

A Qualitative Exploration of the Experiences of Lesbian and Heterosexual Patients With Breast Cancer

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Purpose/Objectives: To explore similarities and differences between lesbian and heterosexual survivors of breast cancer regarding cancer experiences, medical interactions related to cancer treatment, and quality of life (QOL).

Design: Qualitative study using focus groups.

Setting: Urban, community-based health center.

Sample: A convenience sample of lesbians ($n = 13$) and heterosexual women ($n = 28$) with a diagnosis of breast cancer within the past five years. Participants were recruited via posted advertisements.

Methods: Focus groups were conducted as part of a larger study exploring coping and adjustment in lesbian survivors of breast cancer. Transcribed focus group data were analyzed through thematic and representative case study methods.

Main Research Variables: Broad aspects of medical interactions and the patient-provider relationship that may be associated with improved QOL of lesbian and heterosexual patients with cancer.

Findings: Data suggested similarities between lesbians and heterosexual women in their overall QOL. However, differences did emerge between the groups. Lesbians reported higher stress associated with diagnosis, lower satisfaction with care received from physicians, and a trend toward lower satisfaction with the availability of emotional support.

Conclusions: Study findings have important implications for future research on adjustment and coping among lesbian patients with breast cancer and for the improvement of their mental and physical healthcare services.

Implications for Nursing: Study findings may help improve healthcare services for lesbians with cancer.

Key Points . . .

- The literature suggests that lesbians may face challenges and emotional difficulties after a cancer diagnosis that differ from those experienced by heterosexual women.
- Disclosure of sexual orientation to healthcare providers was a unique decision and concern for lesbian respondents.
- Although breast cancer represents a significant health threat for all women, few systematic attempts have been made to study lesbians with breast cancer.
- Study findings have implications for patients' adjustment to cancer, patient and provider education, and provision of care.

The companion document to "Healthy People 2010" (Gay and Lesbian Medical Association, 2001) highlighted the potential for disparities in health status among lesbians. A number of studies have suggested that lesbians are at increased risk for the development of breast and other types of cancer because of behavioral and lifestyle factors such as higher rates of smoking and alcohol consumption, poor diet, higher body mass index, and null parity (Rankow, 1995; White & Levinson, 1993). Despite the possibility of increased cancer risk among lesbians, a panel of experts cautioned that, in the absence of epidemiologic studies, conclusions about the cancer risk status of lesbians are premature (Solarz, 1999).

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Breast cancer is the second most common cancer in women, with an estimated 203,500 new cases expected to have occurred in U.S. women in 2002 (American Cancer Society, 2002). Although overall breast cancer survival rates are improving, poor, nonwhite, and other underserved populations do not share the positive gains. For example, African American women are less likely to develop breast cancer than Caucasian women, yet they are more likely to die from the disease after diagnosed (Ries et al., 2000).

Although additional studies are needed to determine whether cancer affects lesbians and heterosexual women with similar frequency, the extant literature suggests that lesbians may face challenges and emotional difficulties after a cancer diagnosis that differ from those experienced by heterosexual women (National Gay and Lesbian Task Force, 1993). For example, studies have suggested a number of specific barriers to adequate health care for lesbians, including physician ignorance regarding lesbian health issues (O'Hanlan, 1995; Stevens, 1992), discrimination in healthcare settings (Bradford & Ryan, 1987), decreased access to care (Cassidy & Hughes, 1997), and mistrust of the medical establishment (Trippet & Bain, 1992).

The availability of social support, a factor associated with emotional well-being among patients with cancer, may differ based on sexual orientation. For example, studies suggest that social support is associated with better adjustment and decreased emotional distress among patients with cancer (Maes, Leventhal, & de Ridder, 1996; Wineman, Durand, & Steiner, 1994). However, in general, lesbians who are open about their sexual orientation often experience decreased social support, social stigma from family and friends, loss of financial and occupational resources, and prejudice from society (McGough, 1990). Family members and healthcare providers also may withhold emotional support from partners of lesbian patients (Matthews, 1998). As such, lesbians may be more vulnerable to the adverse psychosocial effects of cancer and, therefore, experience a decrease in quality of life (QOL).

The current preliminary study was conducted as part of a larger investigation of QOL of lesbian and heterosexual survivors of breast cancer. QOL has been defined as "the extent to which one's usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment" (Cella, 1995). Satisfaction with medical treatments (Aaronson, 1988) and the quality of the patient-provider relationship (Lerman et al., 1993) are other important determinants of QOL. Previous studies have suggested that lesbians have less access to health care (Millman, 1993), are subject to bias and discrimination in healthcare settings (Eliason & Raheim, 2000), receive substandard or inadequate treatment (Bradford & Ryan, 1987; Dean et al., 2000), and underutilize needed healthcare services because of perceptions of bias (Millman). Determining the specific applicability of this body of literature to lesbian patients is critical to improving their adjustment to cancer, patient and provider education, and provision of care.

The objectives of this article are to qualitatively describe broad aspects of healthcare interactions and the patient-provider relationship that may be associated with QOL among lesbians and heterosexual women with a history of breast cancer. Qualitative methods, focus groups in this case, typically are used in the exploration of a new area of investigation and generate hypotheses that can be tested with more quantitative methods. As such, the study's aims were to explore the following broad categories associated with receipt of cancer care without any attempt to place findings within a theoretical or conceptual model.

- Attitudes about medical decision making
- Preferences for providers
- Patient-provider relationship
- Disclosure of sexual orientation to providers
- Satisfaction with care
- Use of alternative and complementary therapies
- Cancer supportive services

Information regarding a broad range of issues as they relate to healthcare interactions will provide a foundation for improvement of services and hypothesis development and testing.

Methods

Overview of Focus Group Methodology

Qualitative methods, such as focus groups, are useful tools for investigating new areas of research, designing questionnaires, developing new intervention protocols, and interpreting findings (Denzin & Lincoln, 1994). Because of the paucity of information about the health experiences and behaviors of lesbians with cancer, qualitative methods are useful for discovery and generation of hypotheses (Manfredi, Lacey, Warnecke, & Balch, 1997; Matthews et al., 2000; Matthews, Sellergren, Manfredi, & Williams, 2002; Patton, 1990).

In a focus group, relatively homogeneous groups of participants are brought together to discuss and stimulate each other's ideas on a specific topic. Unlike a sample-based probability survey, the unit of analysis in a focus group is the group, not individuals. As such, the observations drawn from individuals are not independent, nor are the individuals or the group a probability sample from a known population (Goldman & Schwartz-McDonald, 1987; Krueger, 1994). Sample sizes of focus groups vary but typically are small. Specific guidelines for sample size in focus group studies have not been established. Nonetheless, Morse (2000) suggested that 20–40 participants be sought when exploring a new investigational area.

Study Participants

Women were eligible for the study if they were heterosexual or homosexual, diagnosed and treated for breast cancer within five years, 18 or older, and able to give informed consent. Seven focus groups (N = 41) were conducted at a community-based health center. Each group session had four to eight participants: Four of the groups (n = 28) were comprised of heterosexual women, and three of the groups (n = 13) were comprised of homosexual women. Recruitment activities included newspaper advertisements, community- and hospital-based support groups, and flyers posted in medical centers. Efforts were made to recruit diverse samples of lesbians and heterosexual women by posting advertisements in newspapers for African American and Latino women.

Potential subjects who responded to the advertisements were screened by telephone for eligibility. After providing oral consent to participate in the study, eligible subjects received packets containing written confirmation of the focus group time and location, along with self-report questionnaires. Completed questionnaires were collected at the time of the scheduled focus groups.

Procedures

Focus groups were conducted according to standardized methodology established by Krueger (1994) and used a trained moderator to guide the structured discussions, immediate debriefing to summarize and highlight important findings, and careful review of verbatim transcriptions of audiotapes after each session.

After arriving at the community-based health center, participants were oriented to the setting, methodology, and general objectives of the focus group sessions by the group moderator.

Written consent was obtained. The moderator emphasized the voluntary nature of the study and the importance of respecting confidentiality of the group members. The moderator facilitated each focus group session using a study guide that covered the major topic areas related to receipt of cancer care: attitudes about medical decision making, preferences for providers, patient-provider relationship, disclosure of sexual orientation to providers, satisfaction with care, use of alternative and complementary therapies, and cancer supportive services. Sessions were recorded by audiotape and professionally transcribed. Each session lasted about two hours. Each subject was paid \$20 for her participation.

Measures

Study participants completed a self-report survey instrument. **Demographic characteristics** collected included age, race, education, income, insurance coverage, and relationship status. For lesbian participants, disclosure of sexual orientation was measured using the following questions.

- Are you “out” as a lesbian?
- If yes, have you disclosed your sexual orientation to your family?
- Have you disclosed your sexual orientation to your friends?
- Have you disclosed your sexual orientation to your cancer medical providers?

Medical characteristics included cancer stage at diagnosis, age at diagnosis, time since initial diagnosis, recurrence history, treatment received for initial occurrence and subsequent recurrences, and whether the participant currently was receiving treatment for cancer. A one-item index of perceived health was completed (1 = poor to 4 = excellent), which has been demonstrated to be associated with all-cause morbidity and mortality (Gatz, Harris, & Turk-Charles, 1995).

Cancer-related distress was measured by asking patients to rate their levels of emotional functioning for the 30 days prior to completion of the survey (1 = poor to 4 = excellent). Stress associated with cancer diagnosis and treatment and the level of life disruption associated with treatment were measured on a 10-point scale ranging from 1 (not at all true) to 10 (very true).

Level of social support was measured by the **Multidimensional Scale of Perceived Social Support (MPSS)** (Zimet, Dahlem, Zimet, & Gordon, 1988), a 12-item inventory developed to assess perceived social support from family members, friends, and significant others. Higher scores reflect greater perceived social support. The instrument has documented reliability and validity (Zimet et al.). Additionally, tangible social support was measured by two statements: “I had someone to assist me with coping with my illness” and “I had someone to accompany me to my medical appointments”; subjects responded with “yes” or “no.” Respondents also were asked about participation in individual psychotherapy or cancer support groups since initial diagnosis.

Satisfaction with treatment and treatment-related support was assessed by seven items developed for use in this study. The items were rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), measuring satisfaction with

- The information received from medical providers
- Treatment and care received from physician(s)
- Care received from treating nurses
- Emotional support received from medical providers

- Emotional support that spouse or partner received from medical providers
- Inclusion in medical decisions
- Spouse’s or partner’s inclusion in medical decisions.

Data Analysis

Quantitative findings from the study questionnaire are presented as summary statistics (i.e., percentage distributions or means) to provide descriptive information about the focus group participants. Given the study’s aims and size of the sample, the major findings reported are derived from the qualitative methods. For analysis of focus group data, the researchers used thematic analysis and representative case study methods of analysis of transcribed focus group data (Shontz, 1985). Thematic reliability analyses focused on the agreement among participants in each group, consistency of findings across groups, and concordance among the independent assessments of observers.

Results

Demographic Characteristics

Sample characteristics are shown in Table 1. Forty-one patients with breast cancer were recruited from a large mid-western city. The average age of participants was 51 years (range = 36–75). The participants mostly were European American (66%), heterosexual (68%), were married or in long-term relationships (59%), had a college education (93%), were employed outside the home (63%), and had private insurance coverage (66%). Median income range was \$50,000–\$55,000. Eighty-five percent of the lesbians reported that they considered themselves to be “out” as lesbians, with the majority reporting being out to their family (82%) and friends (91%). However, a smaller percentage reported revealing their sexual orientation to their physicians (46%).

Medical Characteristics

Medical characteristics of the sample are summarized in Table 2. The majority of participants had early stage breast cancer (stage I or II) at initial diagnosis (86%). Fifteen percent experienced a recurrence of the disease. Average age at the time of cancer diagnosis was 48 years (range = 31–71) and average time since diagnosis was 3.2 years (SD = 2.3). The majority of participants (90%) received combined treatments, including surgery, chemotherapy, and radiation therapy. Twenty-one participants were being treated for cancer at the time of the study. The majority (80%) of those not currently receiving treatment were seen by their healthcare providers at least every six months. Seventeen percent of respondents reported their health to be “fair to poor” before diagnosis. This percentage increased to 27% of the sample after cancer diagnosis and treatment.

In terms of emotional health during the previous 30 days, similar proportions of lesbians (39%) and heterosexual women (36%) rated their emotional health as “fair to poor.” Although current mean stress levels were equivalent between lesbians and heterosexual women (5.6 and 5.4, respectively), lesbians reported higher mean levels of stress associated with initial diagnosis and treatment than heterosexual women (9.3 versus 7.7, $t(39) = -2.1, p < 0.05$). Although not statistically significant, heterosexual women reported higher mean levels of life disruption associated with medical treatments (7.0 versus 5.4, $t(39) = 1.6, p = 0.11$).

Table 1. Demographic Characteristics

Variable	Heterosexual Women (n = 28)		Lesbians (n = 13)	
	n	%	n	%
Age (years)				
\bar{X} = 51	–	–	–	–
Range = 36–75	–	–	–	–
Race/ethnicity				
African American	11	39	1	8
European American	16	57	11	84
Other	1	4	1	8
Education level				
High school or less	3	11	–	–
Some college or college degree	14	50	8	61
Advanced degree	11	39	5	39
Relationship status				
Single/dating	7	25	5	38
Married/committed relationship	17	61	7	54
Separated/divorced/ widowed	4	14	1	8
Employment status				
Full-time	12	43	7	54
Part-time	5	18	2	15
Disabled	5	18	1	8
Other	6	21	3	23
Annual income				
Less than \$24,000	9	32	1	8
\$24,000–\$50,000	6	21	4	31
More than \$50,000	13	47	8	61
Medical insurance				
None	3	11	2	15
Private	17	61	10	77
Medicare or Medicaid	7	25	1	8

Note. Because of nonresponses, not all n values total 28 and not all percentages total 100.

Social Support

Lesbians and heterosexual women obtained similar scores on the MPSS (4.9 and 5.3, respectively). The majority of lesbians (100%) and heterosexual women (96%) reported having someone to assist them in coping with the illness. However, a higher, but not statistically significant, proportion of lesbians reported having someone available to attend medical appointments with them (69% versus 46%). Statistically equal proportions of lesbians (77%) and heterosexual women (71%) reported participating in a cancer support group since diagnosis. Of the women who reported participating in a cancer support group, heterosexual women were more likely to report current involvement (57% versus 18%, $[1, n = 34] = 4.4, p < 0.05$). Higher proportions of lesbians reported participating in individual psychotherapy since diagnosis (69% versus 39%, $\chi^2 [1, n = 41] = 3.1, p = 0.07$) and that their involvement in therapy was because of their cancer history (69% versus 25%, $\chi^2 [1, n = 41] = 7.2, p < 0.01$).

Medical Interactions

In all areas assessed, heterosexual women reported greater satisfaction with medical interactions. Most notably, satisfaction

with care received from doctors differed by sexual orientation, with heterosexual women reporting significantly more satisfaction (96%) than lesbians (75%) ($\chi^2 [4, n = 39] = 9.1, p < 0.05$).

Other findings were not significant but reflected consistently greater heterosexual satisfaction, including satisfaction with care received by nurses (92% versus 83%), overall emotional support received from medical providers (74% versus 58%), emotional support received by spouses or partners from medical providers (52% versus 33%), inclusion in medical decisions (92% versus 83%), and inclusion of spouses or partners in medical decisions (52% versus 42%) (see Table 3).

Focus Group Results

Key qualitative findings were organized according to the following broad categories associated with receipt of medical services for cancer: attitudes about medical decision making, preferences for providers, patient-provider relationship,

Table 2. Medical Characteristics

Variable	Heterosexual Women (n = 28)		Lesbians (n = 13)	
	n	%	n	%
Mean age at time of diagnosis (years)	48.6		47.1	
Mean time since diagnosis (years)	2.9		3.6	
Cancer stage				
Stage I	14	50	8	62
Stage II	9	32	4	30
Stage III	2	7	–	–
Unknown	3	11	1	8
Cancer therapies				
Surgery alone	3	11	1	8
Surgery and radiation	5	18	6	46
Surgery and chemotherapy	9	32	3	23
Radiation and chemotherapy	1	3	–	–
All three treatments	10	36	3	23
Recurrence of cancer				
Yes	5	18	1	8
Currently undergoing treatment				
Yes	13	46	8	62
Mastectomy				
Yes	17	61	5	39
Breast reconstruction				
Yes	12	71	2	40
Health rating before diagnosis				
Fair to poor	6	21	1	8
Good	14	50	9	69
Excellent	8	29	3	23
Current health rating				
Fair to poor	9	32	2	15
Good	16	57	8	62
Excellent	3	11	3	23

Table 3. Medical Interactions

Variable	Heterosexual Women (n = 28)		Lesbians (n = 13)	
	n	%	n	%
Satisfaction with medical care				
Agree/strongly agree	26	96	9	75
Satisfaction with information received				
Agree	24	89	9	75
Neither agree nor disagree	1	4	1	8
Disagree	2	7	2	17
Satisfaction with care from physicians				
Agree	26	96	9*	75*
Neither agree nor disagree	–	–	2	17
Disagree	1	4	1	8
Satisfaction with care from nurses				
Agree	25	92	10	83
Neither agree nor disagree	1	4	2	17
Disagree	1	4	–	–
Satisfaction with emotional support from providers				
Agree	10	74	7	58
Neither agree nor disagree	4	15	1	8
Disagree	3	11	4	33
Satisfaction with emotional support spouse or partner received				
Agree	14	52	4	33
Neither agree nor disagree	2	7	1	8
Disagree	3	11	–	–
Not applicable	8	30	7	58
Satisfaction with inclusion in medical decisions				
Agree	25	92	10	83
Neither agree nor disagree	1	4	–	–
Disagree	1	4	2	17
Satisfaction with inclusion of spouse or partner in medical decisions				
Agree	14	52	5	42
Neither agree nor disagree	3	11	–	–
Disagree	1	4	–	–
Not applicable	9	33	7	58

* p < 0.05

Note. Because of nonresponses, not all n values total 28 or 13. Because of rounding, not all percentages total 100.

disclosure of sexual orientation to providers, satisfaction with care, use of alternative and complementary therapies, and cancer supportive services (see Figure 1).

Attitudes about medical decision making: Lesbians and heterosexual women did not differ in the types of responses they gave related to medical decision making. Participants in both groups reported using a range of sources to learn about their medical options. These included written materials, physi-

cians, friends, knowledgeable acquaintances, and family members. Patients typically began exploring their options immediately after diagnosis by discussing treatment alternatives with a number of healthcare providers until they found a good medical and philosophical fit. Most respondents were relatively satisfied with the treatment options their physicians discussed and the way they were presented. The majority of respondents preferred their physicians to list all possible alternatives, explain the pros and cons of each, and outline the rationale behind the most typical approach used for their condition. Ultimately, respondents usually wanted some guidance in choosing a specific course of action. Women who relied most heavily on their physicians' judgment tended to feel too emotionally and intellectually overloaded to choose on their own. For instance, one woman who carefully directed her medical care until feeling overwhelmed said, "I ended up just turning to my oncologist and saying, 'I'm in your hands; you do what you want.' . . . I just couldn't make any decisions anymore. I felt like everything was my responsibility, and I just couldn't deal with that."

Preferences for providers: Both heterosexual and lesbian respondents preferred female physicians for routine care, particularly gynecologists, but were far less concerned with the gender of their healthcare professionals for cancer-related treatment. For instance, a heterosexual respondent stated, "I just chose somebody that my brother-in-law, who is a physician, wanted. . . . Gender had nothing to do with it." In contrast to previous studies (Bradford & Ryan, 1987; Cassidy & Hughes, 1997), lesbians did not favor a specific sexual orientation for healthcare providers. One lesbian respondent said, "I've often tried to find women physicians . . . [but in this case] . . . I found that there were women who were just as insensitive to my need . . . to be treated as a partner as there were men, and I attributed that not so much to gender but to the training they received."

Most respondents preferred medical centers in or near large cities because they expected better care at larger hospitals in such areas. A small number of respondents, restricted by insurance coverage to specific medical facilities, believed that they received care inferior to that of patients treated at more prestigious institutions.

Patient-provider relationship: Respondents in both groups reported that they sought skilled healthcare professionals who gave them attention and time, answered their questions, treated them with consideration, and regarded them as partners in the treatment process. One respondent said

When I went to the first doctor . . . [he] decided everything for me . . . and never even explained anything. . . . That upset me a little that I really wasn't part of the decision process. . . . [With the second doctor] I felt and it was said that this is a team decision. . . . That's what I liked, was that it wasn't just the decision of the doctor, it was, "We'll explain this to you and it's your ultimate decision."

Although respondents found the bedside manner of their healthcare providers important, they valued competence and success rates more than expressions of concern or empathy.

Disclosure of sexual orientation: Disclosure of sexual orientation to medical providers was a unique decision and concern for lesbian respondents. A number of them disclosed their sexual orientation to healthcare professionals they saw regularly, such as primary care physicians, but did not disclose it to medical personnel they saw infrequently. Before the

1. Medical decision making
 - a. Physicians were an important source of information.
 - b. Respondents preferred to review all possible alternatives with physicians.
 - c. Patients and providers should share treatment decision making.
 - d. Patients preferred some guidance on decisions; overwhelmed patients relied more heavily on physicians' judgments.
2. Preferences for providers
 - a. Most women stated a preference for female primary care providers.
 - b. Neither gender nor sexual orientation was mentioned as a significant factor when considering cancer care providers.
 - c. Respondents sought skilled healthcare professionals who gave them attention and time, treated them with consideration, and regarded them as partners in the treatment process.
 - d. Providers who did not discourage use of complementary and alternative therapies were preferred.
3. Factors contributing to satisfaction with treatment
 - a. Satisfaction generally was defined by a successful outcome.
 - b. The patient-provider relationship also contributed to satisfaction.
4. Barriers to treatment satisfaction
 - a. Dissatisfaction with treatment was more prevalent among respondents with less comprehensive or flexible insurance plans.
 - b. Dissatisfaction also was associated with doctors who appeared rushed and treated patients like "a number."
 - c. Participants also were dissatisfied with doctors who misinterpreted a need for information as a challenge to their authority.
5. Disclosure of sexual orientation
 - a. Most lesbian respondents considered sexual identity of little or no importance in the healthcare environment.
 - b. Discussion of sexual identity with healthcare providers usually was prompted during gynecologic examinations.
 - c. Disclosure became relevant to clarify the nature of their relationships with their partners.
 - d. In almost all cases, medical staff treated partners respectfully.
 - e. Respondents who hid their sexual orientation during treatment and recuperation endured an additional burden of secrecy.
6. Use of alternative or complementary medicine
 - a. A substantial number of women in both groups used complementary medicine.
 - b. A strong preference was found for therapies or practitioners that acknowledged a mind-body connection.
7. Coping and emotional support
 - a. Partner or spouse was the most frequently reported source of support.
 - b. For lesbians, barriers to participating in support groups were lack of perceived acceptance and overemphasis on breasts as sexual objects.

Figure 1. Summary of Qualitative Findings

diagnosis of cancer, discussion of sexual identity with healthcare providers typically was prompted, if it occurred at all, during gynecologic examinations in response to questions about the possibility of pregnancy, use of birth control, and history of sexual activity. Lesbian respondents who disclosed their sexual orientation to healthcare providers during treat-

ment noted no discernible change in their physicians' attitudes toward them or decline in the quality of treatment.

Although most lesbian respondents said they considered sexual identity of little or no importance in the healthcare environment, many found reason to disclose their sexual orientation in the course of their treatment for breast cancer. The patients typically introduced their partners to medical staff members early in the course of treatment to ensure them the same recognition and treatment that heterosexual spouses would receive. For instance, one respondent said, "Every time I would go to a doctor, I would introduce my partner. . . . It was important for me to know that [he or she] . . . would understand that this is affecting this other person, because they're being affected in a very dramatic way." In almost all cases, respondents found that medical staff treated their partners with the same respect and professional courtesy that heterosexual spouses likely would receive.

Some lesbian respondents who were previously ambivalent or disinclined to identify themselves as lesbians before their illness found a catalyst for disclosure with their diagnosis. Other respondents continued to hide their sexual orientation (and their partners) from family members, friends, and coworkers during treatment and recovery. Lesbians who reported that they did not disclose their sexual orientation during their illness experienced an additional burden of secrecy.

Satisfaction with care: The majority of respondents in both groups were relatively satisfied with their cancer treatment. Satisfaction generally was defined by a successful outcome (i.e., survival and returning to levels of QOL that approximated prediagnostic QOL). Another contributing factor was the nature of interactions between patients and their healthcare providers. Dissatisfaction with treatment appeared only slightly more prevalent among respondents with less flexible insurance plans and was associated most often with limited choice of physicians or facilities. Dissatisfaction was associated with physicians who appeared rushed, were unable to discuss medical options at length, or were otherwise unable to address concerns and fears. Participants also were dissatisfied with physicians who misinterpreted a need for information as a challenge to their authority, responded to questions in a patronizing or defensive manner, dismissed patients' research efforts, and devalued patients' familiarity and knowledge of their own bodies. Respondents preferred caregivers who did not discourage their pursuit of alternative therapies to promote physical and emotional well-being. One respondent said, "It's hard to find a physician who seemed to believe that alternative medicine can in some instances work just as well. My position is, let me have them both." Another was dissatisfied with her first physician because, "He did not take seriously my questions and my need to be treated as a partner in my healing, and he trivialized my questions about alternative therapies." Another survivor expressed frustration with her physician's inability to understand the effect that her mastectomy had had on her whole being, saying, "She basically . . . said I was crazy and said I should see a psychiatrist because I wasn't dealing with the fact that . . . we cut it out of you. It's gone."

Respondents expressed greater satisfaction with surgical procedures that involved minimal removal or minimal mutilation of the breast. Satisfaction with breast reconstruction was associated with aesthetically pleasing results (e.g., minimal scarring). Women who continued to experience long-term

side effects such as limited range of motion, numbness, pain, or prolonged lymphedema were less likely to be satisfied with their care than respondents who were largely pain free or had greater range of motion. However, women informed before the procedure of these possible side effects appeared more satisfied with their surgeons than those who believed they were not prepared adequately, regardless of physical results. Few lesbians in the sample (39%) had undergone a mastectomy, and fewer than half of those (40%) opted for breast reconstructive surgery. Of the respondents who chose not to have breast reconstruction after mastectomy, lesbians more often noted that any benefits that they might derive from reconstruction would not outweigh the physical, emotional, and financial costs of additional surgery. One respondent stated, "It doesn't matter. Having a breast . . . does not configure in my self-image. . . . It's just not an issue for me."

Alternative or complementary medicine: Many women in both sample groups supplemented traditional treatment methods with a variety of approaches they labeled as alternative therapies. These included acupuncture, massage therapy, visual imagery or visualization, counseling or talk therapies, art therapy, and unspecified "Eastern" and "Chinese medicine." The appeal of these therapies, in large part, was the perception that they were holistic and acknowledged a mind-body connection.

Cancer supportive services: Respondents sought emotional support from a diverse range of sources and found their needs met with varying degrees of success. Sources of support mentioned by respondents included formal and informal support groups, religious affiliations, spiritual beliefs, community associations, hospital and healthcare resources, and networks of family and friends. For instance, a woman who was active in her church commented, "I was a member of our choir, I'm an alto, and . . . seven altos . . . had had mastectomies. So I went to choir . . . and I'd get my support there." Some lesbians reported having a difficult time finding a cancer support group that seemed appropriate to their needs and concerns. Among lesbian participants who previously had participated in support groups comprised mostly of heterosexual women, dissatisfaction was associated with the emphasis on the importance of breasts for sexual attraction to men. One woman said, "I sat through two . . . heterosexual support groups. So finally I had had it. . . . [The issue] was the man's attachment to the woman's breast. It had nothing to do with whether she was going to get better." Lesbians also did not feel enough openness and acceptance to disclose their sexual orientation. As such, many of their emotional needs associated with the effects of the illness on their relationships or partners were unmet in such settings. The women who were able to participate in lesbian-specific cancer support groups emphasized the level of safety that they felt in such settings. However, women who had participated in lesbian-specific groups also said that these groups and agencies did not have enough resources.

Discussion

Although breast cancer represents a significant health threat for all women, few systematic attempts have been made to study lesbians with breast cancer. This has resulted in a paucity of empirical data describing the physical, emotional, and social experiences of lesbians after the diagnosis of breast cancer. The overall objective of the present study was to compare the experiences of lesbian and heterosexual survivors of breast cancer.

Quantitative findings suggested differences between the groups in areas that may have important implications for overall physical and emotional outcomes among lesbian survivors. Lesbians reported higher stress associated with initial diagnosis and treatment, lower satisfaction with care received from physicians, and a trend toward lower satisfaction with the availability of emotional support from healthcare providers.

Although not the primary focus of the study, quantitative results regarding the patient-provider relationship were consistent with a recent study examining experiences of patients newly diagnosed with cancer (Fobair et al., 2001). Fobair and colleagues reported that lesbians had significantly more negative perceptions of their care than heterosexual women. They were less satisfied with their physicians' care and the inclusion of their partners in medical treatment discussions than heterosexual patients. No differences were found between the groups regarding perception of communication with physicians or sense of control over treatment.

Despite differences in quantitative measures of interactions with healthcare providers, the findings from this study's focus groups suggest similarities between lesbians and heterosexual women in many aspects of the overall cancer experience, including factors contributing to satisfaction with treatment, the patient-provider relationship, and emotional response to their illness. Important differences did emerge, however, with regard to medical decision making and satisfaction with mainstream cancer support services. Although fewer lesbians had mastectomies, breast reconstructive surgery was reported to be less of a priority for the lesbians in this sample. Furthermore, lesbian participants reported that a lack of perceived acceptance and an overemphasis on breasts as objects of male sexual desire were significant barriers to their use of cancer support resources. The limited availability and resources of lesbian-specific cancer support groups also was a concern for the lesbians in this study.

The current study has several limitations. Although appropriate for focus group studies, the number of lesbian participants was small; therefore, their experiences may not be representative of the experience of lesbians in general. Because of the small sample sizes, the researchers may not have been able to detect differences that exist between the groups. The sample was from a large urban setting, so the lesbian participants may have been more "out" and comfortable with their sexual orientation. This also may have contributed to their willingness to participate in the project. However, fewer than half of the lesbians in the sample reported disclosing their sexual orientation to their healthcare providers. Finally, most of the participants received their care in a large metropolitan area where they may have had increased access to providers who were less discriminatory. This may not be representative of the experiences of the majority of lesbians. The authors hope to address many of these limitations in their ongoing study of health outcomes and QOL in lesbians with a history of breast cancer.

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For more information . . .

- Feminist Majority Foundation: Breast Cancer Information Center
www.feminist.org/other/bc/bchome.html
- National Cancer Institute: Breast Cancer Home Page
www.cancer.gov/cancerinfo/types/breast
- National Breast Cancer Coalition
www.natlbcc.org

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.