiratory Diseases, 2008). Part of cancer risk education is encouraging all women to receive the vaccine and continue getting Pap tests when appropriate.

Limitations

Several of the study's limitations warrant consideration. Women who partner with women were solicited

for their participation in this research study, and that might have biased the data. The surveys were distributed at events that are frequented by many "outed" women, and the respondents may or may not be representative of the general lesbian population. An additional limitation is the small sample size. Lastly, imprecise definitions of the term lesbian make clearly defining this group of women difficult.

Conclusions

Lesbians often avoid accessing health care because of real or perceived homophobia and heterosexism, instead accessing health care only in times of acute need. Therefore, routine screenings are not performed and cancers may be detected at later, less treatable stages. The *Healthy People 2010* companion document for Lesbian Gay Bi-Sexual Transgender Health (Sell & Becker, 2001) focuses on critical areas and lists specific recommendations regarding improved access, preventive

medicine, and cultural competency (Gay and Lesbian Medical Association, 2001). The U.S. Department of Health and Human Services must recognize gaps with regard to sexual orientation data and recommend taking immediate steps to monitor and eliminate health disparities (Sell & Becker, 2001).

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Oncology Nursing Forum Podcast

Listen as *Oncology Nursing Forum* Associate Editor Ellen Giarelli, EdD, RN, CRNP, interviews Carolee Polek, RN, PhD, AOCNS®, and Thomas Hardie, EdD, PMHCNS-BC, about how every woman, regardless of sexual orientation, needs to be informed about routine health screenings and relative risk for the development of diseases.

Polek is an associate professor in the School of Nursing at the University of Delaware in Newark. She is an oncology clinical nurse specialist with AOCNS® certification. Her specialty is cancer disparities and cancer in vulnerable populations. Polek sits on the Detection and Early Prevention Committee of the Delaware's State Cancer Consortium.

Hardie's specialty is psychiatry. He is a professor and director of nursing research and grants at Widener University in Chester, PA. He also is an adjunct professor in the School of Nursing at the University of Pennsylvania in Philadelphia.

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