Cervical Cancer Risk and Papanicolaou Screening in a Sample of Lesbian and Bisexual Women

Elizabeth J. Rankow, PA-C, MHS, and Irene Tessaro, RN, DrPH
Durham, North Carolina

BACKGROUND. Previous studies of lesbian and bisexual women have suggested that negative experiences with health care practitioners, combined with misinformation about the health needs of this diverse population, have led to an underutilization of medical services.

METHODS. This study combined focus group data (N=44) with a self-administered questionnaire (N=576) to explore the health concerns of lesbian women, including the prevalence of risk factors for cervical cancer, the frequency of Papanicolaou (Pap) test screening, and the barriers to obtaining care. We examined the influence of women's perceptions regarding the knowledge and sensitivity of their clinicians to lesbian issues and their experiences of discrimination in the medical setting on Pap test utilization.

RESULTS. Respondents reported risk factors for cervical cancer, including multiple past or current sexual partners (both male and female), early age at first coitus, history of sexually transmitted diseases, and cigarette smoking. One fourth of respondents had not had a Pap test within the last 3 years, including 39 (7.6%) who had never had a Pap test. Women who reported that their health care providers were more knowledgeable and sensitive to lesbian issues were significantly more likely to have had a Pap test within the last year, even when controlling for age, education, income, and insurance status.

CONCLUSIONS. Lesbian women are at risk for cervical cancer and should receive routine cytologic screening according to individual risk assessment. The quality of clinician-patient interactions strongly influences care-seeking within the population sampled.

KEY WORDS. Homosexuality, female; lesbian (non-MeSH); Papanicolaou smear; cancer; physician-patient relations. *(J Fam Pract 1998; 46:139-143)*

Lesbian and other women who partner with women may represent an underserved and at-risk population with unique barriers to routine medical care. Previous studies of lesbian and bisexual women have suggested that negative experiences with health care practitioners, combined with misinformation about the health needs and concerns of this diverse community, have led to an underutilization of medical services.[1,2] Research has documented the homophobic attitudes and behaviors of medical professionals[3-9] and the reluctance of lesbians to reveal their sexual orientation to providers for fear of receiving compromised care.[10-14] These studies have shown that lesbians will often delay or not obtain needed care, even in the face of worrisome symptoms.[10,11] In both published and unpublished reports, from 5% to 8% of lesbians surveyed had never had a Papanicoulou (Pap) smear.[15-19] The impression exists among both clinicians and women who partner with women that lesbians are a low-risk group not requiring cytologic screening with the same frequency as their heterosexual counterparts.

The purpose of the present study was to better understand the attitudes, behaviors, beliefs, and experiences affecting the health of lesbians and other women who partner with women. We combined focus group data with a self-administered questionnaire to explore health concerns, including the prevalence of risk factors for cervical cancer, the frequency of Pap test screening, and the barriers to obtaining care.

Submitted, revised, November 6, 1997.
From Cancer Prevention, Detection and Control Research, Duke University Medical Center, Durham, North Carolina. All correspondence should be addressed to Elizabeth J. Rankow, PA-C, MHS, 5931 Mazuela Drive, Oakland, CA 94611. E-mail: Rankow@earthlink.net

METHODS

Data Collection

Focus group data (N=44) were employed in the development of a 76-item anonymous self-report survey that was distributed through social networks and community organizations of lesbian and bisexual women in North Carolina between June and November 1995. Women were invited to complete the questionnaire if they either self-identified as lesbian or bisexual or had past or present sexual relationships with other women, regardless of self-definition as homosexual or heterosexual. Targeted outreach methods were employed to broaden the demographic diversity of respondents. Approximately 1000 to 1200 questionnaires were distributed.

Study Measures

Sociodemographic characteristics used in analysis were race/ethnicity, educational level, income, insurance, age, area of residence, and self-reported health status. Measures for cervical cancer screening included ever having had a Pap test, having had a Pap test within the last year, and barriers to screening for those women who had not had a Pap test within the last 3 years. Risk factors assessed included number of lifetime sexual partners (male and female); age at first consensual sexual experience with a woman and with a man; and whether respondents had engaged in any of 14 listed sexual risk behaviors within the past 3 years. History of sexually transmitted disease (STD) included report of infection with human papillomavirus (HPV), genital or anal herpes, chlamydia, gonorrhea, syphilis, tri chomonas, bacterial vaginosis, or human immunodeficiency virus (HIV). Positive smoking status indicated a current smoker. Two Likert-type scales were employed to assess women's perceptions of their clinician's knowledge about and sensitivity to lesbian health issues (α = .86) and any experiences of discrimination in the health care setting because of age, race, income or sexual orientation (α = .79).

RESULTS

Of 591 respondents, 15 male-to-female transsexual or transgendered individuals were excluded from this analysis because of the absence of a uterine cervix. Table 1 summarizes the sociodemographic characteristics of the remaining 576 respondents. Fifty-three of these women reported having had a hysterectomy and 11 reported a history of cervical cancer. Because their medical history would alter guidelines for care, these women were not included in the analysis of Pap test frequency, leaving a sample of 512 for those calculations.

Risk Factors for Cervical Cancer

Table 2 shows the prevalence of selected risk factors for cervical cancer for the full sample of 576 women in the study. Two thirds of respondents had had at least four female sexual partners (66.6%), and about one third (31.5%) of respondents were younger than 18 years when they had their first sexual experience with a woman. Forty-five percent of respondents had had at least four male sexual partners, and half (50.9%) were younger than 18 when they had their first sexual experience with a man. More than half (55.8%) of the women reported engaging in four or more risky sexual behaviors in the past 3 years, with younger women significantly more likely to report this (P = <.0001). The most common risk behaviors cited were unprotected digital stimulation or penetration of the vagina (87.5%), unprotected oral-vaginal contact (85.6%), and tribadism, or genital-to-genital contact (73.4%). Twenty-eight percent of our sample were current smokers, compared with 24.6% of all North Carolina women reported in the 1994 Behavioral Risk Factor Surveillance System data.[3]

TABLE 1

Sociodemographic Characteristics of 576 Lesbian or Bisexual Women Compared with 1990 North Carolina Census Data

Characteristic	Lesbian or Bisexual Women No. (%)		All NC Women %
Race			
White	415	(72.3)	75.1
Black	110	(19.2)	21.7
Native American	22	(3.8)	1.2
Latina	16	(2.8)	0.8
Asian/Pacific Islander	7	(1.2)	0.8
Other	2	(0.3)	0.3
Education			
High school or less	56	(9.8)	54.4
Some college	14	(25.8)	29.6
College/some graduate	203	(35.7)	11.8
Graduate/professional	63	(28.6)	4.2
Residence			
Rural	90	(15.7)	NA
Small town	136	(25.8)	
Suburb	119	(20.8)	
City	227	(39.7)	
Insurance			
No	93	(16.2)	12.7†
Yes	80	(83.8)	
Income*			
<$10,000	85	(14.9)	27.3
$10,000 - $19,999	155	(27.2)	32.4
$20,000 - $29,999	140	(24.6)	20.4
$30,000 - $39,999	97	(17.0)	10.8
≥$40,000	92	(16.2)	9.1
Age, years			
17-29	170	(30.0)	30.6
30-39	193	(34.1)	26.2
40-49	135	(23.9)	20.6
50-77 (50-64 for NC census)	68	(12.0)	22.6

* 1990 North Carolina Census income data is for female householder aged 15-64.
† 1993 North Carolina Behavioral Risk Factor Surveillance System data.[20]

Use of Pap Testing

Most of the 512 women (92.1%) reported that they have had a Pap test, and 43.5% reported having had a Pap test within the last year (Table 3). Women who were more educated ($P = <.0001$), had higher incomes ($P = <.0001$), and were older ($P = <.0001$) were more likely both to have ever had a Pap test and to have had one within the last year. Women with insurance were also more likely to report they had had a Pap test within the last year ($P = .006$). One hundred twenty-seven women (24.8%) had not had a Pap test within the last 3 years, including 39 (7.6%) who had never had one.

Those women who reported positive experiences with their health care providers were more likely to have ever had a Pap test ($P = .05$) and to have had one within the last year ($P = <.0001$). Controlling for age, education, income, and insurance status, women who had positive attitudes toward their providers were still more likely to have had a Pap test within the last year, but no more likely to have ever had one. For those women who had experienced discrimination, there was no association with ever having had a Pap test, but there was a strong association with not having had a Pap test within the last year ($P = <.0001$), even when controlling for age, education, income, and insurance status.

TABLE 2

The Prevalence of Recognized and Possible Risk Factors for Cervical Cancer in the Study Sample of Lesbian or Bisexual Women (N=576)

Risk Factor	No. (%)
No. male sexual partners	
0	113 (19.5)
1 to 3	205 (35.4)
4 to 10	159 (27.5)
11+	102 (17.6)
Younger than 18 at first sexual experience with a man	227 (50.9)
Current smoker	161 (28.4)
History of sexually transmitted disease	166 (29.8)
No. female sexual partners	
0	10 (1.7)
1 to 3	183 (31.7)
4 to 10	252 (43.6)
11+	133 (23.0)
Younger than 18 at first sexual experience with a woman	176 (31.5)
Four or more sexual risk behaviors with either male or female partner	319 (55.8)

DISCUSSION

Any research on lesbian and bisexual women is inherently subject to sample bias resulting from the stigma associated with nonheterosexual identity or behavior. This study sought to minimize these limitations through targeted peer outreach in a variety of community and social networks of women who partner with women. While our sample achieved a degree of ethnic diversity representative of the overall population in North Carolina, our results cannot be considered a random sample nor generalizable to all women who partner with women. The element of selection bias resulting from the possibility that women with an interest in health concerns may have been more likely to complete the survey must also be considered. This would, however, tend to overestimate the level of compliance with screening examinations, since such women would presumably be more active in their own health-seeking behaviors.

Our data support the finding of significant risk factors for cervical cancer among lesbians. Eighty percent of our sample had engaged in heterosexual intercourse, half of these for the first time at age 17 or younger. Forty-five percent of respondents reported four or more male sexual partners during their lifetime to date. The number of female sexual partners is similar, although the age of onset for female partners was slightly later for many women. Although lesbians (especially those who have been sexually active exclusively with other women) appear to be at lower risk for STDs,[19,21,22] almost one third of our respondents reported a history of some type of sexually transmitted infection. Six women (1%) reported testing positive for HIV, and 2% reported a history of cervical carcinoma in situ. (No cases of invasive cervical cancer were reported.) Sexual risk behaviors were common, with oral-genital contact, unprotected digital-genital stimulation, and genital-to-genital contact being the most prevalent.

Cervical neoplasia, related to HPV infection, has been reported in lesbian women with no history of heterosexual activity.[23-25] While oral transmission of HPV has been identified,[26-28] it is possible that a more likely route between female sexual partners might be genital-to-genital contact, allowing direct exposure of HPV-infected tissues and fluids to the labia and vaginal mucosa of a partner. Another common practice, the sharing of sex toys such as dildos or vibrators without the application of a fresh condom or a thorough cleaning between partners, literally places the cervical secretions of one woman on the cervix and genital tissues of the other. These seldom-considered sexual activities may place women who have sex with women at risk for HPV (and other STD) transmission.

Despite the risk of cervical cancer among women who partner with women, many respondents do not obtain routine Pap screening. Almost 8% of our respondents had never had a Pap test. This is consistent with previous studies of lesbian women[10,15-19] and slightly higher than statistics for all North Carolina women.[20] Respondents' perceptions

of clinician attitudes appear to have a significant influence on the regularity of Pap screening. Those women who felt that their providers were more sensitive to and knowledgeable about sexual issues and the health concerns of lesbians and bisexual women were more likely to have been screened within the past year. Similarly, women who reported they had experienced discrimination (based on age, race, socioeconomic status, or sexual orientation) were less likely to have had a Pap test in the past year. Overall, 43.5% of our sample have had a Pap test in the past year, compared with 67% of all North Carolina women.[20]

TABLE 3

Pap Smear Status by Sociodemographic Characteristics

Characteristic	Ever Had a Pap Smear No. (%)	P	Had a Pap Smear Within Last Year, %	P
All respondents (N=512)	506 (92.1)	43.5		
Race				
Black	96 (89.6)		42.7	
White	365 (93.4)	.20	44.9	.70
Education				
High school or less	50 (82.0)		26.0	
Some college	132 (87.1)		40.2	
College/Some graduate	179 (93.3)		39.1	
Graduate/Professional	139 (98.6)	<.0001	58.3	<.0001
Insurance				
No	86 (91.9)		30.2	
Yes	417 (92.1)	.94	46.5	.006
Income				
<$19,999	220 (85.9)		33.2	
$20,000 to $29,999	122 (95.9)		46.7	
$30,000 to $39,000	82 (96.3)		52.4	
≥$40,000	75 (98.7)	<.0001	58.7	<.0001
Age, years				
17 to 29	165 (81.8)		30.3	
30 to 39	176 (96.6)		45.5	
≥40	155 (98.7)	<.0001	54.8	<.0001
Health Status				
Poor/Fair	56 (85.7)		35.7	
Good	296 (94.3)		42.6	
Excellent	145 (91.0)	.62	49.0	.07

CONCLUSIONS

Lesbians and other women who partner with women are at risk for cervical cancer. Financial barriers, negative encounters within the medical setting, and misperceptions about risk held by both lesbians and clinicians may lead many women to forgo needed care. Making assumptions about an individual's health needs on the basis of limited observations about an entire population is a dangerous practice. A thorough assessment of cervical cancer risk, including numbers of past and present sexual partners (of either sex), age at onset of sexual activity, history of STDs, specific sexual activities engaged in, history of smoking, and DES exposure is necessary for all women seeking care (see Appendix). Health practitioners should counsel patients regarding the risk of cervical neoplasia, and together they should arrive at an appropriate plan for preventive care. Clinicians and health educators must become knowledgeable about the full range of human sexual behavior and be comfortable offering harm-reduction guidance to their lesbian clients. Education on lesbian health issues and training in cultural sensitivity should be integrated into the curricula for both students and practicing clinicians. By improving their knowledge of and sensitivity to the health concerns of women who partner with women, providers can enhance rapport, increase patient comfort, and improve screening adherence. By the ensuring of access to affordable, respectful, and well-informed medical care, all women are better served.

ACKNOWLEDGMENTS

The authors acknowledge funding support from the National Institutes of Health grant No. 5RO1-CA-63782-02. We would like to thank Barbara K. Rimer, DrPH, of Duke Cancer Control Research for contributions to the study design, and Pauline R. Lyna, MPH, and Andrew L. Kavee, MA, also of Duke, for their contributions to data preparation and analysis.

REFERENCES

1. Stevens PE, Hall JM. Stigma, health beliefs and experiences with health care in lesbian women. Image: J Nurs Scholarship 1988; 20:69-73.
2. Trippet SE, Bain J. Reasons American lesbians fail to seek traditional health care. Health Care Wom Int 1992; 13:145-53.
3. Douglas CJ, Kalman CM, Kalman TP. Homophobia among physicians and nurses: an empirical study. Hosp Community Psychiatry 1985; 36:1309-11.
4. Matthews WC, Booth MW, Turner JD, Kessler TP. Physicians' attitudes toward homosexuality: a survey of a California medical society. West J Med 1986; 144:106-10.
5. Randall CE. Lesbian phobia among BSN educators: a survey. J Nurs Educ 1989; 28:302-6.

6. Eliason MJ, Randall CE. Lesbian phobia in nursing students. West J Nurs Res 1991; 13:363-74.
7. Smith GB. Homophobia and attitudes toward gay men and lesbians by psychiatric nurses. Arch Psychiatr Nurs 1993; 7:377-84.
8. Schatz B, O'Hanlan KA. Anti-gay discrimination in medicine: results of a national survey of lesbian, gay and bisexual physicians. San Francisco, Calif: American Association of Physicians for Human Rights, 1994.
9. O'Hanlan KA, Cabaj RP, Schatz B, Lock J, Mayer KH. A review of the medical consequences of homophobia with suggestions for resolution. J Gay Lesbian Med Assoc 1997; 1:25-39.
10. Cochran SD, Mays VM. Disclosure of sexual preference to physicians by black lesbian and bisexual women. West J Med 1988; 149:616-9.
11. Dardick L, Grady KE. Openness between gay persons and health professionals. Ann Intern Med 1980; 93:115-9.
12. Hitchcock JM, Wilson HS. Personal risking: lesbian self-disclosure of sexual orientation to professional health care providers. Nurs Res 1992; 41:178-83.
13. Stevens PE, Hall JM. Stigma, health beliefs and experiences with health care in lesbian women. Image: J Nurs Scholarship 1988; 20:69-73.
14. Stevens PE, Hall JM. Abusive healthcare interactions experienced by lesbians: a case of institutional violence in the treatment of women. Response: To the Victimization of Women and Children 1990; 13:23-7.
15. Bybee D. Michigan lesbian health survey. Lansing, Mich: Michigan Organization for Human Rights, 1991.
16. Bradford J, Ryan C. The national lesbian health care survey. Washington, DC: National Lesbian and Gay Health Foundation, 1987.
17. Becker BL, Robinson AJ. Houston area health care needs assessment for lesbian, bisexual and transgender women. Houston, Tex: Lesbian Health Initiative, 1995.
18. Mills S, Garcia D, Martinez T, et al. Health behaviors among lesbian and bisexual women: a community-based women's health survey. San Francisco, Calif: The San Francisco Department of Public Health, AIDS Office, Prevention Services Branch, 1993.
19. Johnson SR, Guenther SM, Laube DW, Keettel WC. Factors influencing lesbian gynecologic care: a preliminary study. Am J Obstet Gynecol 1981; 140:20-8.
20. Behavioral Risk Factor Surveillance System, Office of Epidemiology, North Carolina Department of Environment, Health and Natural Resources, 1994.
21. Johnson SR, Smith EM, Guenther SM. Comparison of gynecologic health care problems between lesbians and bisexual women. J Reprod Med 1987; 32:805-11.
22. Robertson P, Schachter J. Failure to identify venereal disease in a lesbian population. Sex Transm Dis 1981; 8:75-6.
23. O'Hanlan KA, Crum CP. Human papillomavirus-associated cervical intraepithelial neoplasia following lesbian sex. Obstet Gynecol 1996; 88:702-3.
24. Ferris DG, Batish S, Wright TC, Cushing C, Scott EH. A neglected lesbian health concern: cervical neoplasia. J Fam Pract 1996; 43:581-4.
25. Marrazzo J. STDs and cervical neoplasia among lesbians: research review and update. Presentation at the 19th Annual National Lesbian and Gay Health Association Conference. Seattle, Wash: July 1996.
26. Panicini PB, Scambia G, Perrone L, et al. Oral condyloma lesions in patients with extensive genital human papillomavirus infection. Am J Obstet Gynecol 1992; 167:451-8.
27. Coutlee F, Trottier AM, Ghattas G, et al. Risk factors for oral human papillomavirus in adults infected and not infected with human immunodeficiency virus. Sex Transm Dis 1997; 24:23-31.

APPENDIX
How to Conduct a Sensitive and Inclusive Sexual History Interview

It is often helpful to preface sensitive questions with an explanation about their importance in providing appropriate care, and to reassure your patient about confidentiality (if that can be promised honestly). For example: "People are at risk for different diseases and need different tests depending on what activities they're engaging in now and what they have done in the past. I will need to ask you several personal questions that I ask all my patients about their sexual activity to help me give you the best care tailored to your specific needs." This can then be followed by more detailed questions about specific sexual practice; age at first intercourse; the number and gender of past and present partners; any history of trading sex for money, drugs, food, or shelter; sexual activity while under influence of drugs or alcohol; history of sexually transmitted diseases; reproductive history; and so forth.

Ask About Relationships
- Are you involved in a significant relationship?
- Tell me about your living situation. Who shares the household with you?
- Tell me about the people who are important to you. From whom do you get the most support?
- Are your relationships satisfying? Are there any concerns you'd like to discuss?

Ask About Behaviors
- Are you sexually active? With men, with women, or with both?
- Have your sexual partners in the past been men, women, or both?
- Have you had a new partner(s) or a change in your sexual activity since your last visit?
- Do you have any need to discuss birth control?
- How are you dealing with the issues of "safer sex" and STD risk?