

Lesbians and Breast Cancer: A review of referred literature

Introduction

Some researchers and health professionals hypothesize that lesbians are at greater risk for breast cancer than heterosexual women. The hypothesis is based upon the idea that lesbians have higher prevalence rates of certain risk factors for breast cancer. The Safeguards Project and LGBT Health Resource Center conducted this review of referred literature to understand and represent the quantity and quality of research that exists on the subject of breast cancer among lesbians. Research studies are analyzed and their major findings are summarized along with an examination of methodology of each study. The most significant aspect of the review is that it highlights the lack of published research on health issues of lesbian women.

Lack of information on health issues of sexual minorities has been a cause of concern among health professionals for a number of years. Realizing the need for more information, the American Medical Association [AMA], as far back as 1996, encouraged "...research to identify the unique health care issues of gay men and lesbians in order to improve diagnosis and treatment" (JAMA. 1996). Apparently, absence of epidemiological data is a result of not recording information on sexual orientation on national level, a fact underlined by the CDC's Healthy People 2010 LGBT Companion Document that relates that currently none of the "...Federal health surveys incorporate sexual orientation or gender identity as a demographic or population variable in relevant data collection."

Review Methods

Searches were conducted on electronic databases to collect research literature on the subject. Databases used include *MEDLINE*, *PsychINFO*, *CINAHL*, *Social Science and Medicine*, *ISI*, *Sociology of Health and Wellness*, *CDSR/ACP* and *Cancer Lit*. A search of CDC databases and Google.com was also carried out. The literature search was conducted using the phrase "lesbians and breast cancer." The word "lesbian" was expanded to include homosexuality while "breast cancer" was expanded to include breast neoplasm when available. These terms were combined in all databases. An attempt was made to expand the terms further, for example, breast neoplasm was expanded to breast self-examination (BSE) but did not produce additional articles. In all, 32 articles were found. The original articles were examined for relevance to the following themes:

- Epidemiology including prevalence and incidence, risk factors, and patterns of occurrence among lesbians
- Psychosocial impact as it relates to lesbian identity
- Preventive care and community prevention interventions in lesbian communities
- Clinical care and health outcome for lesbians

Twenty-two articles were included in this review. Articles excluded from this review were articles that were editorial or narrative in nature or those that did not specifically utilize both "lesbian" and "breast cancer" together.

The articles reviewed can be categorized as follows:

- 1) Epidemiology and risk behavior (five articles)
- 2) Utilization of prevention services such as Breast Self Examination (BSE) or mammography (seven articles)
- 3) Provider-specific research (three articles)
- 4) Psycho-social issues (five articles)
- 5) Genetics (two articles).

Review by category

Epidemiology and risk behavior

The five articles covered under this category include

1. "Health Care Needs of Gay Men and Lesbians in the United States: Healthy People 2010 and the AMA council report." (Journal of American Medical Association [JAMA], 1996).
2. "Cancer-Related Risk Indicators and Preventive Screening Behaviors Among Lesbians and Bisexual Women." (Cochran et al., 2001).
3. "Lesbians Are More Likely Than US Women Overall to Have Risk Factors for Gynecologic and Breast Cancer." (Rosenberg, J., 2001).
4. "The Influence of Sexual Orientation on Health Behaviors in Women." Powers, B., Bowen, D& White, J. 2001)
5. "Breast and Cervical Cancer Among Lesbians." (Rankow, E., 1995).

Healthy People 2010 and the AMA call for a reduction in breast cancer deaths for all women and recommend identification of health needs specific to LGBT populations and programs to assist both providers and consumers in creating better access to services. Susan Cochran and her colleagues provide the best information to date through an analysis of research involving a convenience and snowball sample of 11,876 lesbian or bisexual women. The analysis is focused on behavioral risk factors and access to health care. Seven regional lesbian health surveys conducted between 1987 and 1996 were pooled and analyzed. The data indicates that lesbian/bisexual women show higher prevalence rates of obesity, tobacco and alcohol use. Lesbian/Bisexual women also demonstrate lower rates of nulliparity, a condition that some researchers consider a risk factor for breast cancer. Rosenberg, meanwhile, reviews the Cochran analysis and calls for the development of culturally competent interventions for cancer prevention among lesbian women. Powers, Bowen and White used public announcements to recruit 829 women measured for sexual orientation and outcomes related to use of preventive measures. The study results indicate that lesbian women utilize preventive measures (BSE and Pap Smear) at lower rates than women in the general population do.

Utilization of prevention services:

The seven articles that fall under this category include:

1. "Health Related Behaviors and Cancer Screening of Lesbians: Results from the Boston Lesbian Health Project." (Roberts, S. & Sorensen, L., 1999)



2. "Understanding Lesbians' Healthcare Behavior: the Case of Breast Self-Examination." (Fish, J. & Wilkinson, S., 2003).
3. "Patterns of Breast Cancer Screening among Lesbians at Increased Risk for Breast Cancer." (Burnett, C., Steakley, C., Slack, R., Roth J & Lerman, C., 1999).
4. "Understanding Lesbians' Mammography Utilization." (Lauver et al, 1999).
5. "Receipt of Preventive Healthcare Services by Lesbians." (Diamant, A., Schuster, M. & Lever, J., 2000).
6. "Breast Self-examination, the Health Belief Model, and Sexual Orientation in Women," (Ellingson, L. & Yarber, W., 1997).
7. "Lesbian Health Issues for the Primary Care Provider." (Rankow, E., 1995).

1. Roberts and Sorensen utilize a subset of questions from the Boston Lesbian Health Project, one of the seven regional surveys used by Cochran et al in their analysis (listed in the previous topic section). Roberts and Sorensen mailed 5,000 questionnaires to Community Based Organizations and LGBT bookstores, of which, 1,633 were returned. Their sample was young (more than 53% were 17-34 years of age), mostly White (78.1%) and they included Jewish as a racial/ethnic category (10.1%). Their data indicates that lesbian women utilize prevention services.

2. Fish and Wilkinson report on a national study conducted in the UK. The authors do not explain how the surveys were administered. What they do relate is that the survey was largely quantitative but allowed for the collection of a subset of qualitative data. From the quantitative data, Fish and Wilkinson report that 20% of lesbian women in the UK never practice BSE. The qualitative data attempts to provide an insight into the factors for this behavior. One of the reasons that is discussed in this study is the prevalence among lesbians of the notion that it is the partner's responsibility to perform BSE.

3. Burnett et al used telephone interviews with 139 self-reported as lesbian women who had a first-degree relative with a diagnosis of breast cancer. The authors do not report how the sample was selected but state that the sample was young (mean age 43), white (94%) and educated (78% with a college degree). Sixty eight per cent of these women were in a long-term relationship. Eighty per cent of these women had never been pregnant (a possible risk factor for breast cancer), 64% currently used alcohol, and 38% were obese (defined by a BMI >27). Only 29% reported adherence to prevention screening guidelines (BSE and Pap Smear).

4. Lauver et al also used telephone interviews with 107 older lesbians (51-80 years of age). Participants were recruited through targeted outreach at gay-specific events, ads in lesbian publications and snowball techniques. Thirty six per cent of their sample of lesbian women had not under gone mammography in the past year. Barriers to prevention services included homophobia, practitioner discrimination, cost and lack of social support.

5. Diamont et al printed a health care utilization questionnaire in a national LGBT publication mailed to all 50 states and received 6,935 responses. The respondents were mostly white (88%) and educated (41% had attended graduate school). Out of 401 women aged 50 years or more, 280 (70%) received mammograms within the past year. However, there was no discussion of BSE. Sixty three per cent of respondents reported current alcohol use and 27% were currently using tobacco.



6. Ellingson and Yarber investigated relationships among sexual orientation in women, BSE practice and the Health Belief Model (HBM). The women were recruited using snowball-sampling techniques. The Champion Health Belief Scale was administered to 303 women over 35 years of age, with nearly equal samples of heterosexual and lesbian women. Of the study participants, heterosexual women were older and less educated than lesbians, and more likely to follow guidelines for BSE. The authors suggest that BSE practice may have a stronger association with sexual orientation than with either age or education.

7. Rankow provides a review of current literature and reiterates the notion that many lesbian women do not follow recommended guidelines for BSE.

Provider-Specific Research

The three articles in this category include:

1. "Lesbian Health Issues for the Primary Care Provide," (Rankow, E., 1995)
2. "A Comparison of Breast Cancer Diagnosis and Treatment Between Lesbian and heterosexual Women," (Dibble, S. & Roberts, S., 2002)
3. "Optimal Gynecologic and Obstetric Care for Lesbians," (Carroll, N., 1999).

1. Rankow reports on currently available data citing the unique health concerns particular to lesbian women. Citing risk factors such as nulliparity, excessive alcohol and tobacco use, provider homophobia and the notion that lesbians do not use preventive services to the degree that heterosexual women do, Rankow urges providers to educate themselves on the needs of this population and improve access to services and care.

2. Dibble and Roberts report on an observational study established through convenience-sampling techniques by getting respondent from another unidentified survey. The authors submitted a 58-question survey to the respondents (n=80, with heterosexual n=30; lesbian n=50). The women in this study had a previous cancer diagnosis, were mostly white (95% of heterosexual women and 94% of lesbians) and the lesbian cohort had a higher education and income level. There were no significant differences in the two populations except that lesbian women reported a greater incidence of side effects from chemotherapy than the heterosexual women (p< .006).

3. Carroll discusses available data on lesbian women with a focus on the lack of awareness by providers of the health issues experienced by lesbians.

Coverage of psycho-social issues

Five articles dealing with psychosocial issues include

1. "National Lesbian Health Care Survey: Implications for Mental Health," (Bradford, Ryan & Rothblum, 1994).
2. "Comparison of Lesbian and Heterosexual Women's Response to Newly Diagnosed Breast Cancer," (Fobair et al, 2000)
3. "A Qualitative Exploration of the Experiences of Lesbian and Heterosexual Patients with Breast Cancer," (Matthews et al, 2002)
4. "Distress and Internalized Homophobia among Lesbian Women Treated for Early Stage Breast Cancer," (McGregor et al, 2001)
5. "Psychosocial Interventions for Lesbians with Primary Breast Cancer," (Fobair et al, 2002).

1. Bradford, Ryan and Rothblum present results from 1984 National Lesbian Health Care Survey (n=1,925). To gather the data, 4,600 surveys were distributed but the sampling method is not discussed. The respondents were mostly 25-44 years of age (80%), white (88.2%), and educated (69% with college degrees). The Authors report that 37% of lesbians had been sexually abused as children, 33% used tobacco daily, 30% used alcohol daily and nearly 75% had received professional counseling.
2. Fobair et al compared data between lesbian women (n=29) and heterosexual women (n=246) with breast cancer. The heterosexual subjects were recruited through two different intervention studies while the lesbian cohort was solicited through flyers, brochures, newspaper articles and advertisements. Inclusion criteria were diagnosis within the past year confirmed by biopsy, completion of surgical treatment and current status of “no detectable disease”. The authors used measures of emotional distress from the Profile of Mood Stress (POMS) and evaluated subjects for emotional support. Subjects were also measured for an assessment of body image. Assessments predict that lesbians suffer fewer problems with body image than heterosexual women and are more likely to gain emotional support from friends and partners versus familial support. In addition, lesbians reported a poorer perception of the medical care system and greater dissatisfaction with medical care than heterosexual women.
3. Mathew et al conducted a qualitative study (focus groups) through a convenience sample of lesbians (n=13) and heterosexual women (n=28). The authors explored coping mechanisms in breast cancer survivors. Their findings mirror that of Fobair et al in that lesbians report lower satisfaction with care received from physicians and the availability of emotional support outside friends and partners, including support groups for lesbian cancer survivors. Again, the lesbian participants were white (n=11), all had college degrees and more than 50% earned more than \$50,000 per year.
4. McGregor et al recruited lesbian respondents (n=57) through advertisements and flyers. Of this sample, 53 were white, 37 had partners and the mean length of education was 16.7 years. Five women were breast cancer survivors. The participants were measured for health care utilization, mood states, symptoms of depression, social support, disclosure of sexual orientation and internalized homophobia. The data indicated an association between internalized homophobia and psychological distress but did not find evidence of an association between distress and disclosure of sexual orientation.
5. Fobair et al examined the effects of group therapy for lesbians (n=20) with early-stage breast cancer. Participants were recruited through flyers and brochures, advertisements and newspaper articles. This particular cohort had a mean age of 47; the members were highly educated (60% with post-graduate education), white and professional. Sixty seven per cent of the women had partners. The women participated in Supportive-Expressive group therapy and were assessed at baseline, three, six and 12 months. The authors report significant but unexpected changes in social support. Instrumental and informational support declined as did conflict in family relations. Meanwhile trends were found towards more cohesiveness and expressiveness.

Genetics

The two articles related to genetics include:

1. “Attitudes and Interest in Genetic Testing for Breast and Ovarian Cancer Susceptibility in Diverse Groups of Women in Western Washington,” (Durfy et al, 1999)

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2. “Comparisons of Two Breast Cancer Risk Estimates in Women with a Family History of Breast Cancer,” (McTiernan et al, 2001).

1. Durfy et al recruited women (n=537) with family histories of breast cancer through straight and gay mass media advertisement. Eligibility was confirmed through telephone interviews. Their sample was 18-74 years of age and from within 60 miles of the research center. Interestingly, the sample was divided by race/ethnicity and sexual orientation, with lesbians as a group (n=76), African Americans as a group (n=36), Ashkenazi Jewish as a group (n=116) and a control group (n=309) that was 93% white. The demographics for all groups included sexual orientation, but only the lesbian group had n=0 for heterosexual orientation. All other groups had some homosexual and bisexual women included. Since the focus of the study was genetic testing, of interest here is that all groups expressed favoring ready access to testing.

2. McTiernan et al use this study to focus on the need to counsel all women with family histories on genetic testing using the Gail and Claus model risk estimates for breast cancer.

Evaluation of data

Research that was examined in this literature review cannot be generalized to all lesbians with great authenticity for a number of reasons. The majority of available research summarized here is self-limiting due to the methodology of data collection. Most of these studies did not use were randomized sampling. Much of the data is a result of convenience and snowball sampling and cannot be generalized to all lesbians. Most of the studies have small number of participants. Finding and reporting on special or hidden populations in a randomized fashion is problematic at best. The majority of lesbian women reported on are white, educated and professional, and not representative of lesbians as a unique population. There is a need for further research to identify issues unique to lesbians belonging to other racial/ethnic and socioeconomic groups. Some of the qualitative data raises certain hypotheses, but no follow-up data has been reported. The absence of sound epidemiological data is obvious. The efforts of Cochran and her colleagues to combine and analyze the epidemiological data gathered from independent/regional surveys provide the best possible picture at this time. Much of what has been reported by Cochran et al is supported in the other studies examined here.

The reviewed research highlights some key issues:

- Lesbians may use alcohol and tobacco at rates higher than women in the general population. Both factors have some association with cancer risk.
- Lesbians may have higher rates of obesity. The relationship of obesity to breast cancer has not been demonstrated, but this is an overall risk factor for various health problems. At the same time, lesbian perception of body image does not follow national trends. Lesbians may have a tendency of not perceiving themselves as obese even if they can be categorized as such by scientific standards.
- As expected, rates of nulliparity are high among lesbian populations. Some researchers consider nulliparity as a risk factor for breast cancer but a complete agreement among medical researchers and professionals on the issue does not exist.
- Lesbians may not utilize health care services to the same degree as women of the general population. A number of reasons may cause these low utilization trends including homophobia (both external and internal) and discrimination by providers. In addition, most medical insurance providers do not



recognize lesbian partnerships and cost of services may be an additional factor for low rates of use of healthcare services among lesbians.

- Lesbians may not practice BSE or undergo mammography at the same rate women of the general population do. There may be a number of reasons for this trend. Homophobia and discrimination may be the key factors. Additionally, some lesbian women may believe that their partner should perform BSE. Some lesbians may believe that they would notice if something were wrong.
- The sources and mechanisms of emotional and social support available to lesbian women may differ from the support available to other women. Lesbians may receive more emotional support from friends and partners rather than from their families. Lesbian women who participated in some of the studies reported here have higher rates of receiving counseling than heterosexual women. Lack of social support through group therapy is evident, although research examined here demonstrates the value of such support.

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