

COMPARISON OF LESBIAN AND HETEROSEXUAL WOMEN'S RESPONSE TO NEWLY DIAGNOSED BREAST CANCER

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SUMMARY

In a study comparing lesbian and heterosexual women's response to newly diagnosed breast cancer, we compared data from 29 lesbian with 246 heterosexual women with breast cancer. Our hypotheses were that lesbian breast cancer patients would report higher scores of mood disturbance; suffer fewer problems with body image and sexual activity; show more expressiveness and cohesiveness and less conflict with their partners; would find social support from their partners and friends; and would have a poorer perception of the medical care system than heterosexual women. Our predictions regarding sexual orientation differences were supported for results regarding body image, social support, and medical care. There were no differences in mood, sexual activity or relational issues. Not predicted were differences in coping, indicating areas of emotional strength and vulnerability among the lesbian sample. Copyright © 2001 John Wiley & Sons, Ltd.

INTRODUCTION

Discovering how women from different cultural and sexual experiences respond to the psychological, social and emotional challenges of breast cancer is now part of the national agenda (Blumenthal, 1998). During recent decades psychosocial research increasingly focused on women's health as well as on the effects of cultural diversity (Haynes *et al.*, 1979) as it effects quality of life following a life threatening illness (Bloom, 1982; Bloom *et al.*, 1998; Kang and Bloom, 1999). Researchers have begun to focus on lesbian demo-

graphics in response to a call for quality investigations of women (O'Hanlan, 1991, 1995a). Current with the growing concern about risk factors contributing to the incidence of breast cancer among lesbians (Roberts *et al.*, 1998), there is greater interest in learning what lesbians in particular think and feel about having breast cancer (O'Hanlan, 1995b). How does breast cancer affect their mood, sexual identity, social support, or experience of medical care?

Recent surveys suggest that about 3.6% of American women identify as lesbians (Diamond, 1993). Lesbians, women who sexually prefer and couple with other women, have historically been seen as different from and inferior to their heterosexual counterparts (Berkman and Zinberg, 1997). There is evidence (Pagelow, 1980) that lesbians have been marginalized in American culture. Previous reviews and survey's have found that the

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women who identify as lesbian can as a consequence experience higher levels of stress, reduced social support from families of origin, and a strained relationship with the health care system (Stevens and Hall, 1988; O'Hanlan, 1995b; Rankow, 1995; Bradford and Ryan, 1998).

While much has been much written on the psychological experience of women following a breast cancer, most studies have not made comparisons with heterosexuals. It may be assumed that the data predominantly describes the experience of heterosexual women, as research results were not obtained or stratified by sexual identity. A critical question raised and discussed by (O'Hanlan, 1995b) is whether lesbians with health problems such as breast cancer might face either greater or different challenges than heterosexual women in coping with breast cancer. Studies similar to those of (Pagelow, 1980; Roberts *et al.*, 1998) comparing lesbian and heterosexual groups to determine differences are needed.

Mood

Previous research demonstrates that women with a diagnosis of breast cancer experience significant emotional and social distress (Bloom, 1987; Fallowfield *et al.*, 1990; Ganz *et al.*, 1992, 1998; Bloom *et al.*, 1998). Expressing emotions is helpful in reducing social isolation and improving coping (Greer *et al.*, 1979; Spiegel, 1999). Cancer patients who are able to ventilate strong feelings directly may cope better with cancer (Spiegel, 1999). A substantial minority of breast cancer patients suffer persistent symptoms of emotional distress following treatment which can interfere with medical treatment and quality of life (Ell *et al.*, 1989). None of these studies identify the psychosocial distress was experienced differently between the lesbian and heterosexual groups.

Coping styles

Coping with cancer involves both managing medical information about the disease and treatment as well as balancing the many other aspects of life (Jarrett *et al.*, 1992; Classen *et al.*, 1996; Spiegel, 1999). Coping patterns range from passive to active in behavior, and from emotionally optimistic with fighting spirit to stoic acceptance, denial, or helpless/hopelessness. Previous research has demonstrated a relationship between coping

style, and current and long-term psychological adjustment among breast cancer patients (Watson *et al.*, 1991; Jarrett *et al.*, 1992; Carver *et al.*, 1993). In addition, Carver *et al.* (1993) found a general attitude of optimism at the time of diagnosis, before surgery, was predictive of better 3-, 6-, and 12-month subjective well-being.

Lesbians experiencing exclusion from the mainstream culture develop a coping style to deal with the stresses of their minority status (Pagelow, 1980; Sophie, 1987), are more independent than their heterosexual counterparts, and have developed a positive self-image (Pagelow, 1980; Sophie, 1987). It would be important to know if lesbians with breast cancer have a different adjustment than heterosexual women in the mainstream culture.

Interpersonal relations: body image, intimacy and sexual functioning

Changes in body image, loss of libido, and sexual dysfunction from surgical removal of the breast have been documented. While previous research has shown that body image may be influenced by mastectomy, or lumpectomy (Fallowfield and Hall, 1991; Schover, 1991), research suggests that lesbian culture places less emphasis on size, body weight, and is less focused on the visual aspects of breasts or physical appearance. Loulan (1984), Herzog *et al.* (1992) and O'Hanlan (1995a,b) reported that in lesbian culture, there may be less overt focus on appearances or sexual anatomy, and more focus on an individual's personality traits (O'Hanlan, 1995a,b). This finding leads to an important question regarding women diagnosed with breast cancer; do lesbian and heterosexual women differ regarding mood, body image, and loss of libido following treatment for breast cancer?

The role of interpersonal relationships and intimacy may differ between same-sex couples and heterosexual couples. Interpersonal dependency, compatibility and intimacy was examined in a study of lesbian and heterosexual relationships among college students, ages 23–35 (Hurlbert and Apt, 1993). While sexual satisfaction was similar for both, lesbians demonstrated greater interpersonal dependency, compatibility, and intimacy. Heterosexual women scored significantly higher on sexual desire, sexual fantasy, sexual assertiveness and frequency of sexual activity. What isn't

known is whether these results remain similar with older age groups and/or with breast cancer survivors.

Social support

Social support is an important buffer in coping with the stresses of life (Berkman and Syme, 1979). Social support from immediate family, friends, co-workers or religious organizations has been shown to be important in accommodating the stress of adjusting to a new breast cancer diagnosis (Bloom, 1982). Lesbians may not have the same degree of social support as their heterosexual counterparts have from their families of origin, coworkers or religious organizations (Bradford *et al.*, 1994). However, lesbians frequently develop a broad chosen family as a social and support network, which may include prior domestic partners, close friends, accepting family, and the family of their current domestic partners (Bradford *et al.*, 1994). Such differences in social support may dramatically affect the quality of life and recovery from breast cancer among lesbians and deserves study.

Access to and utilization of medical care

Lesbians have been shown to access and utilize modern medical care less than heterosexual women (Trippet and Bain, 1992; O'Hanlan, 1995b). This may be due to: prior experience of insensitive or uninformed healthcare providers (Dardick and Grady, 1980; Smith *et al.*, 1985; Kass *et al.*, 1992; Bradford *et al.*, 1994; Berkman and Zinberg, 1997), problems with access to and invisibility in mainstream medical care (Glascock, 1981; Deevey, 1990; Robertson, 1999), internalized homophobia or learned shame (Stevens, 1994), the anticipation of discriminatory medical care (Stevens and Hall, 1988; Hitchcock and Wilson, 1992), lower income (Bybee, 1990), and failure to perceive their need for routine care (Bradford *et al.*, 1994). Sensing hostility toward them, between 67 and 72% of the lesbians elected not to reveal their orientation to health providers (Glascock, 1981; Johnson *et al.*, 1981; Cochran and Mays, 1988).

In this study, we compared questionnaire responses of lesbian and heterosexual women, following a breast cancer diagnosis regarding their psychosocial experience of emotional distress,

coping, body image, sexual attractiveness and activity, social support from family of origin, or partners and friends, their family expressiveness, cohesion and conflict, their attitudes about medical care for breast cancer, and whether the lesbian group was at greater risk for psychosocial distress.

Hypotheses

In this paper, responses of lesbian and heterosexual breast cancer survivors who volunteered to be in an intervention study are compared. Based on the literature as well as informal interactions, we predicted that:

1. *Mood*: Due to lack of supportive relationships with families of origin and/or medical staff, lesbian breast cancer patients would report higher scores in mood distress.
2. *Body image/sexual activity*: Lesbians would suffer fewer problems with body image and fewer problems with sexual activity as a result of a breast cancer diagnosis.
3. *Relational issues*: Lesbians would show more expressiveness and cohesiveness, and less partnership conflict than heterosexual women.
4. *Social support*: Lesbians would more likely obtain social support from their partners and friends than heterosexual women. We predicted better partner and community support and poorer extended family support scores for lesbians.
5. *Medical care*: Lesbians would have a poorer perception of the medical care system than heterosexual women. We predicted that lesbian breast cancer survivors would report less satisfaction and more suspicion of their health care providers than heterosexual breast cancer survivors and more difficulty communicating and less of personal control with their health care providers.

METHODS

Data sources

The present study of lesbians with primary breast cancer was designed as a 'special population' comparison with heterosexual women with primary breast cancer participating in a

multicenter trial. Along with testing specific hypotheses, this is also intended to be a descriptive study given that so little has been reported in the literature describing lesbians with breast cancer.

In this paper we report on baseline data from two separate intervention studies—a multicenter trial for heterosexual women with breast cancer and a single site trial for lesbians with breast cancer. The heterosexual trial included 273 patients recruited from two academic sites and nine oncology practices which were members of the Community Clinical Oncology Program (CCOP) (Classen *et al.*, 2000). The data from the lesbian sample came from 29 women recruited in the greater Bay Area of Northern California who agreed to provide information about their breast cancer experience.

In this paper the baseline data from 29 lesbians are compared with 246 women from the multicenter trial who indicated that they were heterosexual and had a college education. A later paper will examine the changes experienced for the 20 lesbians who completed the intervention and were studied at three additional points of time.

The lesbian patients were solicited for participation in this study by newspaper stories, advertisements, fliers, and brochures distributed to physicians' offices and community agencies, as well as talks at community agencies and physicians' offices.

For both samples, eligibility to participate in the psychosocial intervention trial required: (1) a biopsy-confirmed diagnosis within the past year of primary breast cancer in stages I through IIIA; (2) completion of initial surgical treatment; and (3) no detectable disease present. All subjects could undergo, during this period, chemotherapy, radiation therapy, and/or hormone therapy. Women were ineligible to participate if they had any of the following: (1) evidence of metastases beyond adjacent lymph nodes, including chest wall involvement, bone, or viscera; (2) cancer recurrence prior to randomization; (3) other cancers except for basal cell or squamous cell carcinoma of the skin or in situ cervical cancer within the past 10 years; (4) other major medical problems were present and likely to limit life expectancy to less than 10 years; (5) a history of major psychiatric illness for which the patient had been hospitalized or medicated, with the exception of depression or anxiety treated for a period of less than 1 year; or (6) attendance at a cancer support group for more than 2 months prior to study recruitment.

Measures

The Background questionnaire, an 11-item measure, was used to collect demographic information, including age, education, employment status, main occupation, household income, sexual orientation, religious affiliation, marital/relationship status, and the number of children (Miller EL. 1991. Background Questionnaire. Unpublished Measure).

Distress

Two measures of emotional distress were used in this study, the Profile of Mood States (POMS) and the Impact of Events Scale (IES). The POMS (McNair *et al.*, 1971) was used to assess mood disturbance. Participants were asked to indicate the extent to which 65 mood-descriptive adjectives (such as: tense, angry, sad, clearheaded) describes their mood during the past week. Each adjective is rated on a 5-point Likert scale ranging from not at all to extremely. The POMS yields a score for total mood disturbance based on five subscales: anxiety, depression, hostility, confusion, vigor, and fatigue. Internal consistency has been shown to range from 0.87 to 0.95. Test-retest reliability for individual subscales has been shown to range from 0.65 to 0.74 (McNair *et al.*, 1971) on comparisons made between initial intake and the follow-up after psychosocial treatment. Concurrent validity has been demonstrated by correlating the POMS subscales with the subscales of the Hopkins Symptoms Distress Scale (Parloff *et al.*, 1954). Internal consistency for the lesbian sample was 0.98 for total mood disturbance.

The IES (Horowitz *et al.*, 1979) was used as a measure of traumatic stress symptoms after a stressful life event. This 15-item scale assesses the extent to which the participant experiences intrusion and avoidance symptoms following the traumatic stressor of being diagnosed with breast cancer. Intrusion is characterized by unbidden thoughts and images, troubled dreams, strong pangs or waves of feelings. Avoidance responses included ideational constriction, denial of the meanings and consequences of the event, blunted sensation, behavioral inhibition or counter phobic activity, and awareness of emotional numbness. Respondents are asked to indicate 'how frequently these comments were true for you during the past seven days' by endorsing 'not at all',

'rarely', 'sometimes', or 'often', which are scores 0, 1, 3 and 5, respectively. The IES has been used extensively in research on stressful life events and has been shown to have good psychometric properties (Horowitz *et al.*, 1993). Cronbach's alpha for the present sample was 0.92 for the total score, 0.87 for intrusion, and 0.87 for avoidance.

Body image/sexual activity

The Body Image and Sexuality Scale for Women With Breast Cancer (BISS: Zarcone J, Classen C, Smithline L, Spiegel D. 1993. The Body Image and Sexuality Scale for Women with Breast Cancer (BISS). Unpublished Scale) is designed to assess the impact of having breast cancer on a woman's sexuality and body image. There are 28 items that ask the respondent questions about her experience prior to having breast cancer and since having breast cancer. These include questions regarding satisfaction with her physical attractiveness, how comfortable she is with her body, satisfaction with her sex life, how breast cancer has impacted her sex life, and the importance of her breasts to herself and her partner. The respondent indicates her answer on a 5-point scale with the option of indicating that the item is not applicable. In addition, there is a list of 18 symptoms that are common following treatment for breast cancer. The respondent is asked to indicate the extent to which each of them has negatively affected her sexual experience. The 18 items are rated on a 4-point scale from 'no effect' to 'extremely negative' with the option of indicating the item is not applicable. This is an unvalidated measure that was designed for the parent study as a first step towards understanding the impact of breast cancer on women's sexuality and body image. In this study six items were used for analysis: 'How comfortable are you showing your body to others before/since having breast cancer?', 'How comfortable were you with your body weight prior to/since having breast cancer?', 'How satisfied are you with your sex life before/since having breast cancer?'

The Sexual Activity Questionnaire (SAQ) (Thirlaway *et al.*, 1996) consists of three sections assessing marital/partner status, reasons for sexual inactivity (if applicable) and levels of sexual functioning. Inadvertently, only the first two sections were used in this study concerning the presence of an intimate relationship and sexual

activity at the moment. Additional questions provide patients opportunity to explain why they are not sexually active. This measure was shown to be valid and reliable in a study of the effects of long-term tamoxifen on the sexual functioning of women at high risk of developing breast cancer (Thirlaway *et al.*, 1996).

Relational issues

The Family Relations Index (FRI) is a subscale of the Family Environment Scale (Moos and Moos, 1986). This 27-item true/false subscale consists of three domains: cohesion, expressiveness, and conflict. It includes such items as 'we fight a lot in our family . . . family members really help and support one another', and 'we are usually careful about what we say to each other'. The scale has been widely used, with good concurrent and predictive validity described in the manual. We have previously found it to predict later mood disturbance among metastatic cancer patients (Bloom, 1982; Spiegel and Bloom, 1983; Spiegel *et al.*, 1983). In the present sample, the Cronbach alpha was 0.91 for the total FRI, 0.88 for cohesion, 0.76 for expressiveness, and 0.80 for conflict.

Social support

The Social Network and Support Assessment (SNSA) is a paper and pencil measure adapted from Berkman's Social Network Index, a structured interview used in the Established Populations for Epidemiological Studies of the Elderly (EPESE) and from the MacArthur Foundation Research Network on Successful Aging. It was used to assess the amount and quality of social contacts and support. Berkman's Social Network Index has been used extensively to explore patients' social networks (number of contacts; Berkman and Syme, 1979), the quality of support contact (Berkman, 1986), how satisfied patients are with the support they receive (Seeman and Berkman, 1988), and the inverse relationship between social support and mortality (Seeman *et al.*, 1993). The SNSA includes such items as 'How often does your spouse/partner make you feel loved and cared for?' and 'How satisfied are you with the kinds of relationships you have with your friends and relatives?'. The lesbian and heterosexual samples were compared on each of the individual item.

Medical care

Two measures of satisfaction with medical care were used in this study the Medical Interaction Scale of the Cancer Rehabilitation Evaluation System (CARES) and the Patient Rating Scale of Physicians (PRSP). The Medical Interaction Scale is an 11-item component of the CARES (Schag and Heinrich, 1989, 1990). One of the five subscales of the CARES, it was developed to assess the extent to which patient have problems with one's medical team around obtaining information, control and communication. It includes such items as 'I find that the medical team withholds information from me about my cancer' and 'I have difficulties asking doctors questions'. The respondent is asked to indicate how best the statement applies to her using a 5-point scale from 'not at all' to 'very much'. The CARES scale is used both as a clinical and research tool and has been validated and shown to have excellent test-retest reliability. Cronbach's alpha on the lesbian sample was 0.83.

The PRSP was developed to assess the patient's attitudes toward health care providers (Warner D, Zarcone J. 1993. Patient Rating of Physician Scale. Unpublished). The PRSP consists of the following three items: 'I am satisfied with the care I received from my treating physician'; 'I trust that my physician represents my best health care interest'; and 'my health care provider includes my partner/spouse in discussions of my medical care regarding breast cancer'. The respondent is asked to indicate how best the statement applies to her by using a 5-point Likert scale ranging from 'not at all' to 'extremely'. These items were added to augment the CARES Medical Interaction Scale. The content validity of this measure was supported by the favorable evaluations of an expert panel comprised of ten researchers with extensive experience in breast cancer treatment and research. In this sample, the Cronbach alpha was 0.63 for raw variables, 0.71 for standardized variables for the PRSP. This low score can be understood, perhaps as the result of creating a short scale to cover a large domain.

Coping

The following coping measures were included for descriptive purposes only.

The Courtauld Emotional Control Scale (CECS: [Watson and Greer, 1983](#)) is a 21-item measure which asks the respondent to indicate the extent to which they control expressions of anger, anxiety and depression. The participant is asked to indicate how far each of seven statements describes how she generally reacts when she feels angry. Similar statements are rated for when she feels anxious and when she feel unhappy. Examples of the statement include 'I keep quiet' or 'I let others see how I feel'. In our sample, Cronbach's alpha was 0.85 for anger, 0.91 for anxiety, and 0.88 for depression.

The Mini-MAC ([Watson et al., 1994](#)) is a 29-item version of the Mental Adjustment to Cancer scale (MAC: [Watson et al., 1988](#)), a self-report questionnaire designed to assess coping responses to cancer. There are five subscales: fighting spirit, helpless/hopeless, anxious preoccupation, fatalism, and denial/avoidance. Respondents are asked to indicate the extent to which item applies to them on a 4-point scale from 'definitely does not apply to me' to 'definitely applies to me'. Examples of items are 'At the moment I take one day at a time', 'I see my illness as a challenge', and 'I feel like giving up'. Although the original MAC has been used with cancer patients to determine the extent to which they have adjusted to living with cancer ([Pettingale et al., 1985](#); [Greer et al., 1989](#); [Schwartz et al., 1992](#)), there has been limited research using the Mini-MAC. Internal consistency of the subscales for the present sample are 0.56 for fighting spirit, 0.89 for anxious preoccupation, 0.72 for fatalism, 0.91 for helpless/hopeless, and 0.79 for cognitive avoidance, from 0.65 (fatalism) to 0.84 (fighting spirit). The MAC is widely used with breast cancer patients to determine the extent to which they have adjusted to living with cancer ([Pettingale et al., 1985](#); [Watson et al., 1988](#); [Greer et al., 1989](#)).

Data analysis

Means and standard deviations (S.D.s) were calculated to describe the distributions of the lesbian and heterosexual women demographic, medical and psychological factors that were measured on continuous scales. Percentages were computed to describe the distributions of the demographic variables that were assessed using categorical measures, followed by chi-square tests of significance. *t*-Tests for independent samples were used

to examine the statistical significance of differences in mean scores on the demographic variables assessed on continuous scales (e.g. age), and the following measures: POMS, IES, CECS, MAC, BISS, SAQ, FRI, Yale Social Support Index, and PRSP. These *t*-tests were computed on mean raw scores at baseline. In this paper the two samples are compared.

RESULTS

Demographic characteristics for both samples are summarized in Table 1. Among the socio-economic demographics there were no differences between the two samples in age, number of women employed, income, or ethnicity. Lesbians in this sample had more years of graduate education ($p = 0.01$). Lesbians were more likely to report employment in professional careers ($p = 0.02$), than heterosexual women. Heterosexual women were more likely to be partnered ($p = 0.01$) and to have had children ($p = 0.00$).

In examining medical variables, lesbian and heterosexual samples were comparable in stage of disease, and experience with surgery, radiation, hormone and chemotherapy treatments. An area where a significant difference did appear was 'time since diagnosis'. Lesbian participants were further from treatment, 15 months versus 7 months for heterosexual women ($p = 0.05$) at assessment.

Tests of the hypotheses

Results for both samples are presented on Table 2.

Mood. The first prediction, that lesbians would report greater emotional distress was not supported. Using 2-tailed *t*-tests, lesbian mean scores reported more intrusive reactions (on the IES) and less avoidance in reaction to having cancer ($p = 0.07$). Although mean scores of emotional distress were somewhat higher on the POMS for lesbians, there was no significant difference between lesbian and heterosexual breast cancer patients on the POMS total score.

Body image/sexual activity. The prediction that lesbians would suffer fewer problems with body image was confirmed by the data, while the corol-

lary predicting better sexual functioning at baseline than heterosexual breast cancer patients, was not confirmed. Lesbians were significantly more comfortable in showing their body to others both prior to having breast cancer ($p = 0.001$), as well as following having breast cancer ($p = 0.01$). There was no significant difference in the number of lesbian or heterosexual patients who were currently engaged in having intimate relationships or engaging in sexual activity. There was a trend ($p = 0.07$) for heterosexual breast cancer patients to report having greater satisfaction with their sex lives before cancer. There was no difference between the groups in sexual satisfaction after breast cancer. Among the women who said they were not currently sexually active, lesbians were more likely than heterosexual patients to say that they were not interested in sex ($p = 0.05$).

Relational issues. The data did not confirm the hypothesis that lesbians would demonstrate greater ability to express their feelings, show more cohesiveness in their relationships, or score higher in their ability to deal with conflict. Using the FRI measure, no significant differences were observed between the lesbian and heterosexual groups in mean scores on expressiveness, cohesiveness or ability to deal with conflict.

Social support. Lesbians were shown to be more likely to obtain social support from their partners and friends. Lesbian patients more than the heterosexual women felt that their partners made them feel loved and cared for ($p = 0.03$); that their partners were willing to listen ($p = 0.03$); and could be counted on for daily tasks to help them during the cancer experience ($p > 0.01$). Furthermore, lesbians rated their friends higher than did heterosexual women in being helpful to them by giving advice about medical, financial or family problems ($p = 0.004$). However, contrary to our prediction, lesbians, compared to heterosexuals, rated their friends as being potentially more critical of them ($p < 0.01$).

Heterosexual breast cancer patients were more likely than lesbians to report that their spouses made 'too many demands on them' ($p = 0.03$). As predicted heterosexuals received greater social support among from their relatives than did lesbians, and had significantly more relatives living nearby ($p < 0.0001$), especially relatives with whom they felt close ($p > 0.05$). The heterosexual women reported having more supportive relatives

to count on to help them with their daily tasks ($p < 0.001$), and felt more satisfied with their relationships with relatives than did the cohort of lesbian breast cancer patients ($p < 0.01$).

Medical care. The hypothesis predicting that lesbians would have a poorer perception of the medical care system than heterosexual women was supported on the PRSP. The lesbian breast cancer patients were significantly less satisfied with their physicians' care and the inclusion of their partner in medical treatment discussions than were the heterosexual patients ($p < 0.01$). However, there were no significant differences between groups using the 11-item subscale of the CARES measure of communication with physicians and the patient's sense of control over treatment.

Coping. No predictions were made about group differences on the two measures of coping, the CECS, and the MAC, collected originally as process measures. Although there were no significant differences between the two groups in anxiety or depression control (on the CECS), lesbians were significantly more likely to report expression of their anger than were the heterosexual patients ($p = 0.05$). Also, on the MAC, lesbians reported significantly less fighting spirit ($p = 0.02$), although they also reported significantly less fatalism than did heterosexual women ($p = 0.02$). Furthermore, lesbians used significantly less cognitive avoidance ($p = 0.03$). No significant differences were found (on the MAC) between groups in their anxiety/preoccupation, or feelings of helplessness/hopelessness.

DISCUSSION

We found both important similarities and important differences between the groups, demonstrating the value of systematic research comparing lesbian with heterosexual breast cancer patients. While scores on mood (POMS), sexual activity and relational issues were similar, differences were found in lesbian comfort with body image, some aspects of coping, sources of social support, and views of medical care.

Lesbian and heterosexual patients were similar in most of the demographic, medical, and psychological responses to their breast cancer experience. Important differences, in education, relationship

status, and time since diagnosis require further discussion. While the lesbian sample had achieved more education, there were no significant differences between the two groups in income. It should be noted that previous research found lesbians typically achieving lower income despite higher education (O'Hanlan, 1991). Geographic location of the comparison study may account for the difference in education. The heterosexual group was dispersed throughout the eastern and mid-western states, where opportunities for access to higher education may vary. Not only were more heterosexual women married more often than the lesbians, they had significantly more children, pointing to an important difference in opportunity for education.

The difference in time since treatment between the two samples points to the difficulty in recruiting the small population of lesbian breast cancer patient to participate in the study. Although the San Francisco bay area is perceived as a haven for homosexuals due to the widespread local acceptance of diversity, it took considerable time for the lesbian research assistants to recruit the sample. Based on a statistical review of San Francisco bay area women diagnosed with breast cancer, the potential number of lesbians available to be in the study was higher than the number of participants who actually enrolled. Therefore, the time requirement (diagnosis 12–18 months before entrance to the study), important to the multicenter group therapy trial, was expanded to increase lesbian enrolment into the study. We hope there will be further studies with lesbian identified institutions able to provide effective and timely outreach.

Looking more closely at the measures for mood and coping, a complex picture evolves. While there were no significant differences between groups in emotional distress using the POMS, there were differences between the two groups using other related measures. The resulting picture is mixed in terms of strengths and vulnerabilities. On the one hand, the lesbians showed the strengths of active coping when they used less avoidance, expressed their anger and felt less fatalistic about having cancer, when compared with heterosexuals. On the other hand there was a trend for lesbian breast cancer patients to report more intrusive thoughts about their cancer and to experience less fighting spirit. These results indicate a delicacy of balance between optimism–pessimism and coping patterns (Classen *et al.*,

1996). This complexity obtains for the heterosexual breast cancer patients as well. Heterosexuals were significantly more inclined to use avoidance in their thoughts about breast cancer. They coped by using more control over their expression of anger, were more fatalistic, and expressed more fighting spirit.

Results showing that lesbians in this study were comfortable with their body image before and after breast cancer are consistent with the observations of Loulan (1984), Herzog *et al.* (1992), and O'Hanlan (1995a,b), who found that lesbians had less concern about appearance, body size and weight than heterosexual women. According to these authors the lesbian culture places less emphasis on physical aspects of appearance than the heterosexual culture.

Two pictures of social support emerge from the results. Lesbian partners were rated significantly higher in providing love and care, being willing to listen, and helping with tasks, than heterosexual spouses. Friends of the lesbian breast cancer patients were significantly more likely to both give advice and to be more critical of their lesbian friend. While heterosexual breast cancer patients were more likely to have a spouse who made demands, they were also likely to have relatives who lived nearby, who helped them with tasks. The relatives were people the heterosexual patients felt close to, and with whom they felt they had a satisfying relationship. These results are consistent with the work of Bradford *et al.* (1994), who found that while lesbians did not have the same degree of social support from their given families, they had developed a broad chosen family that provided a supportive network of relationships.

That lesbian breast cancer patients were less satisfied with their physicians is not surprising given the results of scholarship given to this topic. Stevens and Hall (1988) found that 40% of the lesbians interviewed in their study feared receiving inferior care if they 'came out' with their doctor. Hitchcock and Wilson (1992) found that lesbian patients were uncomfortable in many health care situations, which led them to develop a strategy in which they anticipated the degree of risk in self-disclosure to health professionals. As lesbians interacted with physicians and health care providers they observed their internal reactions and reevaluated how open to be in their communication.

Implications of the study

Health care professionals will find it helpful to know that there are differences in coping styles and sources of support between their lesbian and heterosexual populations. Being informed of the areas of cultural diversity, the increased vulnerability that lesbians experience in relation to the health care setting as well as the differences in coping style, i.e. expressing negative affect, can be useful in providing health care that is more understanding and sensitive to lesbians.

At the moment there are few comparison studies using lesbian subjects or reporting the Cronbach's alpha on total scores. In this study we were able to report the Cronbach's alpha on lesbian breast cancer patients using the following measures: The POMS, the IES, the CECS, the MAC, the FRI, the CARES: Medical Interaction Scale and the PRSP. For some measures, i.e. the BISS, the SAQ, and the SNSA, Cronbach's alphas were computed as single-item comparisons and are not reported here.

LIMITATIONS OF THE STUDY

The size of the lesbian sample creates a limitation in interpreting the data results. As a pilot study it was unknown how difficult patient accrual would be. Future studies will hopefully be created and enjoy a more robust attendance in recruitment. Even with the limitation of this small initial sample, significant differences were found between lesbian and heterosexual breast cancer patients in ways of coping with the disease and treatment problems, comfort with their body image, sources of social support and comfort with their physicians.

This study did not stratify data by current or past treatments due to the size of the sample. The inability to separate or control for post-operative treatment and timing of this questionnaire may have impacted data. It is possible that ongoing radiation therapy, ongoing chemotherapy, those treatments remote in the prior year or never received at all may result in different perceptions and scores.

The significant difference in time since diagnosis can affect scores in variables sensitive to time such as mood and emotional distress. The difference between the two samples points to our desire

to include lesbian breast cancer patients who were interested in the study. A time requirement (diagnosis 12–18 months before entrance to the study), important to the multicenter group therapy trial, was expanded to encourage lesbian access to the study. Future investigations are advised to recruit vigorously at the offices of breast surgeons, chemotherapists and radiotherapists.

Two additional limitations need to be discussed. The first relates to an administrative error in our use of the SAQ (Fallowfield LJ, 1993. Personal communication with Catherine Classen; Thirlaway *et al.*, 1996). When the measures for this study were chosen, we used an incomplete version of the SAQ (Fallowfield, 1993). After the data was collected and analysed, we learned that we had only two-parts of a three-part measure. Questions about the quality of patients' sexual life were added in a separate measure, the BISS (Zarcone *et al.*, 1993. The Body Image and Sexuality Scale for Women with Breast Cancer (BISS). Unpublished Scale). Though not identical measures, there is overlap between the missing section of the SAQ and the questions which were asked in the BISS. A second limitation involves the need for test-retest reliability studies using the Rating of Physician Scale designed by Warner and Zarcone, in 1993. This three-item PRSP was written to meet the needs of the multicenter study for early stage breast cancer patients (Classen *et al.*, 2000). While significant results were found comparing lesbian and heterosexual breast cancer patients, we noticed that the Cronbach's alpha was low. We hope future studies will use the measure and provide further review of the Cronbach's alpha.

CONCLUSION

We have demonstrated that research concerning lesbian and heterosexual breast cancer patients can be carried out. The first prediction, those lesbians would report greater emotional distress was not supported. The prediction that lesbians would suffer fewer problems with body image was confirmed by the data, while the corollary predicting better sexual functioning at baseline than heterosexual breast cancer patients was not confirmed. We did not find confirmation for the prediction that lesbians would show greater ability to express their feelings, more cohesiveness in

their relationships, or that they would score higher in their ability to deal with conflict. Lesbians were shown to be more likely to obtain social support from their partners and friends. The hypothesis predicting that lesbians would have a poorer perception of the medical care system than heterosexual women was supported on the PRSP. We found differences in the way lesbian breast cancer patients coped with the problems of breast cancer. Lesbians were more likely to express their anger, were less fatalistic, used less cognitive avoidance, but reported less initial fighting spirit than the heterosexual women. We believe that these results are useful in describing areas of difference between lesbian and heterosexual breast cancer patients and will be helpful in future research.

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