

# PSYCHOSOCIAL INTERVENTION FOR LESBIANS WITH PRIMARY BREAST CANCER

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## SUMMARY

This study examined the effects of a Supportive–Expressive group therapy intervention offered to lesbians with early stage breast cancer. Twenty lesbians diagnosed with breast cancer in the previous 12-months were recruited and assessed at baseline, and at 3, 6, and 12 months after the group intervention. During the 12-week intervention, group members focused on the problems of a new diagnosis, coping with the illness and treatment, mood changes, coping responses and self-efficacy, improving relationships with family, friends and physicians, the impact of the illness on life, pain and sleep, and changes in body image and sexuality. A within-subject slopes analysis was conducted on data collected for each woman over the first year. As predicted, women reported reduced emotional distress, intrusiveness, and avoidance, and improved coping. There were significant changes in their social support, but in the unexpected direction. Instrumental support and informational support declined. However, conflict in family relations also declined, while trends were found towards more cohesiveness and expressiveness. Participants reported less pain and better sleep. There were no changes in body image, sexuality, or attitudes toward health-care providers. These results suggest that Supportive/Expressive group intervention appears to be helpful for lesbians with breast cancer. Copyright © 2002 John Wiley & Sons, Ltd.

## INTRODUCTION

Illnesses such as cancer can be stigmatizing because they represent a threat to life and the potential for physical limitations. Cancer patients may experience a loss of social status, and they may feel that they are discounted and discredited in the minds of others following diagnosis or treatment (Fife and Wright, 2000). Although studies of marital stability after breast cancer have not shown differences with non-patients among heterosexual couples (Dorval *et al.*, 1999), breast disease has sometimes led to abandonment

for the patient (Yalom, 1997). Breast cancer among lesbians symbolically involves two possible sources of stigma: being lesbian and having breast cancer (Albrecht *et al.*, 1982), resulting in discrimination in medical care (Diamant, 2001; van Dam, 2001). Having breast cancer can lead to the sensation of being treated differently and subsequent feelings of stigma. Penman *et al.* (1986/1987) found that patient self-esteem became worse at years end for mastectomy patients with adjuvant treatment. Most at risk were those with less social support, greater changes in their life during the past 3 months, and those who viewed their life outcomes as less under their own personal control. Being lesbian is often stigmatized, and sexual behaviors between women are illegal in some jurisdictions (Solarz, 1999a). Stigma and reactions to it have been found to reduce social interaction,

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emotional well-being, and self-esteem (Link *et al.*, 1997; McGregor *et al.*, 2001; Miles *et al.*, 1997).

Group therapy has been found to be helpful in providing psychological support to people coping with cancer (Gordon *et al.*, 1980; Worden and Weisman, 1984; Cain *et al.*, 1986). In the last 20 years, group interventions offered to cancer patients have been found to improve mood (Spiegel *et al.*, 1981), psychological adjustment (Worden and Weisman, 1984; Cain *et al.*, 1986; Fawzy *et al.*, 1990), coping strategies (Telch and Telch, 1986; Fawzy *et al.*, 1990; Heinrich and Schag, 1985; Bergland *et al.*, 1994), quality of life (Telch and Telch, 1986; Bergland *et al.*, 1994; Fawzy *et al.*, 1990), and social support (Bloom *et al.*, 1999), as well as to reduce traumatic stress (Classen *et al.*, 2001).

One of the issues that is less well understood pertains to identifying characteristics of subpopulations of patients most likely to benefit from support groups. Research has identified that people who experience problems with stress, social isolation, or who are in need of social support as those most likely to benefit from participation in groups (Irvine *et al.*, 1991; Woods and Earp, 1978; Jamison and Wellisch, 1978; Northouse, 1981; Reynolds and Kaplan, 1990). Bloom (1982) also confirmed that adjustment among breast cancer patients was greater among those who had more social contact and perceived family cohesiveness, further suggesting that group support may be particularly helpful for subpopulations that feel isolated.

Learning how women from different cultural backgrounds and sexual orientations respond to the challenges of breast cancer is now a focus of the national health-care agenda (Blumenthal, 1998). Employing cultural competence in the care of diverse patients has been shown to enhance compliance (Kang and Bloom, 1993). The health problems of some subgroups of women have continued to receive little attention. Women who self-identify as lesbian may experience the stress of stigma both within and outside the health-care setting. Although research regarding lesbian health issues has been limited (Solarz, 1999a, 1999b), there are data indicating that lesbian alienation from health care results from a lack of others' awareness about the lesbian patients' needs. Health-care professionals who are sensitive to the particular needs of subgroups of cancer patients have called for further research to determine the extent to which lesbian patient needs differ from

those of heterosexual patients (O'Hanlan, 1995a,b; Solarz, 1999a,b).

Although it is not known how many lesbians there are in the United States, the estimated prevalence of being lesbian ranges from 2 to 10% of American women (Solarz, 1999a). There is evidence that lesbians have been marginalized in American culture, (Pagelow, 1980), encounter discrimination based on sexual orientation (Krieger and Sidney, 1997), experience social isolation (Savin-Williams, 1994), undergo higher levels of depression (Nurius, 1983; Bradford *et al.*, 1994), endure stress and reduced social support from families of origin (Bradford *et al.*, 1994), and have a poorer perception of the medical care system than do heterosexual women (O'Hanlan, 1995b; Rankow, 1995; Trippet and Bain, 1992; Stevens and Hall, 1988). In a recent document on lesbian health, Solarz (1999a) writes, 'In addition to facing many of the same stressors as heterosexual women, women who self-identify as lesbian may also experience stressors not commonly faced by heterosexual women, such as 'stigmatization' both within and outside the health care setting'. (p. 59)

The literature also supports the idea that lesbians who experience exclusion from the mainstream culture develop a specific coping style to deal with the stresses of their minority status (Sophie, 1987). This view argues that lesbians become more independent than their heterosexual counterparts, develop a positive self-image, place less emphasis on body image and focus more on an individual's personality (Herzog *et al.*, 1992; Loulan, 1984; O'Hanlan, 1995b). To date, there has been a paucity of systematic research to study the coping patterns of lesbian breast cancer patients.

Among women with breast cancer, do lesbians face either greater or different challenges than heterosexual women? In a recent study, we (Fobair *et al.*, 2001) examined the needs of lesbian breast cancer patients, comparing baseline data from educationally matched participants in two separate intervention studies (each of which used the same intervention). The groups consisted of 246 heterosexual women from a multicenter breast cancer trial and 29 lesbian women from a single site trial. We predicted lesbian patients would report higher scores on measures of mood disturbance due to possible problems with lack of support from families of origin and/or medical staff; would suffer fewer problems with body image and sexual activity; would show more expressiveness and cohesiveness, and would ex-

perience less partnership conflict than heterosexual women. Furthermore, we predicted that lesbians would be more dissatisfied with their support; would more likely obtain social support from their partners and friends; and would have a poorer perception of the medical care system. Using standardized measures, we found that lesbian patients did not report higher scores in mood disturbance. However, lesbians did experience fewer problems with body image and were significantly more comfortable in showing their bodies to others both prior to and following breast cancer. No differences were found between groups in the number who had intimate relationships or engaged in sexual activity, nor were there differences in relational expressiveness, cohesiveness or conflict. Lesbian patients were more likely to obtain social support from their partners and friends while heterosexuals received more support from their families of origin. While there were no differences between groups in specific domains of social support (including emotional, negative, instrumental, or informational support), lesbian patients were less satisfied overall with their social support (Fobair *et al.*, 2000). Lesbians were more likely to perceive the medical care system as less supportive than were heterosexual breast cancer patients. There were also differences in expressions of coping. Lesbians expressed anger with greater ease, they used less cognitive avoidance, and they were less fatalistic. Lesbians reported less 'fighting spirit' when compared with heterosexual breast cancer patients.

In the present study, our aim was to examine the usefulness of Supportive/Expressive group therapy in helping lesbians with the problems of a recent diagnosis of breast cancer. To do this, we compared baseline scores for 20 lesbian group participants with their post-treatment scores at 12 months. We predicted that there would be improvement in mood, psychological distress, coping, body image, interpersonal relationships, sexuality, social support, attitudes toward health care providers, and impact of illness on life, pain and sleep.

## METHODS

### *Research participants*

Lesbians with primary breast cancer were solicited for participation in this study by two

recruiters who used newspaper stories, advertisements, fliers, and brochures distributed to physicians' offices and community agencies throughout the greater Bay Area of Northern California. All participants provided informed consent prior to their participation in this study.

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–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) presence of other major medical problems 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.

In our original survey of lesbians with breast cancer, 29 women were eligible to participate and therefore participated in the baseline and follow-up surveys; however, only 20 of these women agreed to participate in the group intervention. All 20 women recruited for this study provided consent, participated in the group intervention, and completed the questionnaires at baseline, 3, and 6 months. Three women were unavailable for the final assessment at 12 months. However, because a slope can be calculated based on two or more points, individual slopes for each measure were created from all available data for each of the 20 participants. All available data for the three women with incomplete follow-up were included in the slopes analysis; final sample sizes are given in the table.

Overall, the 20 participants were a mean age of 47, highly educated (60% post-graduate education), and predominantly European American. Most of the women were employed (90%) with the majority working in professional jobs (80%). Seventy percent of the sample earned \$60,000 or less. At baseline, 67% were partnered, and these

relationships remained stable. Six (30%) of the women had children. Half of the women had Stage 1 breast carcinoma, and 50% had nodal involvement. The mean time elapsing from diagnosis to participating in this study was 9.3 months. Fifty-eight percent underwent a mastectomy, 53% had chemotherapy, 55% had radiation therapy, and 32% were taking tamoxifen at baseline.

### Procedure

Questionnaires were completed at baseline and at 3, 6 and 12 months after the group intervention began. The group intervention consisted of 12 meetings each of 90 min length. During the study there were four groups (Peninsula, San Francisco (2), and Santa Rosa) each having four or more group members. Group leaders were licensed clinical social workers and lesbian. All groups were audio taped. Group attendance records showed that 95% of group members attended each meeting.

### Group intervention

In Supportive-Expressive group therapy, the emphasis is on allowing open and honest expression of thoughts and emotions, receiving and offering support, and learning new ways to cope with having cancer. Therapists serve to guide the quality of discussion to be personal, specific to cancer, emotionally expressive, and relevant to others in the group. While patients' pressing problems take precedence for group discussion, therapists encourage the frank discussion of important themes when they arise spontaneously in the group. These topics include the realization of mortality, 'why me?' feelings of uncertainty and lack of control, treatment-related concerns, doctor-patient relationships, self and body image, the effect of illness on the family, social relationships, coping with problems, learning from each other, and reordering life values, personal goals and the meaning of the illness in one's life. The Supportive-Expressive group therapy intervention was not altered for this pilot study with lesbian group members, except to select co-leaders who were lesbians.

### Measures

Most measures listed below were described in a previous publication. For a fuller description of these measures see Fobair *et al.* (2001).

*Demographic and medical variables.* The Background questionnaire was used to collect demographics information, including age, education, employment status, main occupation, household income, sexual orientation, religious affiliation, marital/relationship status, and the number of children (Miller, 1991, Background Questionnaire. Unpublished Measure).

Medical variables included number of months elapsed since diagnosis, stage (stages I-III), type of cancer treatment, whether or not the patient had a mastectomy, and whether or not the patient was in constant pain.

*Primary outcome measures.* The Impact of Event Scale (IES) is a 15-item measure designed to assess symptoms of subjective distress that can occur in response to any kind of stressful event, such as being diagnosed with breast cancer (Horowitz *et al.*, 1979). In this study, participants were asked to estimate the frequency of experiencing a variety of intrusive and avoidance symptoms during the past 7 days in response to having cancer. This measure has been used with a variety of populations and has been demonstrated to be a valid and reliable measure (Zilberg *et al.*, 1982; Horowitz *et al.*, 1993). In this study, the Cronbach's alpha for the IES total was 0.92, 0.88 for intrusion, and 0.87 for avoidance.

The Profile of Mood States (POMS; McNair, *et al.*, 1971) is a 65-item measure that assesses mood disturbance. It yields a total score and scores for each of its five subscales: anxiety, depression, hostility, confusion, vigor, and fatigue. Internal consistency has been shown to range from 0.87 to 0.95 (McNair *et al.*, 1971). Cronbach's alpha for the lesbian sample was 0.98 for total mood disturbance.

The Hospital Anxiety and Depression Scale (HADS) is a 14-item measure (Zigmond and Snaith, 1983) that evaluates two major indices of emotional distress: anxiety and depression. It was designed for use with physically ill patients and has been used extensively in medical settings. It has good internal consistency on both the anxiety and depression subscales. In this sample, the Cron-

bach's alpha was 0.94 for the HADS total score, 0.90 for anxiety, and 0.90 for depression. The HADS has been found to provide clinically meaningful results and is sensitive to change (Herrmann, 1997). The POMS screens for normal variation in mood disturbance, while the HADS specifically measures symptomatology of clinical depression and anxiety.

The Mini-Mental Adjustment to Cancer (Mini-MAC; Watson *et al.*, 1994) is a 29-item version of the Mental Adjustment to Cancer Scale (MAC; Watson *et al.*, 1994) designed to assess coping responses to cancer. 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). It includes five subscales: fighting spirit, helpless/hopeless, anxious preoccupation, fatalism, and denial/avoidance. Internal consistency of the subscales for the present sample was 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.

The Stanford Emotional Self-Efficacy Scale – Cancer (SESES – C; Giese-Davis *et al.*, in press) assesses self-efficacy in three domains: the ability to communicate feelings to significant others, the ability to face issues of death and dying, and the ability to remain focused in the present. It includes 15 items rated in 10-point increments on a scale ranging from 0 = 'not at all confident' to 100 = 'completely confident'. The total score was the mean response across all 15 items on the 0–100 point scale. This scale has been shown to have adequate internal consistency, test–retest reliability and generalizability among cancer patients (Giese-Davis *et al.*, in press). The Cronbach's alpha for the lesbian sample were 0.92 for all items, 0.92 for the subscale on ability to express emotions, 0.77 for the subscale on confronting death and dying, and 0.86 for the subscale on ability to focus on and enjoy the present.

*Secondary outcome measures.* The Body Image and Sexuality Scale for Women With Breast Cancer (BISS; Zarcone *et al.*, 1993) assesses the impact of breast cancer on a woman's sexuality and body image. In this study, five items were used to assess current satisfaction and comfort with body image, e.g. 'How comfortable are you showing your body to others since having breast cancer?' 'How comfortable are you with your body

weight since having breast cancer?' Twelve items were used to assess satisfaction with sexuality, e.g. 'Since cancer how satisfied are you with your sex life?' 'Has having breast cancer affected the frequency with which you feel sexually satisfied?' In this study, the Cronbach's alpha for body image was 0.78 and 0.94 for satisfaction with sexuality.

The Family Relations Index (FRI; Moos and Moos, 1986) is a subscale of the Family Environment Scale. This subscale assesses 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 with cancer patients (Spiegel *et al.*, 1983). In the present sample, the Cronbach's alpha was 0.91 for the total FRI, 0.88 for cohesion, 0.76 for expressiveness, and 0.80 for conflict.

The Social Network and Support Assessment (SNSA) is a 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 (Berkman and Syme, 1979, Berkman, 1986, Seeman and Berkman, 1988). It was used to assess the amount and quality of social contacts and support. The SNSA includes five subscales: emotional support (availability of caring individuals to whom to share one's feelings); informational support (the provision of knowledge relevant to the situation); instrumental support (helpful assistance that others provide); negative support (help offered, but experienced as intrusive, or unhelpful); and satisfaction with support. 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?' Using the five subscales commonly used with this measure, the Cronbach's alpha for this sample was 0.61 for emotional support, 0.59 for negative support, 0.59 for instrumental, 0.47 informational support, and –0.23 for satisfaction with support.

Two measures of satisfaction with medical care were used in this study: (1) the Medical Interaction Scale of the cancer rehabilitation evaluation system (CARES) and (2) the Patient Rating Scale of Physicians (PRSP). The Medical Interaction Scale is an 11-item component of the CARES

(Schag and Heinrich, 1989, 1990). 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 the statement best 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. In this study, the Cronbach's alpha was 0.83.

The Patient Rating of Physician Scale (PRSP) was developed to assess the patient's attitudes toward health-care providers (Warner and Zarccone, 1993). 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 the statement best applies to her by using a 5-point Likert scale ranging from 'not at all' to 'extremely'. The Cronbach's alpha was 0.95 for the first two questions and 0.71 for the standardized scores on all three items.

Quality of life was assessed using the Impact of Illness on Your Life questionnaire. This was a modified version of a questionnaire developed to assess the emotional impact of end-stage renal disease (Devins *et al.*, 1983–1984). Participants were asked to rate the extent to which their illness and/or its treatment had interfered with different aspects of their lives during the past two weeks on a 7-point Likert scale with options ranging from 'not very much' to 'very much'. The different aspects of life included health, diet, work, active recreation, passive recreation, financial situation, relationship with one's spouse, sex life, family relations, other social relationships, self expression/self improvement, religious expression and community and civic involvement. This measure has been shown to be positively associated with mood disturbance in end-stage renal patients (Devins *et al.*, 1983–1984; Devins *et al.*, 1993) and multiple sclerosis (Devins *et al.*, 1993). The Cronbach's alpha for this sample was 0.91.

Pain was measured by self-report using a standard 10 cm linear analog scale whose validity was supported by findings of Spiegel and Bloom

(1983a,b) that changes in this measure were related to mood disturbance, pain sensation, suffering, frequency and duration. Constant pain was assessed using a self-report question of: 'Approximately how many times in the past six months has the pain occurred?' The response options included either checking a box to indicate that the respondent experienced 'constant pain' or writing a number to indicate the number of times. If the respondent checked constant pain, we scored a '1'; if the respondent wrote a number of zero or greater we scored that as an '0' for constant pain.

The quality and quantity of sleep and daytime sleepiness was assessed by a brief questionnaire based upon the Structured Insomnia Interview. This scale was developed in collaboration with the Stanford University Medical School Sleep Disorders Clinic who has used it extensively (Stanford Sleep Disorders Clinic, 1979).

#### *Data analysis*

Means and standard deviations were calculated to describe the distributions of the demographic, medical and psychological variables that were measured on continuous scales. Percentages were computed to describe the distributions of the demographic and medical variables that were assessed using categorical measures. For psychosocial measures, baseline means and standard deviations were computed, as were individual slopes of scores for each woman for each measure over time. One sample *t*-tests were conducted to test whether slopes differed significantly from zero.

## RESULTS

#### *Tests of the hypotheses*

Significant improvements were found on all of the primary outcome measures of mood disturbance and distress (POMS, IES, HADS, the MAC and Self-Efficacy). Table 1 summarizes results showing the treatment effect using a slopes analysis for each woman participating in the study over the first year. The mean slope values presented in Table 1 show that both the scores on POMS total mood disturbance and the tension/anxiety subscale declined over time, as did the IES intrusion and avoidance scores, the HADS anxiety

Table 1. Baseline means, standard deviations, and slopes analysis for psychosocial measures ( $n=20$ )

Variable	<i>n</i>	Baseline mean	S.D.	Slope	<i>T</i> -value	<i>P</i> -value
POMS-TMD	20	34.6	33.6	-1.17	-2.43	0.03
POMS-tension	20	11.3	6.3	-0.30	-3.11	0.01
HADS-anxiety	20	8.2	4.2	-0.15	-2.52	0.02
IES-intrusion	20	16.6	8.8	-0.38	-3.53	0.002
IES-avoidance	20	12.1	9.1	-0.23	-2.45	0.02
MAC-anxiety	20	21.6	5.5	-0.23	-3.57	0.002
Self-efficacy enjoy at present	20	68.6	21.6	0.49	2.31	0.03
BISS-body Image	20	2.6	0.9	0.01	0.71	0.48
BISS-sexuality	20	3.0	0.9	0.01	0.62	0.54
FRI-conflict*	16	2.8	2.3	-0.09	-2.78	0.01
Yale- SNSR	20	3.1	0.9	-0.03	-2.49	0.02
<i>Instrumental</i>						
Yale- SNSR information	20	3.1	0.6	-0.02	-2.42	0.03
CARES	20	6.6	5.4	0.04	0.44	0.66
Patient rating of physicians	20	3.9	0.9	0.02	0.85	0.41
Impact of illness	20	39.6	18.9	-0.49	-1.62	0.12
Sleep	20	2.7	1.0	-0.03	-2.27	0.03
Pain	20	1.7	1.8	-0.06	-2.42	0.03

\*The only measure on which the sample size differed ( $n=16$ ).

subscale, the MAC anxiety/preoccupation subscale, and the Self-Efficacy subscale enjoy at present.

Table 1 also describes changes in the secondary outcome variables following group therapy. Two components of social support (SNSA), instrumental and informational social support showed a significant reduction over time, contrary to our hypothesis. Family relations, however, showed signs of improvement. Scores on the Family Environment Scale (FRI) showed less conflict [ $t(18)=-2.78$ ,  $p=0.01$ ], and there were trends towards better family cohesion, and expressiveness. Furthermore, there were significant reductions in pain (at the moment) and improvement in sleep (waking during the night) by the end of the study. There were no changes in body image, sexuality, and attitudes towards health-care providers or on the impact of illness on life.

## DISCUSSION

The findings of this study suggest that a 12-week group intervention can help lesbian breast cancer patients to adjust to their diagnoses. We found that, over time, participants showed lower traumatic stress (fewer intrusive thoughts and less avoidance), better mood (less anxiety reported on

two measures), less anxiety/preoccupation as a coping strategy, and a better sense of self-efficacy (i.e. enjoying the present moment). There was a reduction of conflict in the home, less pain and better sleep. However, contrary to our hypotheses, levels of two types of social support, instrumental and informational support, declined significantly following the intervention.

Our results are consistent with those of previous studies showing that following group intervention patients report improved mood and psychological adjustment (Fawzy *et al.*, 1990; Spiegel *et al.*, 1981, 1999), reduced traumatic stress (Classen *et al.*, 2001), and better coping (Bergland *et al.*, 1994; Heinrich and Schag, 1985; Greer *et al.*, 1992). Lesbian group members in the present study showed significant improvements in all the three of the measures of distress (IES, POMS, HAD) and in both measures of coping (MAC, Self-Efficacy), providing a strong indication of the groups' impact.

Our results are also similar to the work of van den Borne *et al.* (1986) and Thoits *et al.* (2000), who found improved mood among cancer patients following contact with fellow patients, and to Giese-Davis *et al.* (in press), who found that the ability to focus on the present moment improved among metastatic breast cancer patients following a group intervention. As a traumatic stressor, cancer spans past events, current experience, and

future concerns (Butler *et al.*, 1999). For many lesbians, the stress of cancer may be a reminder of earlier stresses (Pagelow, 1980; Nurius, 1983; O'Hanlan, 1995a,b; Stevens and Hall, 1988; Stevens, 1992; Savin-Williams, 1994). Horowitz (1986) proposes that the cycle of intrusion and avoidance characteristic of stress reflects the difficulty in integrating trauma-related information into existing schemas and in tolerating painful negative affect associated with the thoughts and memories. Cognitive processing is achieved when the meaning of the event has been reframed so that it is assimilated into prior beliefs. Many aspects of Supportive-Expressive group therapy, such as encouraging open expression of emotion, dealing directly with fears, encouraging mutual support and exploring the meaning of one's present situation, make the Supportive-Expressive model of group therapy a useful intervention for subpopulations who have endured stressful experiences.

We were puzzled by the significant reduction in scores for instrumental and informational social support found over the course of the study. This was contrary to our expectation that we would show improvements in social support among lesbians who participated in group therapy. Social support is considered as a coping resource, and it refers to functions performed for individuals by others like family members, friends and co-workers who provide instrumental, informational, and/or emotional assistance (House and Kahn, 1985; Thoits, 1995). Perhaps our participants became more critical of how these functions were performed among their sources of social support. A literature review by van den Borne, *et al.* (1986) reported in Taylor and Lobel (1989), found that cancer patients' contacts with fellow cancer patients consistently led to a higher level of information, which perhaps led them to raise their level of expectations regarding social support. Unpublished notes from the group leaders as well as weekly audiotapes suggest that lesbians attending the Supportive-Expressive groups experienced a good deal of social support during the group sessions. Among metastatic patients, Spiegel and Yalom (1978) found that patient's social isolation was countered by developing strong relationships among members. Ending the group may have returned lesbian group members to a sense of comparative isolation, a problem noted in the lesbian literature by Kirkpatrick (1991), see also Rankow (1995), Savin-Williams (1994) and Matthews (1998).

A few words about areas where predicted changes did not occur: body image, sexuality, relations with health-care providers, and the impact of the illness on their life. Previous work supports (Herzog *et al.*, 1992; Bradford and Ryan, 1998) the idea that lesbians are comfortable with their body image. Perhaps because lesbian breast cancer survivors rate their body image higher than heterosexual breast cancer survivors (Fobair *et al.*, 2001), there was less need for improvement. The stability of lesbian scores on body image is in contrast to the work of Ganz *et al.* (1992) and Bloom *et al.* (1998), who observed that body image scores among breast cancer patients changed with time. Ganz *et al.* (1992) found initial low scores in body image, while later scores among women with breast cancer improved with time. Bloom *et al.* (1998) found that breast cancer patients interviewed soon after diagnosis had higher initial scores on body image than those interviewed 6-7 months after diagnosis. Differing results suggest the need for further study.

The absence of change in sexual functioning or sexual activity following the intervention may also be a positive outcome. We note that partnered relationships were maintained. Furthermore, sexual functioning among women who have had breast cancer may be largely due to treatment effects that subside over time. It is yet unclear as to whether a 10-week intervention using Supportive-Expressive group therapy is specific enough in addressing the emotional factors involved in sexual functioning.

In the present study, ratings of physician and medical care did not change following the intervention. According to our previous research (Fobair *et al.*, 2001), there was room for improvement, since lesbian breast cancer patients were more likely to have a poorer perception of the medical care system than heterosexual breast cancer patients. We expected that group members would encourage one another, be more assertive and thereby improve their relationships with physicians, and we observed evidence for this in the groups. Nonetheless, this was not reflected on the measures used in this study. One might wonder if the experience of feeling marginalized by American culture may have contributed to the lesbians' views of medical care as suggested by Robertson (1999) and Solarz (1999a).

It is important to acknowledge several limitations of this study, including the small sample size and the absence of a control group of lesbians who

did not receive group therapy. Previous research has shown that women with breast cancer improve on psychosocial measures even without psychosocial intervention (Bloom *et al.*, 1987), so further research with lesbians that uses a control group design would overcome this limitation. Furthermore, the sample was predominantly highly educated and European American and hence may not be representative of lesbians of other socioeconomic and ethnic backgrounds. In addition, the outcome measures that were used were not chosen because of their relevance to lesbians' issues, and therefore they may have failed to pick up changes specific to this population that resulted from participating in the intervention. For example, if lesbians benefited in becoming more comfortable with handling others' reactions to their sexual orientation or with issues in their relationships with their partners, we would have been unable to detect this with our measures. Finally, the measures were self-report and therefore assessed changes that occurred only from the lesbians' perspective (e.g. not from that of their partners or physicians).

Despite these limitations, there are important strengths of this study. First, this study examines outcomes following a group therapy intervention with a population of women who have had breast cancer and for which there are no previous published psychosocial intervention studies. Second, specific measures were adequately sensitive to show significant and beneficial changes even in this small sample. Furthermore, the results are consistent with previous research showing the efficacy of Supportive–Expressive group therapy, which supports the likely generalizability of this therapeutic approach to lesbians with primary breast cancer.

The results of this study suggest that lesbians with breast cancer experienced improvements in their quality of life on a number of dimensions following group therapy. It is our hope that such benefits can also bolster their ability to cope with the stigma that can accompany being a lesbian with breast cancer.

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#### REFERENCES

- Albrecht GL, Walker VG, Levy JA. 1982. Social distance from the stigmatized: A test of two theories. *Soc Sci Med* **16**: 1319–1327.
- Bergland G, Bolund C, Gustafsson V, Sjoden P. 1994. Starting again: A comparison study of a group rehabilitation program for cancer patients. *Acta Oncol* **32**: 15–21.
- Berkman LF. 1986. Social networks, support, and health: Taking the next step forward. *Am J Epidemiol* **123**: 559–562.
- Berkman LF, Syme SL. 1979. Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda County residents. *Am J Epidemiol* **109**: 186–204.
- Bloom JR. 1982. Social support, accommodation to stress and adjustment to breast cancer. *Soc Sci Med* **16**: 1329–1338.
- Bloom JR, Cook M, Fotopoulos S, *et al.* 1987. Psychological response to mastectomy: A prospective comparison study. *Cancer* **59**: 189–196.
- Bloom JR, Stewart SL, Johnston M, Banks P. 1998. Intrusiveness of illness and quality of life of young women with breast cancer. *Psychooncology* **7**: 89–100.
- Bloom JR, D'Onofrio C, Banks P, *et al.* 1999. A psychoeducational group intervention for young women with breast cancer: Design and process evaluation. *Cancer Res. Ther Control* **8**: 93–102.
- Blumenthal SJ. 1998. Healthy women: 2000 and beyond. In *Textbook of Women's Health*, Wallis L. (ed.). Lippincott, Williams and Wilkins Publishing Co.: Philadelphia.
- Bradford J, Ryan C. 1998. The National Lesbian Health Care Survey: An overview. In *The Sourcebook of Lesbian/Gay Health Care* (2nd edn), Shernoff M, Scott WA (eds). Nation Lesbian/Gay Health Foundation: Washington DC; 30.
- Bradford J, Ryan C, Rothblum ED. 1994. National Lesbian Health Care Survey: Implications for mental health care. *J Consult Clin Psychol* **62**: 228–242.
- Butler LD, Koopman C, Classen C, Spiegel D. 1999. Traumatic stress, life events, and emotional support in women with metastatic breast cancer: Cancer-related traumatic stress symptoms associated with past and current stressors. *Health Psychol* **18**: 555–560.
- Butler LD, Field NP, Hastings TA, Seplaki JC, Spiegel D. Anticipating loss: Temporal stressors and trau-

- matic stress symptoms in husbands/partners of metastatic breast cancer patients (in submission).
- Cain EN, Kohorn EI, Quinlan DM, Latmer K, Schwartz PE. 1986. Psychosocial benefits of a cancer support group. *Cancer* **57**: 183–189.
- Classen C, Butler LD, Koopman C, et al. 2001. Supportive-expressive group therapy and distress in patients with metastatic breast cancer. *Arch Gen Psychiatry* **58**: 494–501.
- Devins GM, Binik YM, Hutchinson TA, Hollomby DJ, Barre PE, Guttman RD. 1983–1984. The emotional impact of end-stage renal disease: Importance of patients' perception of intrusiveness and control. *Int J Psychiat Med* **13**: 327–343.
- Devins GM, Edworthy SM, Leendert CP, Mandin H, Seland TP, Klein CM. 1993. Illness intrusiveness and depressive symptoms over the adult years: Is there a differential impact across chronic conditions? *Can J Behav Sci* **25**: 400–413.
- Diamant AL. 2001. Disparities in health care among women: Studying the effect of sexual orientation. Abstract of The National Lesbian Health Conference 2001: Challenges of the New Millennium, p. 17.
- Dorval M, Maunsell E, Taylor-Brown J, Kilpatrick M. 1999. Marital stability after breast cancer. *J Natl Can Inst* **91**: 54–59.
- Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R, Morton D. 1990. A structured psychiatric intervention for cancer patients. 1. Changes over time in methods of coping and affective disturbance. *Arch Gen Psychiatry* **47**: 720–725.
- Fife BL, Wright ER. 2000. The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J Health Soc Behav* **41**: 50–67.
- Fobair P, O'Hanlan K, Koopman C, Classen C, DiMiceli S, Spiegel D. 2000. Psychosocial changes among lesbian breast cancer patients following supportive-expressive Group Therapy. Paper presented at 5th World Congress of Psycho-Oncology, September 3–7, 2000. Melbourne, Australia.
- Fobair P, O'Hanlan K, Koopman C, et al. 2001. Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. *Psycho-oncology* **10**: 40–51.
- Ganz PA, Lee JH, Sims MD, et al. 1992. Exploring the influence of multiple variables on the relationship of age to quality of life in women with breast cancer. *J Clin Epidemiol* **45**: 473–485.
- Ganz PA, Desmond KA, Belin TR, Meyerowitz BE, Rowland JH. 1999. Predictors of sexual health in women after a breast cancer diagnosis. *J Clin Oncol* **17**: 2371–2380.
- Giese-Davis J, Koopman C, Butler LD, et al. (in press) The Stanford Emotional Self-Efficacy Scale-for Serious Illness: Reliability, validity, and generalizability. In *Biobehavioral Perspectives on Health and Disease Prevention*, Temoshok LP (Ed.). Harwood Academic Publishers: Newark.
- Gordon WA, Freidenbergs I, Diller L et al. 1980. Efficacy of psychosocial intervention with cancer patients. *J Consult Clin Psychol* **48**: 743–759.
- Greer S, Moorey S, Watson M. 1989. Patients' adjustment to cancer: The Mental Adjustment to Cancer (MAC) Scale vs. clinical ratings. *J Psychosom Res* **33**: 373–377.
- Greer S, Moorey S, Baruch JD et al. 1992. Adjuvant psychological therapy for patients with cancer: a prospective randomised trial. *Br Med J* **304**: 675–680.
- Heinrich RL, Schag CC. 1985. Stress and activity management: Group treatment for cancer patients and spouses. *J Consult Psychol* **53**: 439–446.
- Herrmann C, 1997. International experiences with the Hospital Anxiety and Depression Scale—a review of validation data and clinical results. *J Psychosom Res* **42**: 17–41.
- Herzog DB, Newman KL, Kerry L, Yeh CJ, Warshaw M. 1992. Body image satisfaction in homosexual and heterosexual women. *Int J Eat Disord* **11**(4): 391–396.
- Horowitz MJ. 1986. Stress-response syndromes: A review of posttraumatic and adjustment disorders. *Hosp Community Psychiatry* **37**: 241–249.
- Horowitz M, Wilner N, Alvarez W. 1979. Impact of Event Scale: A measure of subjective stress. *Psychosom Med* **41**: 209.
- Horowitz MJ, Field NP, Classen C. 1993. Stress response syndromes and their treatment. In Goldberger L, Breznitz S. (eds). *Handbook of Stress*. (2nd edn.), The Free Press: New York; 757–773.
- House JS, Kahn RL. 1985. Measures and concepts of social support. In *Social Support and Health*, Cohen S, Syme SIL (eds). Academic Press: Orlando, FL; 83–108.
- Irvine D, Brown D, Crooks D, Roberts J, Browne G. 1991. Psychosocial adjustment in women with breast cancer. *Cancer* **67**: 1097–1117.
- Jamison KR, Wellisch DK. 1978. Psychosocial aspects of mastectomy: I. The women's perspective. *Am J Psychiatry* **135**: 432–436.
- Kang SH, Bloom JR. 1993. Social support and cancer screening among older black Americans. *J Natl Cancer Inst* **85**: 737–742.
- Kirkpatrick, M. 1991. Lesbian couples in therapy. *Psychiat Ann* **21**: 491–496.
- Krieger N, Sidney S. 1997. Prevalence and health implications of anti-gay discrimination: A study of black and white women and men in the CARDIA cohort. Coronary Artery Risk Development in Young Adults. *Int J Health Serv* **27**: 157–176.
- Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L. 1997. On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *J Health Soc Behav* **38**: 177–190.

- Loulan J. 1984. *Lesbian Sex*. Spinsters Ink: Minneapolis, MN.
- Matthews AK. 1998. Lesbians and cancer support: Clinical issues for cancer patients. *Health Care Women Int* **19**: 193–203.
- McGregor BA, Carver CS, Antoni MH, Weiss S, Yount SE, Ironson G. 2001. Distress and internalized homophobia among lesbian women treated for early stage breast cancer. *Psychol Women Q* **25**: 1–9.
- McNair PM, Lorr M, Drappleman L. 1971. *POMS Manual*. San Diego Educational and Industrial Testing Services: San Diego, CA.
- Miles MS, Burchinal P, Holditch-Davis D, Wasilewski Y, Christian B. 1997. Personal, family, and health-related correlates of depressive symptoms in mothers with HIV. *J Fam Psychol* **11**: 23–34.
- Miller EL. 1991. Background Questionnaire. Unpublished Measure.
- Moos RH, Moos BS. 1986. *Family Environment Scale Manual* (2nd edn). Consulting Psychologists Press, Inc: Palo Alto, CA.
- Northouse LL. 1981. Mastectomy patients and the fear of cancer recurrence. *Cancer Nurs* **4**: 213–220.
- Nurius PS. 1983. Mental health implications of sexual orientation. *J Sex Res* **19**: 119–136.
- O'Hanlan KA. 1995a. Lesbians in health research. In: *Recruitment and Retention of Women in Clinical Studies. A Report of the Workshop Sponsored by the Office of Research on Women's Health*. Office of Research on Women's Health, National Institutes of Health: [Rockville, MD:] 101–104.
- O'Hanlan KA. 1995b. Lesbian health and homophobia: Perspectives for the treating obstetrician/gynecologist. *Curr Probl Obstet Gynecol Fertil* **18**: 94–133.
- Pagelow MD. 1980. Heterosexual and lesbian single mothers: A comparison of problems, coping, and solutions. *J Homosex* **5**: 189–204.
- Penman D, Bloom JR, Fotopolis S, et al. 1986/1987. The impact of mastectomy on self-concept and social function: A combined cross-sectional and longitudinal study with comparison groups. *Women Health* **11** (3–4): 101–129.
- Pettingale KW, Morris T, Greer S, Haybittle LL. 1985. Mental attitudes to cancer: An additional prognostic factor. *Lancet* **1**: 750.
- Rankow, EJ. 1995. Lesbian health issues for the primary care provider. *J Fam Pract* **40**: 486–493.
- Reynolds P, Kaplan 1990. Social connections and risk for cancer: Prospective evidence from the Alameda County Study. *Behav Med* **16**: 101–110.
- Robertson MM. 1999. Lesbians as an invisible minority in the health services arena. *Health Care Women Int* **13**: 155–163.
- Savin-Williams RC. 1994. Verbal and physical abuse as stressors in the lives of lesbian, gay male, and bisexual youths: Associations with school problems, running away, substance abuse, prostitution, and suicide. *J Consult Clin Psychol* **62**: 261–269.
- Schag CAC, Heinrich RL. 1989. *Cancer Rehabilitation Evaluation System (CARES): Manual* (1st edn). CARES Consultants: Los Angeles, CA.
- Schag CAC, Heinrich RL. 1990. Cancer rehabilitation evaluation system. *Oncology* **4**: 135–138.
- Seeman TE, Berkman LF. 1988. Structural characteristics of social networks and their relationship with social support in the elderly: Who provides support. *Soc Sci Med* **23**: 737–749.
- Solarz AL. 1999a. Lesbian health: Current assessment and directions for the future. *Project Report from the Office of Research on Women's Health at the National Institutes of Health, Institute of Medicine*. National Academy Press: Washington, DC.
- Solarz AL. 1999b. Lesbian health care issues: exploring options for expanding research and delivering care. *AWHONN Lifelines* **3**: 13–14.
- Sophie J. 1987. Internalized homophobia and lesbian identity. *J Homosex* **14**: 53–65.
- Spiegel D, Bloom JR. 1983a. Pain in metastatic breast cancer. *Cancer* **52**: 341–345.
- Spiegel D, Bloom JR. 1983b. Group therapy and hypnosis reduce metastatic breast carcinoma pain. *Psychosom Med* **45**: 333–339.
- Spiegel D, Yalom ID. 1978. A support group for dying patients. *Int J Group Psychother* **28**: 233–245.
- Spiegel D, Bloom J, Yalom ID. 1981. Group support for patients with metastatic breast cancer. *Arch Gen Psychiatry* **38**: 527–533.
- Spiegel D, Bloom JR, Gottheil E. 1983. Family environment as a predictor of adjustment to metastatic breast carcinoma. *J Psychosoc Oncol* **1**: 33.
- Spiegel D, Morrow GR, Classen C, et al. 1999. Group psychotherapy for recently diagnosed breast cancer patients: a multicenter feasibility study. *Psycho-Oncology* **8**: 482–493.
- Stevens PE. 1992. Lesbian health care research: A review of the literature from 1970 to 1990. *Health Care Women Int* **13**(2): 91–120.
- Stevens PE, Hall JM. 1988. Stigma, health beliefs and experiences with health care in lesbian women. *Image J Nurs Sch* **20**(2): 69–73.
- Stanford Sleep Disorders Clinic. 1979. unpublished measure.
- Taylor SE, Lobel M. 1989. Social comparison activity under threat: Downward evaluation and upward contacts. *Psychol Rev* **96**: 569–575.
- Telch CF, Telch MJ. 1986. Group coping skills instruction and supportive group therapy for cancer patients: a comparison of strategies. *J Consult Clin Psychol* **54**: 802–808.
- Thoits PA. 1995. Stress, coping, and social support processes: Where are we? What next? *J Health Soc Behav Spec No*: 53–79.
- Thoits PA, Hohmann AA, Harvey MR, Fletcher B. 2000. Similar-other support for men undergoing

- coronary artery bypass surgery. *Health Psychol* **19**: 264–273.
- Trippet SE, Bain J. 1992. Reasons american lesbians fail to seek traditional health care. *Health Care Women Int* **13**: 145–153.
- van Dam MA. 2001. Lesbian disclosure to health care providers and delay of care. Abstract. *The National Lesbian Health Conference 2001: Challenges of the New Millennium*, p. 18.
- van den Borne HW, Pruyn JFA, van Dam-deMey K. 1986. Self-help in cancer patients: A review of studies on the effects of contacts between fellow-patients. *Patient Educ Counsel* **8**: 367–385.
- Warner D, Zarcone J. 1993. *Patient Rating of Physician Scale*. unpublished.
- Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. 1988. Development of questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med* **18**: 203–209.
- Watson M, Law M, dos Santos M, Greer S, Baruch J, Bliss J. 1994. The Mini-Mac: Further development of the Mental Adjustment to Cancer Scale. *J Psychosoc Oncol* **12**: 33–46.
- Woods NF, Earp JA. 1978. Women with cured breast cancer: A study of mastectomy patients in North Carolina. *Nurs Res* **27**: 279–285.
- Worden JW, Weisman AD. 1984. Preventive psychosocial intervention with newly diagnosed cancer patients. *Gen Hosp Psychiatry* **6**: 243–249.
- Yalom M. 1997. *A History of the Breast*. Knopf: New York; 275–277.
- Zarcone J, Classen C, Smithline, Spiegel, D. 1993. *The Body Image and Sexuality Scale for Women with Breast Cancer (BISS)*. unpublished scale.
- Zigmond AS, Snaith RP. 1983. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* **67**: 361–370.
- Zilberg N, Weiss D, Horowitz M. 1982. Impact of Event Scale: A cross validation study and some empirical evidence supporting a conceptual model of stress response syndromes. *J Consult Clin Psychol* **50**: 409–414.