

# Improving Cancer Screening Among Lesbians Over 50: Results of a Pilot Study

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**Purpose/Objectives:** To explore the impact of two one-hour lesbian-specific educational interventions by a lesbian physician on the cancer screening behaviors of lesbians.

**Design:** A pilot pre- and post-test intervention study.

**Setting:** Two lesbian, gay, bisexual, and transgendered senior organizations in the San Francisco Bay Area (one urban, one suburban).

**Sample:** 36 participants aged 50–81 ( $\bar{X}$  = 60.2, SD = 6.48). The majority were Caucasian (86%), single (61%), living in urban areas (67%), employed (56%), and educated beyond high school ( $\bar{X}$  = 15.47 years, SD = 2.90, range 9–21). Eleven percent ( $n$  = 4) did not have any health insurance and were not on Medicaid or Medicare.

**Methods:** A lesbian physician led a one-hour, didactic, lesbian-specific educational program on cancer screening, including a review of current research findings with regard to lesbians' risk for cancer and 45 minutes of information on recommended cancer screening, followed by a 15-minute question-and-answer period. Participants completed a pre- and postintervention survey.

**Findings:** Follow-up data were available for 22 women. Of the six women (27%) who had not focused their attention on breast screening behaviors for two years or more, one-third had obtained mammograms and half began performing monthly breast self-examinations. Of the four women (18%) who had not undergone a pelvic examination for three years or more, one obtained a pelvic examination. The women reported no changes in colorectal cancer screening behaviors.

**Conclusions:** Some of these difficult-to-reach women changed their behavior in a very short period of time, supporting the need for a larger study to confirm these findings.

**Implications for Nursing:** A need exists to develop appropriate interventions for the underserved population of lesbians older than 50.

## Key Points . . .

- ▶ The risk profile of lesbians for developing cancer is worse than for heterosexual women.
- ▶ They may not be known as such, but lesbians probably are at most work sites either as coworkers or patients.
- ▶ Many screening programs do not have appropriate materials or programs designed for lesbian audiences.
- ▶ The hostility, fear, and discomfort experienced by lesbians in the healthcare system should not be underestimated.

to be higher among lesbians, as would be predicted by studies suggesting that lesbians have increased risk for developing cancer (Cochran et al., 2001; Dibble, Roberts, Robertson, & Paul, 2002; Roberts, Dibble, Scanlon, Paul, & Davids, 1998).

Research into the health concerns of sexual minorities is becoming more prevalent and sophisticated. Scientists are beginning to treat sexual orientation as a demographic variable similar to religion or ethnicity (Sell, 1997). In research studies, lesbian and bisexual women may be grouped together because of overlapping sexual behaviors or separated at other times when their sexual behaviors differ (Johnson, Smith, & Guenther, 1994). Studies, however, hint that lesbian and bisexual women may differ in more than sexual behaviors, such as in their interaction with the healthcare system (Koh, 2000; Smith, Johnson, & Guenther, 1985), their degree of social iso-

In 2003, 658,800 women are estimated to be diagnosed with cancer and 270,600 will die from the disease (Jemal et al., 2003). Approximately 211,300 women will be diagnosed with breast cancers, 77,000 will be diagnosed with colorectal cancers, and 83,700 will be diagnosed with gynecologic cancers (Jemal et al.). Some of the women included in these statistics are lesbians. The actual number of female sexual minorities (lesbian, bisexual, or transgendered women) is unknown; thus, any attempt to report the distribution of sexual orientation in women is subject to some bias and distortion (Solarz, 1999). In the National Health and Social Life Survey, 6.2% of women reported same sex behavior or desire (Laumann, Gagnon, Michael, & Michaels, 1994). If this is true, then an estimated 40,846 lesbians in the United States will be diagnosed with cancer in 2003. These figures may be conservative if the rates of some cancers eventually are found

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lation (Norman, Perry, Stevenson, Kelly, & Roffman, 1996), and their cancer risk (Dibble, Roberts, Davids, Paul, & Scanlon, 1999).

The term "lesbian" describes "not only sexual orientation, but also an identity based on psychological responses, cultural values, societal expectations, and a woman's own choices in identity formation" (White & Levinson, 1995, p. 463). Bisexual women have the potential for attraction to both men and women; they are attracted to individuals rather than to a person of a particular gender or biologic sex (Tucker, Highleyman, & Kaplan, 1995). Lesbians are diverse and represent all religious, ethnic, economic, age, and cultural groups. Because same-sex behavior is stigmatized and lesbians often defy stereotypes, they may remain a hidden population in their interactions with researchers and healthcare providers. The assumption of heterosexuality is so prevalent (Denenberg, 1995; Rankow, 1995) that healthcare providers and researchers may perpetuate the invisibility of lesbians within the healthcare system.

Not only are lesbians often invisible within the healthcare system, they also are less likely than heterosexual women to use preventive cancer-related screening services. A meta-analysis of seven large surveys completed from 1987–1996 (N = 11,876) demonstrated that lesbian and bisexual women were less likely than heterosexual women to undergo routine screening procedures such as mammograms and gynecologic examinations (Cochran et al., 2001). Additional surveys and clinic sampling performed in subsequent years have confirmed this finding (Koh, 2000; Lauver, Karon, & Egan, 1999; Rankow & Tessaro, 1998a, 1998b; White & Dull, 1997).

Cancer-screening behaviors are important because early detection of cancer often can result in a cure and detecting precancerous conditions can result in preventing cancer in the first place. Two population-based studies suggest that the use of cancer-screening services also may vary within the female sexual minority population. The first study is the 1997 Los Angeles County Health Survey of 4,697 women, of whom 51 identified as lesbian and 36 as bisexual. Lesbian but not bisexual women were less likely than heterosexual women to have received Pap tests or clinical breast examinations in the prior two years (Diamant, Wold, Spritzer, & Gelberg, 2000). The second is the Women's Health Initiative, which found that heterosexual women and adult lesbians were more likely than no-adult-sex, bisexual, and lifetime-lesbian women to have received Pap tests and mammograms in the prior year (Valanis et al., 2000). The number of self-identified lesbians in these studies was low, even lower than would be expected from general population estimates.

Numerous programs have been developed during the past 20 years to increase the cancer-screening behaviors of women, particularly in regard to breast cancer screening. The interventions have used communication from physicians and healthcare plans, as well as various community-based interventions. Table 1 offers information about some of these studies. A few of these programs have been subjected to the rigors of research, but none have focused on lesbians.

A number of U.S. studies have focused on ethnic minority women including Latinas, Vietnamese, Asians, and African Americans. The *Por La Vida* intervention program for the Latina women's community was tested using a randomized clinical trial (Navarro et al., 1998). Lay community workers (N = 36) each recruited approximately 14 peers. Each estab-

lished group was assigned randomly to an experimental (breast and cervical cancer early-detection information and coaching) or control group (another program). At the end of the study, the cancer intervention groups (n = 274) practiced more breast self-examination (BSE) (p < 0.001) and had significantly more mammograms (p = 0.029) than the control group.

The Witness Project is an intervention designed for African American women in Arkansas that provides culturally sensitive messages promoting early detection from African American breast cancer survivors in churches and community organizations (Erwin, Spatz, Stotts, & Hollenberg, 1999). Of the 204 participants in the Witness Project, a significant increase was found in the practice of BSE (p < 0.0005) and mammography (p < 0.005) pre- and postintervention using a McNemar chi-square test. No comparable increase existed in the control group (n = 206) screening behaviors.

ENCORE<sup>plus</sup>, a national program from the YWCA designed to reach underserved women from all ethnicities, was tested in 27,494 women (Fernandez, DeBor, Candrea, Wagner, & Stewart, 1999). The program activities included outreach, education, enabling, support services, and provider networking and linkage. Of the participants older than 40 who were nonadherent to breast cancer screening guidelines at baseline (70%), 58% received mammograms in the six months following the intervention. Of the participants older than 18 who were nonadherent to cervical cancer screening guidelines at baseline (69%), 37% received Pap tests in the six months following the intervention. Another program designed to serve women from all ethnicities used formal and informal meetings to disperse written materials, show videos, and generally educate women, all in their native language, about breast and cervical cancer and associated screening guidelines (Kernohan, 1996). Some (37%) of the study sample attended breast cancer screening six months after the program intervention, and an additional 20% of the women had cervical tests. On the other hand, a program that used similar venues to disperse breast cancer screening educational materials in the population's native language and simultaneously launched a media campaign targeting Vietnamese American women did not yield a significant change in clinical breast examinations or mammograms (Nguyen, Vo, McPhee, & Jenkins, 2001).

Two clinical trials have aimed at improving colorectal cancer screening. In the first study (Thompson, Michnich, Gray, Friedlander, & Gilson, 1986), the effectiveness of three interventions was evaluated for improving patient participation in fecal occult blood tests: physician or nurse discussion, a reminder phone call, or a reminder postcard. All the interventions were better than no intervention. The reminder postcard was the best, increasing adherence by 25%. In the second study (Pignone, Harris, & Kinsinger, 2000), 249 patients aged 50–75 in central North Carolina who had not had any colorectal screening tests in five years and did not have a family history of colorectal cancers were randomized into two groups. The first group watched an 11-minute video about colorectal cancer, received an educational brochure about colon cancer screening, and had their charts flagged indicating interest in screening. The other group watched a video about car safety, and their charts were not distinguished. Screening tests were completed by 37% of the intervention group and 23% of the control group (p < 0.03).

Based on the work completed by others in developing targeted cancer-screening programs, the current study's authors decided to test the effect of a lesbian-specific screening program given

**Table 1. Selected Intervention Studies Designed to Increase Breast Cancer Screening**

Authors	Sample	Interventions	Results
McDermott & Marty (1984)	292 female college students	Women were randomly assigned to one of two groups: facilitator-conducted program using modeling plus rehearsal (treatment) and a group receiving pamphlets about breast cancer and breast self-examination (BSE).	Significantly more members of treatment group practiced BSE at least once within three months after the intervention.
McPhee et al. (1989)	62 internal-medicine residents	Women were randomly assigned to one of the following groups: computer-generated reminders of patients with overdue tests at the time of their visit, monthly seminars about screening with feedback about their performance rates, or a control group. Half of the medical residents in each group also received patient-education materials and their patients received notices of overdue tests.	Residents' charts were reviewed to assess performance of seven tests. <ul style="list-style-type: none"> <li>• Group 1 increased performance of six of seven tests.</li> <li>• Group 2 increased performance of four of seven tests.</li> <li>• Patient reminders increased performance of one of two targeted screening tests.</li> </ul>
Marcus et al. (1992)	2,000 women with abnormal Pap tests	Women received either a personalized follow-up letter and pamphlet, a slide-show program on Pap tests, or transportation incentives (bus pass or parking permit).	Bus passes were effective in increasing the return rate for people at county hospital, whereas slides and letters were effective for patients at other clinics.
Rothman et al. (1993)	190 women older than 40 who were not adhering to mammography-screening guidelines	Women viewed persuasive mammography video with one of three attributional emphasis: internal, external, or informational. Attitudes about breast cancer and mammography were assessed immediately and six months later.	Women who viewed internal messaging were more likely than women in other two groups to have had a mammogram 12 months later.
Skinner et al. (1994)	435 women aged 40–65 who had been to a family practice within two years	Women received either individually tailored or standardized mammography recommendation letters with follow-up phone calls eight months later.	Recipients of tailored letters were more likely to have mammograms, especially those with incomes less than \$26,000 and African American women.
Herman et al. (1995)	803 women older than 65 seen by 66 residents attending ambulatory clinic at public hospitals	All staff received intensive training in breast cancer screening. Patients were randomized to one of three groups: control or no intervention, education about breast cancer screening (education), and education plus a flow sheet on chart to facilitate compliance (prevention).	Women in the prevention group were offered clinical breast examination (CBE) 32% more frequently than other two groups (not significant when adjusted for race, age, comorbidity, and physician's gender and training). Women in the prevention group without previous CBE were offered CBE significantly more often than other groups.
Foley et al. (1995)	Five-year follow-up study of 91 women older than 40 who had participated in a nurse-initiated intervention study to improve mammography recommendation and completion rates and 189 controls	The intervention included (a) identification by the nurses of eligible women who were overdue for a mammogram, (b) completion of a checklist by residents indicating whether a mammogram was recommended and why, and (c) a nurse-initiated reminder system for patients.	After charts were audited, the researchers found that mammogram recommendation and completion rates increased over time for both the intervention and control groups. However, the nurse-initiated intervention group had a significantly higher change over time.
Erwin et al. (1996)	204 African American women in eastern Arkansas	Culturally sensitive messages from African American breast cancer survivors were presented at churches and community organizations, emphasizing the need for early detection for survival.	Use of BSE and mammography increased significantly ( $p < 0.001$ ) after participation in program.
Kernohan (1996)	1,628 women from minority ethnic groups (South Asian, African Caribbean, Eastern European, and others)	Two specifically trained health-promotion facilitators conducted formal and informal meetings in ethnically diverse areas, educating women about breast and cervical cancer and related screening guidelines. They conducted these meetings, showed videos, and offered written materials in the clients' native languages.	Significant increases in cervical tests and breast cancer screening were self-reported, as well as anecdotal observations of attendance at local clinics.

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**Table 1. Selected Intervention Studies Designed to Increase Breast Cancer Screening (Continued)**

Authors	Sample	Interventions	Results
Davis et al. (1997)	395 women in Philadelphia health maintenance organizations (HMOs)	Mammography reminders were given in one of three forms: birthday card, personalized letter from medical director with written materials promoting mammography, or a multicomponent telephone call with reminder, counseling, and scheduling appointment.	Women who received a phone call were 28% more likely to obtain a mammogram than those who received a letter, and those who received a birthday card were 15% more likely to obtain a mammogram.
Suarez et al. (1997)	Mexican American women in two communities	Three-year intervention was aimed at increasing Pap test and mammography screening that included the presentation of role models in the media and was reinforced with peer volunteers.	Each community saw a 6% and 7% absolute increase in Pap tests and a 17% and 19% absolute increase in mammograms.
Weber & Reilly (1997)	Urban women 52–77 years old in six primary care practices supported by a computerized clinical information system	Women received a case-management intervention from culturally sensitive community health educators or usual care.	Women in intervention group were nearly three times more likely to receive a mammogram (95% confidence interval, 1.75–4.73).
Navarro et al. (1998)	36 Latina community workers were recruited, as well as approximately 14 peers per worker	Women were randomized to attend a 12-week intensive cancer screening group or “Community Living Skills” group. Pre- and postintervention assessment of breast and cervical cancer screening was performed.	The screening group showed statistically significant improvement in BSE (33% versus 19% for control group), mammography (21% versus 7%), and Pap test (23% versus 16%). No difference was found for CBE.
Street et al. (1998)	108 women 40–70 years old from two clinics (family practice and free clinic)	Women completed a baseline questionnaire assessing their perception of personal importance of breast cancer, knowledge, and anxiety about screening. They were randomized to see educational materials either by way of an interactive multimedia program or brochure, then asked initial questions again to assess learning.	Both groups perceived importance increased after the intervention, although no significant difference was found between the two. Younger women tended to prefer the multimedia experience and learned more from the intervention than older women.
Segnan et al. (1998)	8,385 women due for cervical screening and 8,069 women due for breast cancer screening	Women received one of the following letters: Group A: signed by a general practitioner with a fixed appointment; Group B: open-ended invitation signed by general practitioner; Group C: signed by program coordinator with fixed appointment; or Group D: extended letter highlighting benefits of cancer screening signed by general practitioner with fixed appointment.	The letter signed by a general practitioner with a fixed appointment was more effective for breast and cervical screening than two of the other letters. Group B was 39% less effective, and Group C was 14% less effective. Group D had no difference.
Fernandez et al. (1999)	27,494 women, primarily ethnic minorities with low incomes, attending YWCA	ENCORE <sup>plus</sup> ® (YWCA) is a health promotion program providing outreach, referral, and other services to facilitate breast and cervical cancer screening. Its effectiveness was evaluated.	58% of women who initially were nonadherent with Pap- and breast-screening guidelines had mammograms and 37% had Pap tests.
Taylor et al. (1999)	314 women 50–74 years old with at least one general medicine clinic appointment at university-affiliated hospital in Seattle (due for mammography)	Women were randomized to two groups: one received usual care and the other was educated about screening guidelines and breast cancer risk by physician and nurse, saw video, and, if interested, had an appointment scheduled and was given bus passes. If the mammogram appointment was more than a week later, they were called or sent a reminder. If they missed their appointment, they were called and encouraged to make another appointment.	Mammography completion within eight weeks of clinic visit was significantly higher in the intervention group (49%) than control group (22%). Bus passes and rescheduling efforts did not contribute to the observed increases in screening participation.
Giles et al. (2001)	140 women older than 18 at six community pharmacies and two health-screening fairs	Pharmacists administered the Gail model risk assessment tool and provided education and training on BSE, CBE, and mammography.	Monthly BSE increased from 31% to 56% ( $p < 0.001$ ) after six months. No significant change was found in obtaining CBE and mammograms except for women 40–49 years old.
Simon et al. (2001)	1,717 women at two locations of multisite inner-city health department in Detroit. Most women were African American, older than 50, and had minimal health insurance.	Women were randomized to one of three groups: received letter instructing them to visit their primary care physician; received letter instructing them to contact their clinic to schedule a mammogram; did not receive a letter.	No difference in mammography use occurred among the three groups.

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**Table 1. Selected Intervention Studies Designed to Increase Breast Cancer Screening (Continued)**

Authors	Sample	Interventions	Results
Nguyen et al. (2001)	788 and 807 Vietnamese American women and physicians in pre- and postintervention groups in Alameda and Orange Counties, CA	Women and physicians in Alameda County received interventions of continuing education, health fairs, educational material, and a media campaign. Women in Orange County served as the control.	The intervention group was no more likely to recognize, receive, or be up-to-date with CBE or mammograms than the control group, although they were more likely to have planned a CBE or mammogram.
Hiatt et al. (2001)	1,599 women in an underserved multiethnic population, aged 40–75 in the San Francisco Bay Area from 1993–1996	Women were randomized to a community-based outreach using lay health workers, an “in-reach” intervention targeted at four clinics using provider education and computer reminders, or a patient-navigator intervention to enhance follow-up and resolution of abnormal Pap tests and mammograms.	83% of women in intervention group obtained mammograms and 95% obtained Pap tests versus 68% and 83%, respectively, in the control group.
Valanis et al. (2002)	510 female HMO members 52–69 years old who had no mammograms in the prior two years and no Pap tests in the past three years	Women were randomized to receive one or combination of the following interventions: a clinic office in-reach intervention, sequential letter or telephone outreach intervention, or usual care.	32% of the combined group ( $p = 0.05$ ), 39% of the outreach group ( $p = 0.006$ ), and 26% of the in-reach group obtained both services compared to 19% of the usual-care group

by a lesbian physician. This approach takes advantage of the power of the physician and the power of being a member of the targeted community—an insider. The goal of this project was to determine whether attending a lesbian-specific screening program fostered a behavior change in screening behaviors among lesbians.

## Methods

### Design

This pilot study was conducted using a pre- and post-test design to explore the impact of a lesbian-specific educational intervention from a lesbian physician on the cancer-screening behaviors of lesbians older than 50.

### Settings

The settings for this study were two lesbian, gay, bisexual, and transgendered senior organizations in the San Francisco Bay Area. In the first program, conducted in an urban setting, all the women ( $N = 7$ ) who attended the presentation participated in the study and completed both the pre- and postintervention testing. In the second program, conducted in a suburban setting, 33 women attended the presentation. These women were very concerned about remaining anonymous. Of the 33 women, 29 completed the preintervention questionnaire. However, only 23 would give their contact information to the researchers for the postintervention follow-up. Fifteen of the 23 completed the postintervention testing. Therefore, of the 40 women who received the intervention, 55% ( $n = 22$ ) completed both pre- and postintervention questionnaire packets.

### Sample

To be included in the study, the women had to be aged 50 or older and attend a lesbian-specific educational program about cancer screening.

### Instruments

The pre- and postintervention surveys were created, pilot-tested, and revised prior to being used in this study. A mul-

tidisciplinary panel of experts (two physicians, one epidemiologist, and three oncology nurses) established content validity of the instrument. Most of the questions, except those about colon cancer, had been used in other studies conducted by the principal investigator with excellent results (Dibble et al., 1999, 2002; Roberts et al., 1998). Because these questions were demographic in nature and measured multiple concepts, typical measures of reliability (e.g., Cronbach’s alpha) were not appropriate to calculate. Test-retest reliability estimates also were not appropriate to explore because the authors were looking for change and not stability.

### Procedures

After approval by the institutional review board, both educational programs were scheduled and advertised at an urban and a suburban center. Participants were asked at the beginning of the educational program whether they would be willing to participate in a research study to explore the usefulness of the program. An information sheet about the study was distributed to the audience. Those who were willing to participate completed the pretest in about 10 minutes. Consent was implied by the return of the completed questionnaire. After each program, names, telephone numbers, and e-mail addresses for the follow-up were collected to be kept (in a locked file cabinet, accessible to just one member of the research team) only until the end of the study. The contact information then was destroyed. To protect the women’s privacy, each questionnaire was assigned a study number. Follow-up questionnaires were matched with the initial questionnaire using age, zip code, and education rather than names. Although these safeguards were explained to the women, mistrust of research was evident. Eighteen percent of the participants who answered the pretest prior to the educational program refused to participate in the post-test because of the lack of anonymity. The post-test data were gathered by a research assistant in a telephone interview approximately six months postintervention (range = 5.5–7 months).

## Intervention

The intervention consisted of a one-hour didactic presentation from a lesbian family practice physician followed by a 15-minute question-and-answer session with the audience. The presentation, titled "Cancer Screening Tests: What Lesbians Over Age 50 Need to Know," began with a five-minute biographic sketch during which the physician discussed her background in family medicine, lesbian health research, and lesbian community activism. She then presented a 15-minute review of current research findings with regard to lesbians' risk for cancer.

In this review, the physician discussed the lack of knowledge about the true incidence of various cancers among lesbians because national cancer registries do not gather information about sexual orientation and most researchers do not ask questions about sexual orientation in their demographics. She described what cancer risk differences have been identified between lesbians and heterosexual women and the impact of those differences on the potential development of cancer: Being a lesbian does not increase a woman's risk of cancer, but some differences in lifestyles between lesbians and heterosexual women might. For instance, lesbians are less likely to seek health care because of the discomfort of revealing their sexual orientation to healthcare providers (White & Dull, 1997). In addition, lesbians are less likely to visit a doctor for routine gynecologic services such as birth control (Cochran et al., 2001). Therefore, lesbians are less likely to have cancers detected at earlier, more treatable stages. Lesbians are at higher risk for breast and ovarian cancers because they are less likely to have children by age 30, if at all, and have a higher body mass index (weight-to-height ratio) than heterosexual women (Dibble et al., 2002). Lesbians are more likely to have smoked than heterosexual women (Roberts et al., 1998). This information was followed by 45 minutes of information on recommended cancer-screening procedures for breast, cervical, colon, lung, ovarian, and uterine cancers, with emphasis given to colon cancer screening. The screening procedures described followed the recommendations of the American Cancer Society (2001) and the U.S. Preventive Health Services Task Force (2001). Referral information to a lesbian-sensitive healthcare provider also was offered.

## Data Management and Analyses

Data were entered and verified using the SPSS® Version 11 (SPSS Inc., Chicago, IL). Descriptive statistics were generated to describe the sample characteristics. Although researchers planned to use paired t tests or McNemar chi-square analyses as appropriate for the level of data, the sample sizes did not permit this quantitative analytic plan. Descriptive statistics were used to describe the outcomes of this pilot study.

## Results

### Sample Information

Thirty-six women aged 50–81 ( $\bar{X}$  = 60.2, SD = 6.48) participated in the program. The majority were Caucasian (86%), single (61%), living in urban areas (67%), employed (56%) and educated beyond high school ( $\bar{X}$  = 15.47 years; SD = 2.90, range = 9–21). Eleven percent (n = 4) did not have any health insurance and were not covered by Medicaid or Medicare. Most (60%) of the women reported incomes of less than

\$30,000 per year. Most (72%) had a family history of cancer, and 17% (n = 6) had a personal history of cancer. Twenty-two women (61%) completed the follow-up portion of the study. Table 2 contains a comparison of demographic information by study completion. No significant differences were found between the two groups. Information is not available for the women who chose not to participate in the study. The sample sizes varied by question because of missing data.

## Breast Cancer Screening

All of the women had obtained a mammogram sometime during their lifetimes. However, six women (27%) had not received one in two years or more. The authors constructed a completion ratio of total mammograms obtained to an estimate of best practice (mammograms yearly when older than 50). On average, these six women had only 29% of the mammograms that they should have experienced during their lifetime, whereas the women who had a recent mammogram had a completion ratio of more than 80% (t = 2.81, p = 0.011). Therefore, these six women are the focus of a more detailed analysis of their breast health practices and a marker for the worth of the program in supporting positive breast

**Table 2. Demographic Characteristics of Participants by Follow-Up Status**

Characteristic	Completed Study (n = 22)		Lost to Follow-Up (n = 14)		t	p
	$\bar{X}$	SD	$\bar{X}$	SD		
Age (years)	59.0	4.5	62.0	8.6	1.25	0.228
Education (years)	15.1	2.7	16.1	3.2	1.11	0.275
Characteristic	n	%	n	%	$\chi^2$	p
<b>Ethnicity</b>					0.302	0.357
Caucasian	20	91	11	86		
Other	2	9	3	14		
<b>Area lived</b>					0.097	1.000
Urban	16	73	8	62		
Suburban	6	27	5	38		
<b>Relationship status</b>					1.226	0.175
Partnered	10	45	3	21		
Other	11	55	11	79		
<b>Employment</b>					0.094	0.954
Employed	12	55	8	57		
Retired	6	27	4	29		
Other	4	18	2	14		
<b>Personal income</b>					0.000	1.000
< \$20,000	10	53	7	58		
\$20,000+	9	47	5	41		
<b>Health insurance</b>					0.004	1.000
Yes	19	86	13	93		
No	3	14	1	7		
<b>Individual history of cancer</b>					0.584	0.370
Yes	5	23	1	7		
No	17	77	13	93		
<b>Family history of cancer</b>					0.218	1.000
Yes	17	77	9	64		
No	5	23	5	36		

Note. Missing data exist for some variables.

**Table 3. Breast Cancer Screening Behaviors for At-Risk Lesbians**

Age	Family History	Insurance	Years Since Last Mammogram	Postintervention Mammogram	Clinical Breast Examination (CBE)	Post-Intervention CBE	Breast Self-Examination (BSE)	Postintervention BSE
54	No	Yes	6	No	Yearly	Yes	> Monthly	Monthly
55	No	No	7	No	Yearly	No	> Monthly	Monthly
58	No	Yes	2	Yes	Yearly	No	Monthly	Monthly
59	No	Yes	7	No	> Yearly	No	> Monthly	> Monthly
63	Not known	Yes	2	No	> Yearly	No	Monthly	Monthly
65	No	Yes	5	Yes	Yearly	No	> Monthly	> Monthly

care screening. Table 3 indicates that, after the intervention, one-third of these women received mammograms and half began performing monthly BSE.

### Gynecologic Cancer Screening

All of the women experienced a pelvic examination some time during their lifetime. However, four women (18%) had not had one for three years or more. Therefore, these four women are the focus of a more detailed analysis of their gynecologic health practices and a marker for the worth of the program in supporting positive gynecologic care screening. After the intervention, one woman, whose sister had ovarian cancer, obtained a pelvic examination (see Table 4). Prior to the intervention, she “just could not make [herself] do it.”

### Colorectal Cancer Screening

Of the 22 women, 12 (55%) were up-to-date with their colorectal cancer screening, having had a recent sigmoidoscopy or colonoscopy. Of those 12 women, two stated that they would never have another because of the pain associated with the procedure. The 10 women who had no recent screening for colorectal cancer were the focus of a more detailed analysis of their colorectal health practices. After the intervention, only one of the women obtained screening (see Table 5). The women described three major barriers to screening: (a) lack of money, (b) fear of the pain, and (c) their healthcare provider did not arrange for the test.

## Discussion

In the United States, for most of the 20th century, minority members of society were observed to have had poorer health outcomes than Caucasian, heterosexual, married men. For most of that century, an unchallenged assumption existed that the blame for those less-than-optimal outcomes somehow was located with the minority population. In recent years, the biases inherent in science and in healthcare delivery systems have been exposed, particularly related to racial, ethnic, and cultural differences. However, differences related to sexual

minority status have not been as explicated. In fact, differences among sexual minorities in health beliefs, health behaviors, health outcomes, and experiences with the healthcare industry largely are unexplored. This is the first intervention study examining the impact a lesbian-targeted educational program made to address the cancer-screening behaviors of lesbians.

In this pilot study, some of these challenging-to-reach women changed their behavior in a very short period of time. The success of this pilot program suggests that a future randomized control trial of this intervention should be conducted in the sometimes-hidden population of lesbians older than 50. As is the case with all minority groups, future success may depend on the way in which programs are created and introduced. For women who may put off health care for fear of having their sexual orientation discovered and recorded or because they have found hostility within the healthcare system as a result of their sexual orientation, the use of specialized educational programs is vital. For this minority group, simply identifying the women who comprise it is not enough; healthcare professionals, researchers, and educators must understand that some women belonging to this sexual minority may fear exposure. Many lesbians in this age group have encountered hostility from healthcare professionals and, thus, are reluctant to seek health care. In addition, many of the screening programs do not have culturally appropriate materials designed to appeal to women who are intimate with other women.

### Strengths and Limitations

The intervention occurred in two lesbian, gay, bisexual, and transgendered senior centers by a lesbian physician and was designed to protect the confidentiality of the participants; yet, almost 20% of the women refused to participate in follow-up interviews because of the perceived lack of anonymity. This study was conducted in the San Francisco Bay Area, supposedly a “safe” place for nonheterosexuals; what the rate of refusal would have been elsewhere only can be speculated. This finding may shed some light on the low numbers of lesbians responding to other large, national studies.

**Table 4. Gynecologic Cancer Screening Behaviors for At-Risk Lesbians**

Age	Family History	Insurance	Hysterectomy	Years Since Last Pelvic Examination	Reason for Delay	Postintervention Pelvic Examination
58	No	Yes	No	13	Don't like	No
59	No	Yes	No	5	Disabled—self-care issues	No
63	Not known	Yes	No	3	Plan every 5 years	No
66	Yes	Yes	No	8	Don't like	Yes

**Table 5. Colorectal Cancer Screening Behaviors for At-Risk Lesbians**

Age	Family History	Insurance	Occult Blood Test	Colonoscopy	Postintervention Colonoscopy	Postintervention Sigmoidoscopy	Comments
53	No	Yes	2 years	No	No	No	I will have the colonoscopy in the next six months.
54	No	Yes	Never	No	No	Yes, 7 years ago	Decided to have sigmoidoscopy because of increased risk of perforation
55	No	No	> 5 years	No	No	No	Afraid of the pain
57	No	Yes	1.5 years	No	No	Yes, 8 years ago	Will not have because of pain with first sigmoidoscopy
57	No	Yes	Never	No	No	No	Afraid it will hurt
59	No	No	6 months	No	No	No	Too invasive, afraid of pain, no money
59	No	Yes	> 5 years	No	No	No	Fear of physicians and treatment
60	No	No	1.5 years	No	No	No	I do not have the money.
63	No	Yes	2 years	No	No	Yes, 26 years ago	Healthcare provider did not arrange
63	Not known	Yes	3 years	Yes, 13 years ago	No	Yes, 8 years ago	Afraid it will hurt

The time interval for the study was too short. Some women in the study stated that they were on a waiting list for colon cancer screening, and others were planning on obtaining a mammogram. Whether these women were just trying to please the investigators was not clear. Future studies should follow women for at least two years to determine the actual value of the intervention. Researchers also should use self-report plus medical record confirmation to verify that the women actually have a record of a clinical breast examination, mammogram, sigmoidoscopy, or colonoscopy. The authors also wondered whether a one-time intervention is enough or whether a “screening coach” or some other ongoing reminder system are needed.

Although this was a community-based sample, very few lesbians of color were represented in this study. In fact, the sample size for this pilot study was quite small, which may lead to unbalanced numbers in potential covariates and thus erroneous findings. The next step is a randomized clinical trial of this intervention, which should have a sample size large enough to answer the research question, diversity among the participants, and multiple sites throughout the country to increase the generalizability of the findings. In addition, qualitative studies are necessary to understand more about the

meanings and barriers of the various cancer screening behaviors among lesbians and other sexual minority women.

## Conclusion

The intervention for this study was a culturally sensitive program by a culturally competent provider. The success of this program in increasing cancer screening among lesbians older than 50 suggests that a minority-specific intervention can increase positive health behaviors such as screening for cancer. As research into the health concerns of lesbians increases in size and scope, so must the health care of the women who make up sexual minorities become more culturally competent. That the health or health care of women is compromised by any minority status is universally unacceptable.

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## References

- American Cancer Society. (2001). *Prevention and early detection*. Retrieved November 1, 2001, from [http://www.cancer.org/docroot/PED/ped\\_0.asp](http://www.cancer.org/docroot/PED/ped_0.asp)
- Cochran, S.D., Mays, V.M., Bowen, D., Gage, S., Bybee, D., Roberts, S.J., et al. (2001). Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *American Journal of Public Health, 91*, 591–597.
- Davis, N.A., Nash, E., Bailey, C., Lewis, M.J., Rimer, B.K., & Koplan, J.P. (1997). Evaluation of three methods for improving mammography rates in a managed care plan. *American Journal of Preventive Medicine, 13*, 298–302.
- Denenberg, R. (1995). Report on lesbian health. *Women's Health International, 5*(2), 81–91.
- Diamant, A.L., Wold, C., Spritzer, K., & Gelberg, L. (2000). Health behaviors, health status, and access to and use of health care: A population-based study of lesbian, bisexual, and heterosexual women. *Archives of Family Medicine, 9*, 1043–1051.
- Dibble, S., Roberts, S.A., Robertson, P.A., & Paul, S.M. (2002). Risk factors for ovarian cancer: Lesbian and heterosexual women. *Oncology Nursing Forum, 29*, E1–E7. Retrieved January 18, 2002, from [http://www.ons.org/images/](http://www.ons.org/images/Library/ons_publications/onf/2002/January_February_2002/E1-E7.pdf)
- Library/ons\_publications/onf/2002/January\_February\_2002/E1-E7.pdf
- Dibble, S.L., Roberts, S.A., Davids, H.R., Paul, S.M., & Scanlon, J.L. (1999). A comparison of breast cancer risk factor distributions between lesbian and bisexual women. *Medical Student JAMA*. Retrieved October 7, 1999, from [http://www.ama-assn.org/sci-pubs/msjama/articles/vol\\_282/no\\_13/cancer.htm](http://www.ama-assn.org/sci-pubs/msjama/articles/vol_282/no_13/cancer.htm)
- Erwin, D.O., Spatz, T.S., Stotts, R.C., & Hollenberg, J.A. (1999). Increasing mammography practice by African American women. *Cancer Practice, 7*, 78–85.
- Erwin, D.O., Spatz, T.S., Stotts, R.C., Hollenberg, J.A., & Deloney, L.A. (1996). Increasing mammography and breast self-examination in African American women using the Witness Project model. *Journal of Cancer Education, 11*, 210–215.
- Fernandez, M.E., DeBor, M., Candreia, M.J., Wagner, A.K., & Stewart, K.R. (1999). Evaluation of ENCORE plus. A community-based breast and cervical cancer screening program. *American Journal of Preventive Medicine, 16*(Suppl. 3), 35–49.
- Foley, E.C., D'Amico, F., & Merenstein, J.H. (1995). Five-year follow-up of a nurse-initiated intervention to improve mammography recommendation. *Journal of the American Board of Family Practice, 8*, 452–456.



- Giles, J.T., Kennedy, D.T., Dunn, E.C., Wallace, W.L., Meadows, S.L., & Cafiero, A.C. (2001). Results of a community pharmacy-based breast cancer risk-assessment and education program. *Pharmacotherapy*, 21, 243–253.
- Herman, C.J., Speroff, T., & Cebul, R.D. (1995). Improving compliance with breast cancer screening in older women. Results of a randomized controlled trial. *Archives of Internal Medicine*, 155, 717–722.
- Hiatt, R.A., Pasick, R.J., Stewart, S., Bloom, J., Davis, P., Gardiner, P., et al. (2001). Community-based cancer screening for underserved women: Design and baseline findings from the Breast and Cervical Cancer Intervention Study. *Preventive Medicine*, 33, 190–203.
- Jemal, A., Murray, T., Samuels, A., Ghafoor, A., Ward, E., Thun, M.J. (2003). Cancer statistics, 2003. *CA: A Cancer Journal for Clinicians*, 53, 5–26.
- Johnson, S.R., Smith, E.M., & Guenther, S.M. (1994). Comparison of gynecologic health care problems between lesbians and bisexual women: A survey of 2,345 women. *Journal of Reproductive Medicine*, 32, 805–811.
- Kernohan, E.E. (1996). Evaluation of a pilot study for breast and cervical cancer screening with Bradford's minority ethnic women: A community development approach, 1991–93. *British Journal of Cancer*, 29(Suppl.), S42–S46.
- Koh, A. (2000). Use of preventive health behaviors by lesbian, bisexual, and heterosexual women: Questionnaire survey. *Western Journal of Medicine*, 172, 379–384.
- Laumann, E.O., Gagnon, J.H., Michael, R.T., & Michaels, S. (1994). *The social organization of sexuality: Sexual practices in the United States*. Chicago: University of Chicago Press.
- Lauver, D.R., Karon, S.L., & Egan, J. (1999). Understanding lesbians' mammography utilization. *Women's Health Issues*, 9, 264–274.
- Marcus, A.C., Crane, L.A., Kaplan, C.P., Reading, A.E., Savage, E., Gunning, J., et al. (1992). Improving adherence to screening follow-up among women with abnormal Pap smears: Results from a large clinic-based trial of three intervention strategies. *Medical Care*, 30, 216–230.
- McDermott, R.J., & Marty, P.J. (1984). Seeking an effective strategy for promoting breast self-examination among women. *Patient Education and Counseling*, 6, 116–121.
- McPhee, S.J., Bird, J.A., Jenkins, C.N., & Fordham, D. (1989). Promoting cancer screening. A randomized, controlled trial of three interventions. *Archives of Internal Medicine*, 149, 1866–1872.
- Navarro, A.M., Senn, K.L., McNicholas, L.J., Kaplan, R.M., Roppe, B., & Campo, M.C. (1998). Por La Vida model intervention enhances use of cancer screening tests among Latinas. *American Journal of Preventive Medicine*, 15, 32–41.
- Nguyen, T., Vo, P.H., McPhee, S.J., & Jenkins, C.N.H. (2001). Promoting early detection of breast cancer among Vietnamese-American women: Results of a controlled trial. *Cancer*, 91(Suppl. 1), 267–273.
- Norman, A.D., Perry, M.J., Stevenson, L.Y., Kelly, J.A., & Roffman, R.A. (1996). Lesbian and bisexual women in small cities—At risk for HIV? HIV prevention community collaborative. *Public Health Reports*, 111, 347–352.
- Pignone, M., Harris, R., & Kinsinger, L. (2000). Videotape-based decision aid for colon cancer screening: A randomized, controlled trial. *Annals of Internal Medicine*, 133, 761–769.
- Rankow, E.J. (1995). Breast and cervical cancer among lesbians. *Women's Health International*, 5, 123–129.
- Rankow, E.J., & Tessaro, I. (1998a). Cervical cancer risk and Papanicolaou screening in a sample of lesbian and bisexual women. *Journal of Family Practice*, 47, 139–143.
- Rankow, E.J., & Tessaro, I. (1998b). Mammography and risk factors for breast cancer in lesbian and bisexual women. *American Journal of Health Behaviors*, 22, 403–410.
- Roberts, S.A., Dibble, S.L., Scanlon, J., Paul, S., & Davids, H.R. (1998). Differences in risk factors for breast cancer: Lesbians and heterosexual women. *Journal of the Gay and Lesbian Medical Association*, 2(3), 93–101.
- Rothman, A.J., Salovey, P., Turvey, C., & Fishkin, S.A. (1993). Attributions of responsibility and persuasion: Increasing mammography utilization among women over forty with an internally-oriented message. *Health Psychology*, 12(1), 37–45.
- Segnan, N., Senore, C., Giordano, L., Ponti, A., & Ronco, G. (1998). Promoting participation in a population screening program for breast and cervical cancer: A randomized trial of different invitation strategies. *Tumori*, 84, 348–353.
- Sell, R.L. (1997). Defining and measuring sexual orientation: A review. *Archives of Sexual Behavior*, 26, 643–58.
- Simon, M.S., Gimotty, P.A., Moncrease, A., Dews, P., & Burack, R.C. (2001). The effect of patient reminders on the use of screening mammography in an urban health department primary care setting. *Breast Cancer Research and Treatment*, 65(1), 63–70.
- Skinner, C.S., Strecher, V.J., & Hoppers, H. (1994). Physicians' recommendations for mammography: Do tailored messages make a difference? *American Journal of Public Health*, 84, 43–49.
- Smith, E.M., Johnson, S.R., & Guenther, S.M. (1985). Health care attitudes and experiences during gynecologic care among lesbians and bisexuals. *American Journal of Public Health*, 75, 1085–1087.
- Solarz, A.L. (Ed.). (1999). *Lesbian health: Current assessment and directions for the future*. Washington, DC: National Academy Press.
- Street, R.L., Jr., Van Order, A., Bramson, R., & Manning, T. (1998). Preconsultation education promoting breast cancer screening: Does the choice of media make a difference? *Journal of Cancer Education*, 13, 152–161.
- Suarez, L., Roche, R.A., Pulley, L.V., Weiss, N.S., Goldman, D., & Simpson, D.M. (1997). Why a peer intervention program for Mexican-American women failed to modify the secular trend in cancer screening. *American Journal of Preventive Medicine*, 13, 411–417.
- Taylor, V., Thompson, B., Lessler, D., Yasui, Y., Montano, D., Johnson, K.M., et al. (1999). A clinic-based mammography intervention targeting inner-city women. *Journal of General Internal Medicine*, 14, 104–111.
- Thompson, R.S., Michnich, M.E., Gray, J., Friedlander, L., & Gilson, B. (1986). Maximizing compliance with hemocult screening for colon cancer practice. *Medical Care*, 24, 904–914.
- Tucker, N., Highleyman, L., & Kaplan, R. (Eds.). (1995). *Bisexual politics: Theories, queries, and visions*. Binghamton, NY: Haworth Press.
- U.S. Preventive Health Services Task Force. (2001). *Reviews and recommendations: Screening*. Retrieved November 1, 2001, from <http://www.ahrp.gov/clinic/uspstfix.htm>
- Valanis, B.G., Bowen, D.J., Bassford, T., Whitlock, E., Charney, P., & Carter, R.A. (2000). Sexual orientation and health: Comparisons in the Women's Health Initiative sample. *Archives of Family Medicine*, 9, 843–853.
- Valanis, B.G., Glasgow, R.E., Mullooly, J., Vogt, T.M., Whitlock, E.P., Boles, S.M., et al. (2002). Screening HMO women overdue for both mammograms and Pap tests. *Preventive Medicine*, 34, 40–50.
- Weber, B.E., & Reilly, B.M. (1997). Enhancing mammography use in the inner city: A randomized trial of intensive case management. *Archives of Internal Medicine*, 157, 2345–2349.
- White, J., & Dull, V. (1997). Health risk factors and health-seeking behavior in lesbians. *Journal of Women's Health*, 6, 103–112.
- White, J., & Levinson, W. (1995). Lesbian health care: What a primary care physician needs to know. *Western Journal of Medicine*, 162, 463–466. 

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[www.glma.org](http://www.glma.org)
- ▶ MEDLINEplus: Gay and Lesbian Health  
[www.nlm.nih.gov/medlineplus/gaylesbianhealth.html](http://www.nlm.nih.gov/medlineplus/gaylesbianhealth.html)
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