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Sexual Functioning in Breast Cancer Survivors

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by

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ABSTRACT

Breast cancer diagnosis and treatment has been suggested to effect sexual functioning. Little is known about how breast cancer patients compare to women without a history of cancer on measures of sexual functioning, as well as the psychological and physical factors may contribute to these difficulties. To address these issues, 71 breast cancer patients and 40 of their nominated friends were recruited and served as participants. All women received and returned via the mail measures on general background information, depression, fatigue, marital satisfaction, body image, vaginal symptoms, and sexual functioning. All the psychological and physical variables assessed correlated with a measure of overall sexual functioning in the expected directions. With the exception of the physical variable of vaginal problems ($p = .006$), where the patient group reported more problems, the groups did not differ on any remaining physical or psychological variables. On the overall measure of sexual functioning, no significant differences were found between the two groups. Additional exploratory analyses in which only women treated with chemotherapy were compared to the non-cancer participants yield similar patterns of results. In addition, there was no evidence of interactive effects of age and breast cancer status on sexual functioning. These results suggest that sexual functioning in women treated for breast cancer is similar that of a non-cancer comparison with the exception of more menopausal symptoms. Continued research and interventions towards addressing menopausal symptoms may lead to even improved sexual functioning among breast cancer patients.

Chapter One

Introduction

Breast cancer is the most common type of cancer diagnosed in women after skin cancer. According to the American Cancer Society (2005), 211, 240 new cases of breast cancer will be diagnosed in 2005. The death rate for this same year will be 40,410. The breast cancer death rate in the 1990s declined by the largest amount in over 65 years. This sharp decline is due to both improvements in early detection, as well as multi-modal treatment (e.g., surgery, radiation, chemotherapy, and hormonal therapy). With 97% of all women diagnosed with early stage breast cancer (Stage I or II) surviving for at least five years, research is expanding to deal more with side effects and quality of life issues. Side effects from cancer treatment may include fatigue, nausea, hair loss, compromised immune function, cognitive impairment, memory problems, depression, and sexual problems. Although many of these problems abate after the completion of active treatment, sexual problems appear to persist (Ganz, Schag, Lee, Polinsky, & Tan, 1992; Ganz et al., 1996; Ganz, 1997).

The present study has two aims. The first aim is to compare sexual functioning of women diagnosed and treated with early breast cancer to that of a comparison group of women of a similar age without a cancer history. These women will be compared on the following components of sexual functioning: interest, desire, arousal, frequency of orgasm, sexual satisfaction, sexual activity, satisfaction with sexual relationship, masturbation, and frequency of severe sexual problems. The second aim is to examine demographic (age, race, educational status), physical (fatigue and vaginal dryness), psychological (depression and body image), and social factors (marital dissatisfaction) that may explain individual differences in sexual functioning. This study will compare the two groups of women, those with a history of breast cancer and those without a cancer history, on the demographic, physical, psychological, and social factors. Depending on the results of these analyses, the study may examine potential mediators of

differences in sexual functioning between women with and without a history of breast cancer.

Considerable variability exists in the literature regarding the prevalence of sexual dysfunction in breast cancer survivors. Fifteen to 37 percent of a sample of 218 women (Schover et al., 1995) with early stage breast cancer reported sexual dysfunction. In contrast, Barni and Mondin (1997) reported that 96% of their sample were experiencing one or more sexual problems.

Ganz et al. (1996) examined the occurrence of sexual functioning problems by assessing breast cancer survivors at one year post-diagnosis and again either two years (n=69) or three years post diagnosis (n=70). Women two or three years post-diagnosis were all experiencing significant worsening in the area of sexual functioning compared to their year one data (p=0.0001, p=0.0009, respectively). These data suggest that sexual functioning may deteriorate over time among breast cancer survivors.

Measurement Issues

Inconsistent methodology employed in studies of sexual functioning of breast cancer survivors may account for the discrepant reports of problems. Kiebert, de Haes, and van de Velde (1991) summarized some general methodological issues that plague quality of life research on breast cancer survivors. These issues include inconsistencies with regard to samples studied (e.g., selection and size), types of treatment, evaluation points, and assessment tools.

The selection of samples has varied in terms of different inclusion/exclusion criteria, as well as the means used to recruit survivors. Disease stages included in studies of sexual functioning include women with stage 0 disease (Ganz et al., 1998) through stage III disease (Yurek, Farrer, & Andersen, 2000; Gilbar et al., 1997). Also, the sample sizes across studies have varied from 24 women (Lim, Hoe, Wong, & Soo, 1995) to 1,957 women (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999). Next, women have varied on the types of treatment they received. Currently, a multi-modal approach to treatment is used including a combination of surgery, chemotherapy, radiation, and hormonal therapy.

Another variation in studies is the point at which the participant is evaluated. For example, Schover et al. (1995) collected surveys from 218 women who were anywhere

between 0.4 to 9.5 years post surgery. Along with the variability of time at which the participant is assessed, many studies also lack baseline data or a premorbid assessment of sexual functioning.

Finally, assessment tools used in studies vary in their format, reliability, and validity. The assessment of sexual functioning is complicated. A broad range of facets combine to make-up this construct, and researchers do not always agree on these facets. Often times, researchers develop their own multiple-choice questions about sexual functioning (Schover et al., 1995).

Ganz (1997) points out that sexual functioning in women with breast cancer must be studied in relation to sexual functioning in healthy women. Breast cancer is primarily a disease of aging women. Sexual functioning naturally declines with age. Therefore, in order to accurately gauge the effects of breast cancer and its treatment on sexual functioning, one must compare women with breast cancer to healthy women without a history of breast cancer. Although several studies have used normative data to interpret findings regarding sexual functioning (Mortimer et al., 1999; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998), no other study was found that included a healthy comparison group.

Relationship of Demographic Variables to Sexual Functioning

There has been mixed evidence regarding the relationship of age to sexual functioning difficulties in breast cancer survivors. Schover et al. (1995) examined the relationship of age to sexual functioning in 218 women who were between 0.4 and 9.5 years post surgery for breast cancer. Women in this study were a mean of 54.2 years old (SD = 11.8). The authors found that expression of affection and overall sexual satisfaction did not differ statistically between younger ($\leq$ 60 years) and older (> 60 years) women. In contrast, frequency of sexual activity ($p<0.0001$), as well as sexual desire ($p<0.001$), was higher among the younger women.

Regarding differences in sexual functioning across ethnic/racial groups, most samples to date have consisted primarily of Caucasian women. The numbers for minority women have typically been too small to be analyzed separately. One exception to this pattern is a study by Ashing-Giwa (1999) that compared quality of life, including sexual functioning, in 117 African-American women and 161 Caucasian women who were

diagnosed with breast cancer and were at least six years post-diagnosis. Results indicated that the groups did not differ significantly on a sexual functioning subscale. Scores on the sexual functioning subscale were higher than all other Cancer Rehabilitation and Evaluation Survey-Short Form (CARES-SF; Schag & Heinrich, 1989) scales suggesting that sexual functioning was a concern across ethnic groups.

Relationship of Surgical Variables to Sexual Functioning

The emergence of breast conserving surgery as a viable treatment option (Fisher, et al., 1985) led health care providers to believe that this less mutilating procedure would result in fewer sexual concerns (Ganz & Coscarelli, 1995). Numerous studies have sought to evaluate this possibility. Moyer (1997) performed a meta-analysis, based on 23 studies involving 1,860 women of the effects of type of breast cancer surgery on marital-sexual adjustment. The outcome of marital-sexual adjustment reflects the inclusion of studies that assessed marital satisfaction and/or sexual functioning. The meta-analysis revealed a small, but statistically significant weighted mean effect size (ES=0.093, $p<0.05$). The effect size was in the positive direction indicating that women who had undergone lumpectomies generally reported better marital-sexual adjustment than women who had undergone mastectomies.

Relation of Chemotherapy and Endocrine Therapy to Sexual Functioning

Numerous studies have been conducted to examine the impact of chemotherapy and/or endocrine therapy (tamoxifen) on sexual functioning in breast cancer patients. The following studies serve as examples of research that examined the sexual effects of chemotherapy, chemotherapy plus tamoxifen, or tamoxifen.

Schover et al. (1995) looked at the influence of chemotherapy and tamoxifen use on sexual functioning. When compared to a group of breast cancer survivors treated without chemotherapy (n=175), women treated with chemotherapy (n=43) were found to be experiencing significantly greater problems with desire ($p=0.032$), vaginal lubrication ($p<0.0001$), pain ($p<0.001$), and achieving orgasm during sexual intercourse ($p=0.043$). In addition, they reported significantly poorer sexual satisfaction ($p=.001$) and had sex less frequently ($p=0.013$).

In the same study, Schover et al. (1995) found that women who received tamoxifen (n=44) did not differ significantly from women who did not receive tamoxifen

(n=131) on the following sexual variables (after correcting for age and chemotherapy): frequency, desire, vaginal dryness, pain, ability to reach orgasm during sexual intercourse, or overall sexual satisfaction.

Ganz et al. (1999) found history of chemotherapy to be a significant predictor of sexual dysfunction in two independent samples of early stage (0-II) breast cancer survivors who were between one and five years post-diagnosis (Ganz et al., 1999). The two independent samples (n=863, n=1094) completed the following sexual functioning questionnaires: the Breast Cancer Prevention Trial Symptom Checklist (BCPT; Ganz, et al, 1998), the CARES, the Watts Sexual Functioning Scale (WSFQ; Watts, 1982), and a one-item satisfaction measure. Use of tamoxifen was not consistently associated with sexual interest, dysfunction, or satisfaction. However, in the second sample use of tamoxifen was related to less sexual satisfaction.

Ganz, Rowland, Myerowitz, and Desmond (1998) conducted further research on the second independent sample (1094 women from Los Angeles and Washington D.C.). These women had stage 0, I, or II disease and were one to five years post-diagnosis. They were broken up into the following four groups: no adjuvant therapy (n=265), tamoxifen (n=356), chemotherapy (n=180), or chemotherapy plus tamoxifen (n=295). Controlling for age and time since diagnosis, sexual functioning was significantly related to type of therapy ($p = 0.0078$). Women who received chemotherapy were more likely to report pain during intercourse ($p=0.0076$). Overall, those women receiving chemotherapy ($p=0.0096$), as well as women receiving tamoxifen ($p=0.034$), reported more problems with sexual functioning than those women who received no adjuvant therapy.

Relation of Physical Factors to Sexual Functioning

Few studies have investigated the relationship of menopausal symptoms (i.e., hot flashes, vaginal problems, and urinary problems) to sexual functioning in breast cancer patients (Ganz et al, 1999; Greendale, Lee, & Arriola, 1999). An intervention study conducted by Ganz et al. (2000) compared symptomatic breast cancer patients who received education, skills, medications, and support targeted towards these symptoms (n= 33) to a usual care group (n = 39). Results indicated that both menopausal symptoms (p

= .0004) and sexual functioning (p = .04) improved for those women involved in the intervention group relative to those receiving usual care.

Relation of Psychological Factors to Sexual Functioning

Numerous studies (Mock, 1993; Schover, 1995; Ganz et al., 1998; Ganz et al., 1992) have investigated body image disturbance and depression in breast cancer survivors. Although both these factors have been well studied in this population, only body image has been examined in relation to sexual functioning.

Carver et al. (1998) studied concerns about body image and their relationship to sexual functioning in 66 women with early stage (I or II) breast cancer. Sexual functioning was measured using items assessing attractiveness, sexual desirability, and frequency of sexual activity. Results indicated that body image concerns were related to decreased feelings of sexual desirability. Ganz et al. (1999) tested models for predicting sexual interest, sexual dysfunction, and sexual satisfaction using two samples of sexually active breast cancer survivors (n=472 and n=662, respectively) who were between 1.7 and 4.3 years from diagnosis. Body image was measured using the CARES Body Image Subscale. Body image was found to account for significant variance in the sexual satisfaction in the first sample, but was not a significant predictor of sexual satisfaction in the second sample.

Aims

The current study has two aims. The first aim is to determine whether breast cancer patients experience poorer sexual functioning than women of comparable age with no history of breast cancer. This was undertaken in order to address a major limitation in the existing literature. By including appropriate non-cancer comparison group, the nature and severity of problems in sexual functioning among breast cancer patients would be better identified.

The second aim is to identify psychological and clinical variables that might mediate any observed relationship between breast cancer status (positive versus negative history of breast cancer) and sexual functioning. Variables of interest included depression, fatigue, marital satisfaction, body image dissatisfaction, and vaginal dryness as these variables have been shown to differ, or might be expected to differ based on breast cancer status. As a precondition to examining their role as mediators, it will first

be necessary to test hypotheses that these variables: a) are associated with poorer sexual functioning in the sample as a whole and b) are related to breast cancer status (positive versus negative history of breast cancer).

Hypotheses

The first set of hypotheses posits that women diagnosed and treated for early stage breast cancer would report poorer sexual functioning in comparison to a comparison group of women of a similar age without a history of cancer. Specifically, women with early stage cancer, when compared to a group of women of a similar age with no history of cancer, are expected to report:

1A. Less sexual interest

1B. Less sexual desire

1C. Less sexual arousal

1D. Less frequency of orgasm

1E. Less sexual satisfaction

1F. Less sexual activity

1G. Less satisfaction with sexual relationship

1H. Less desire to and arousal from masturbation

1I. More frequent and severe sexual problems.

A second set of hypotheses posits that the following psychological and physical factors will be associated with poorer overall sexual functioning in the sample as a whole:

2A. Higher levels of fatigue

2B. Greater symptoms of depression

2C. Greater marital dissatisfaction

2D. Poorer body image

2E. Greater vaginal dryness

A third set of hypotheses posits that, compared to a comparison group of women of similar age with no history of cancer, women diagnosed and treated for early stage breast cancer will report:

3A. Higher levels of fatigue

3B. Greater symptoms of depression

3C. Greater marital dissatisfaction

3D. Poorer body image

3E. Greater vaginal dryness.

Depending on results of hypothesis testing, exploratory analyses would be undertaken to determine the extent to which differences in fatigue, depression, marital satisfaction, body image, and vaginal dryness mediate any discovered relationship between history of breast cancer and poorer sexual functioning.

Chapter 2

Method

Participants

Patients. Breast cancer patients treated at the H. Lee Moffitt Cancer in the past five years were identified via the Moffitt registry. Information regarding date of diagnosis, stage, and type of treatment received were obtained from the registry. In addition to being diagnosed with early stage breast cancer (stage 0, I, or II), these women met the following eligibility criteria: 1) at least 18 years of age, 2) proficient in English, 3) able to provide informed consent, 4) no psychiatric or medical conditions that would hinder participation, 5) medical visit in the last year that confirmed no clinical evidence of breast cancer, 6) at least one year and no more than five years post diagnosis, 7) no other cancer history (with the exception of basal skin cancer), and 8) have a spouse or romantic partner. These women were asked to complete a questionnaire through the mail inquiring about their level of fatigue, mood, marital satisfaction, body image, and sexual health. In addition, these women were asked to provide contact information for female friends within fifteen years of their age who had never been diagnosed with breast cancer who may be willing to serve as members of a non-cancer comparison sample.

Of the 563 MCC patients who received initial letters about the study, 230 (41%) were unable to be contacted (see Figure 1). Of the patients contacted, 83 (25%) were found to be ineligible. From the remaining women contacted 179 (72%) refused thus leaving 71 (28%) analyzable questionnaires. The mean age of these women was 61 years (SD = 9.87, range = 39 to 82 years). The majority were Caucasian (96%), married (93%), had greater than a high school education (80%), were employed outside the home (56%), had an annual household income greater than $40,000 (72%), and were postmenopausal (96%) (see Table 1). Medically, the majority of women were diagnosed with Stage I (41%) and Stage II (45%) disease, were treated surgically with

lumpectomies (84%), received radiation treatment only (53%), and were between 3 and 5 years post-diagnosis (83%) (see Table 2).

Non-Cancer Comparison Group. Using peer nomination procedures, a sample of women without a history of breast cancer was also obtained for the study. In addition to having no prior cancer diagnoses (with the exception of basal skin cancer), the nominated group also met the following eligibility criteria: 1) at least 18 years of age, 2) proficient in English, 3) informed consent, 4) no psychiatric or medical conditions that would hinder participation, and 5) have a spouse or romantic partner.

Of the 123 women nominated, 22 (18%) were unable to be contacted (see Figure 2). Of those contacted, 18 (18%) were found to be ineligible. From the remaining women contacted, 34 (41%) refused to participate thereby leaving 49 questionnaires (59%). Upon determining that the non-cancer comparison group had over-sampled women in the fifth decade relative to the patient group, an approximate 2-to-1 matching procedure by decade of age was used that resulted in exclusion of nine women from the non-cancer comparison group. Thus, the final non-cancer comparison group was comprised of 40 women. The mean age of these women was 60 years (SD = 9.83, range 39-82). The majority were Caucasian (100%), married (90%), had higher than a high school education (90%), were not employed outside the home (62%), and had a household income of greater than $40,000.00 (65%). Eighty percent of the women reported being postmenopausal (see Table 1).

Procedure

An introductory letter (see Appendix A) was sent to breast cancer patients from the Moffitt registry selected randomly after stratifying by time since diagnosis and treatment received. A toll-free number was included in the letter that allowed the recipient to decline any further information about the study. Breast cancer patients were then contacted by telephone and read a scripted description (see Appendix B) of the study, were asked questions to confirm eligibility, and were asked whether they were willing to provide verbal consent for participation. Upon receiving verbal consent, each patient received the following materials through the mail: two copies of the written informed consent, two copies of the HIPPA research form, a questionnaire packet, a peer nomination form, personalized nomination cards, and a self-addressed stamped envelope.

Each participant was asked to return one signed copy of the informed consent and HIPPA research authorization form, a completed packet, a completed peer nomination form, and completed personalized nomination cards. The personalized nomination cards had a preprinted summary of the study on a Moffitt card leaving the salutation and closing blank so the participant could personalize the card to the person they were nominating. All nomination cards were returned to the researcher so that they could be tracked.

Initially, breast cancer participants were asked to nominate peers without a history of breast cancer who were anywhere from five years younger to five years older than themselves. However, due to difficulties recruiting, the age range was increased on May 19, 2004 to fifteen years younger to fifteen years older than the breast cancer participants.

Women who were nominated received the invitation (see Appendix C) personalized by the breast cancer patient who nominated her. This card was followed-up with a phone call and scripted description of the study, interest was established, and eligibility confirmed. Upon receiving verbal consent, each woman received the following materials through the mail: two copies of the written informed consent, two copies of the HIPPA research authorization form, a questionnaire packet, a peer nomination form, personalized nomination cards, and a self-addressed stamped envelope. Each participant was asked to return one signed copy of the informed consent and HIPPA research authorization form, and a completed packet.

Follow-up calls and letters were sent out to women who returned packets with missing information. Thank you letters were sent out to all participants. If requested, a pamphlet entitled, *Sexuality and Cancer,* sponsored by the American Cancer Society (2001) was provided.

Measures

The survey battery included measures of demographic and clinical information, along with valid and reliable measures of fatigue, depression, marital satisfaction, body image, symptom concerns, and sexual functioning. The packet was estimated to take approximately 25 minutes to complete.

Demographic and Clinical Information. A standardized self-report measure was used to obtain general demographic and clinical information (see Appendix D and E). The following demographic information was obtained: age, ethnicity, marital and

employment status, income, occupation, and educational level. General medical and sexual history information was also obtained from all participants. Medical history included menopausal status, use of hormone replacement therapy, and height and weight. Sexual history included questions about length of time with current sexual partner, as well as history of sexual problems for self or partner. Participants with a history of breast cancer were asked additional questions specific to cancer diagnosis and treatment. The information obtained included the time since diagnosis, type of surgery, and type of cancer treatment. In addition to participant self-report, the H. Lee Moffitt Cancer Registry, as well as the participant's medical charts were reviewed to obtain relevant medical history such as date of diagnosis, disease stage, type of cancer treatments, and history of cancer recurrences.

Depressive Symptomatology. The Center for Epidemiologic Studies, Depression Scale (CES-D; Radloff, 1977) is a 20-item self-report measure originally developed to assess current depressive symptomatology in the general population (see Appendix F). The following six components of depression are measured on 4-point Likert scales ranging from 1 (rarely or none of the time) to 4 (most or all of the time): depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. Participants are asked to respond to each item based on the degree to which she has been experiencing each symptom for the past week. Scores range from 0 to 60 with higher scores indicating more severe depressive symptomatology. The CES-D is a reliable and valid measure. High internal consistency has been determined with split-half correlations for psychiatric patient groups (0.85), as well as normal groups (0.77) and with coefficient alphas for patient groups (0.90) and normal groups (0.85), respectively. Coefficients alphas calculated in present study for the breast cancer patients (.89) and non-cancer comparisons (.91) reflect high internal consistency. The CES-D has been shown to be a valid measure with its correlation to other depression inventories such as the Beck Depression Inventory (0.81), as well as the Zung Depression Scale (0.90) (Weissman, Prusoff, & Newberry, 1975). Although validated in many different samples, it has been specifically shown to be psychometrically sound for assessing depressive symptoms in

cancer patients (Devins, Orme, Costello, & Binik, 1988; Hann, Winter, & Jacobsen, 1999).

Fatigue Symptomatology. The Fatigue Symptom Inventory (FSI; Hann et al., 1998) is a 13-item self-report measure of fatigue intensity, duration, and interference with quality of life in cancer patients (see Appendix G). Regarding fatigue intensity, respondents indicate on an 11-point scale (0 = not at all fatigued to 10 = maximum fatigue) their most, least, and average fatigue level in the past week, as well as their current level of fatigue. Then, seven items keyed to another 11-point scale (0 = no interference to 10 = extreme interference) are used to assess the level of interference caused by fatigue in the past week to the following areas: general activity level, ability to bathe and dress, work activity, ability to concentrate, relations with others, enjoyment of life, and mood. Finally, two duration items inquire about number of days in the past week the respondent has felt fatigued (0-7 days) and the percentage of each day that fatigue was experienced (0 = none of the day to 10 the entire day). The FSI is a reliable and valid measure. The internal consistency for the 7-item subscale measuring the level of interference caused by fatigue was above 0.90 for young and old cancer patients with a variety of cancer diagnoses, as well as healthy individuals (Hann, Denniston, & Baker, 2000). Regarding test-retest reliability, the FSI subscales produced low to moderate correlations between assessments. Convergent, divergent, and construct validity have all been demonstrated for the FSI (Hann et al., 1998). The 7-item subscale measuring the level of interference caused by fatigue was employed in this study with coefficient alphas for the breast cancer (.93) and non-cancer patient (.95) groups reflecting high internal consistency.

Body Image. The Body Exposure in Sexual Activities Questionnaire (BESAQ; Hangen and Cash, 1991) is a 28-item self-report questionnaire designed to assess body image during sexual activity, or personal ease with physical appearance during differing degrees of sexual activity (see Appendix H). Specifically, it measures physical self-consciousness and body exposure avoidance during sexual encounters. Participants are asked to rate on a 5-point Likert scale (0=never to 4 = always) how representative each item is of their own thoughts and beliefs during differing degrees of sexual activity. Items can be calculated into a total score, as well as separated into two subscales: worry

and self-consciousness (WSE) and comfort with body exposure (CBE). The measure has high internal consistency for the scale as a whole (0.98), as well as for both the WSC (0.97) and CBE subscales (0.92) (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). The total score was utilized in the present study and coefficient alphas calculated for the breast cancer patients (.87) and the non-cancer patients (.90) reflect high internal consistency. In a sample of 145 sexually active college-aged women, lower scores on the BESAQ (less anxiety or avoidant focus on their bodies) were found to be significantly ($p < .01$) correlated with higher sexual functioning scores. The Body-Self Relations Questionnaire: Appearance Evaluation Subscale (BSRQ—AES) is a subscale of the Multidimensional Body Self-Relations Questionnaire (MBSRQ; Cash, 1997). The BSRQ—AES is a 7-item self-report questionnaire designed to assess both satisfaction and evaluation of the body (see Appendix I). Participants are asked to rate on a 5-point Likert scale (1= definitely disagree to 5 = definitely agree) how representative each item is of their own thoughts and beliefs regarding satisfaction and evaluation of the body. The measure has high internal consistency for the scale as a whole (0.88) (Thompson et al., 1999). In the present study, coefficient alphas of .90 for the breast cancer patients and .86 for the non-comparison group reflect high internal consistency. The BRSQ—AES has been used and has strong set of normative data (Brown, Cash, & Milulka, 1990; Cash, Ancis, & Strachan, 1997).

Marital Satisfaction. The Dyadic Adjustment Scale (DAS; Spanier, 1976) is a 32-item multi-dimensional self-report measure designed to measure the quality of adjustment in both committed and marital relationships (see Appendix J). Participants rate each item on a 7-poing Likert scale ranging from "extremely unhappy" to "perfect." The scale is split up into the following four subscales: satisfaction, consensus, cohesion, and affectional expression. The DAS is a reliable and valid measure. The internal consistency reliability is high, with a range of 0.73 to 0.96 for all four subscales as well as the total summary score. This study employed the marital satisfaction and affectional expression subscales. These scales demonstrated adequate to high internal consistency for the following breast cancer patients (.69 and .81, respectively) and the non-cancer comparison group (.81 and .77, respectively). Content, criterion-related, and construct

validity have all been established for the DAS (Busby, Christensen, Crane, & Larson, 1995).

Menopausal Symptoms. The Breast Cancer Prevention Trial (BCPT) Symptom Checklist (Ganz, Day, Ware et al., 1998) is a 43-item self-report measure of physical and psychological symptoms associated with menopause as well as tamoxifen use (see Appendix K). All symptoms are rated on how bothersome they have been in the past 4 weeks using a 5-point Likert scale (0=not at all to 4=extremely). Seven items make up three subscales that are specific to menopausal symptoms: hot flash subscale, vaginal subscale, and urinary symptom subscale. The internal consistency reliability is reported to be high, with alpha coefficients for each subscale above 0.73. These three subscales can be added together to create the Symptoms Scale Score, which has been shown to have an internal consistency reliability of 0.50. The present study utilizes the vaginal subscale only. The internal consistency reliability is low, demonstrated by coefficient alphas of .57 for breast cancer patients and .59 for the non-cancer comparison participants.

Sexual Functioning. The Sexual Function Questionnaire (SFQ; Syrjala et al., 2000) is a 30-item multi-dimensional, self-report questionnaire designed to measure sexual functioning in both medically ill and healthy populations (see Appendix L). The measure is composed of an Overall SFQ Score, two summary scales, Sexual Functioning and Treatment Impact, as well as the following nine subscales: interest, desire, arousal, orgasm, satisfaction, activity, relationship, masturbation, and sexual problems. Respondents answer items based on 6-, 7-, or 11-point Likert scales keyed for the past month. Approximately 10 minutes are needed to complete this questionnaire. The SFQ is a reliable and valid measure. The reported internal consistency for the overall SFQ score for women is high (α = .94), as are the internal reliabilities for all subscales (ranging from α=0.81 for sexual problems to α = 0.93 for orgasm). For both groups of women in this study, the internal reliability for the overall SFQ score was high (α = .93) The internal reliabilities among the subscales are high for breast cancer patients (ranging from α=0.71 for desire to α = 0.97 for orgasm) and range from adequate to high for non-cancer participants (ranging from α=0.65 for interest to α = 0.98 for masturbation). Content, criterion, and discriminant validity have all been demonstrated for the SFQ

(Syrjala et al., 2000). Due to researcher error, the problem subscale score was not obtained. Therefore, the overall sexual functioning score and following eight subscales were used: interest, relationship, desire, masturbation, activity, orgasm, satisfaction, and arousal.

Statistical Power

Statistical power was calculated based on the sample size obtained. For between group differences, with 71 breast cancer patients and 40 non-cancer participants, there was power of .80 ($p<.05$, two tailed) to detect an effect size of between .5 and .6 standard deviation units ($d = .55$). This corresponds to a medium effect size (Cohen, 1998).

Chapter Three

Results

Preliminary Analyses

T-tests or chi-square analyses were conducted, as appropriate, to compare the breast cancer and non-cancer comparison groups on the demographic variables of age, household income, marital status, education, employment, and ethnicity. Results revealed a marginally significant difference for employment status ($p < .1$) (see Table 1). Since employment status was not significantly correlated with the overall sexual functioning score on the SFQ ($r = -0.12$, $p = .22$), it was not included as a control variable in subsequent analyses. Additional analyses indicated a significant difference between groups in menopausal status ($p = .008$), with breast cancer patients more likely to be postmenopausal. Since menopausal status is likely to be affected by treatment for breast cancer, it was not included as a control variable in subsequent analyses.

Group Differences on Sexual Functioning Variables

It was hypothesized that a past diagnosis of breast cancer would be associated with more frequent and more severe sexual problems as measured by the SFQ overall score and the nine subscales: interest, desire, arousal, orgasm, satisfaction, masturbation, activity, satisfaction with sexual relationship, and sexual problems. As noted previously, due to researcher error, the sexual problems subscale was not collected. Therefore, t-tests were performed on the overall score and on each of the remaining subscale scores to determine if significant differences existed between the breast cancer patients and the non-cancer comparison participants. Contrary to predictions, there were no significant ($p < .05$) differences between the two groups on these variables (see Table 3).

Relationship of Psychological and Physical Variables to Sexual Functioning

It was hypothesized that poorer overall sexual functioning would be associated with higher levels of fatigue, greater depressive symptomatology, greater marital dissatisfaction, poorer body image, and greater vaginal dryness. As predicted, each of the psychological and physical variables was significantly ($p \leq .05$) correlated with overall sexual functioning for the sample as a whole (see Table 4). Specifically, scores on the CES-D, FSI, BESAQ, and vaginal subscale of the BCPT were all negatively correlated with overall sexual functioning. The direction of these relationships indicates that, as expected, worse overall sexual functioning was associated with more severe depressive symptomatology (CES-D), more disruption from fatigue (FSI), poorer body image (BESAQ), and more problems with vaginal dryness, genital itching/irritation, and pain with intercourse (vaginal subscale of BCPT). In addition, scores on the two DAS subscales of marital satisfaction and affectional expression, as well as on the appearance evaluation subscale of the BSRQ are all significantly ($p \leq .05$) positively correlated with overall sexual functioning. The direction of these relationships indicates that, as expected, women who were more satisfied in their marital relationships (DAS marital satisfaction subscale), who are better able to express themselves emotionally (DAS affectional expression subscale), and who are satisfied with their physical appearance (BSRQ-AE) reported better overall sexual functioning.

Group Differences on Psychological and Physical Variables

Finally, it was hypothesized that a past diagnosis of breast cancer would be associated with higher levels of fatigue (as measured by the FSI), greater symptoms of depression (as measured by the CES-D), greater marital dissatisfaction (as measured by the two DAS subscales), less emotional expression (as measured by the DAS), poorer body image (as measured by the BESAQ and BSRQ-AE), and greater vaginal dryness (as measured by the vaginal problems subscale of the BCPT). T-tests were performed on each of these psychological and physical variables to determine if significant differences existed between the breast cancer patients and the non-cancer comparison participants. Contrary to predictions, the groups only differed significantly on the vaginal problems subscale of the BCPT ($t = 2.82$; $p = .006$), with the breast cancer patients reporting more vaginal problems (see Table 5) than the non-cancer comparison participants.

Additional Analyses

Because conditions for a mediational model were not met, no further analyses in this vein were conducted. However, additional analyses were pursued. Because of prior research attesting to the intensity of chemotherapy and its effect on menopausal status (Ganz et al., 1998), the women who had received chemotherapy alone (n=7) or in conjunction with radiation (n=26) were combined and evaluated against the non-cancer comparison participants. T-tests were performed on the overall SFQ score and the eight subscales to determine if significant differences existed between the breast cancer patients who had received chemotherapy and the non-cancer comparison participants. Results mirror the results found for the sample as a whole. Specifically, there were no significant differences between breast cancer patients treated with chemotherapy and a non-cancer comparison group on the overall score of sexual functioning on the SFQ or any of the eight subscales (see Table 6).

Finally, exploratory analyses were conducted to examine whether age might moderate the relationship between group membership (cancer vs. non-cancer) and sexual functioning. Previous literature suggests (Schover et al., 1995) that some of the effects of cancer and its treatment might be more evident among younger women. Toward this end, separate hierarchical multiple regression analyses were performed on the overall SFQ score and each of the eight subscales. In each analysis, age and group membership were entered on the first step followed by the interaction of age and group membership on the second step. Of particular interest was whether the interaction term accounted for additional significant variability in sexual functioning. The interaction between age and breast cancer status did not account for a significant amount of variance ($p \leq .05$) in the overall SFQ score or on any of the eight subscales scores (see Table 7).

Chapter Four

Discussion

A goal of the present study was to determine whether sexual functioning was poorer in breast cancer survivors than women with no history of cancer. In addition, the psychological and physical variables of depression, fatigue, marital satisfaction, body image, and vaginal problems were investigated as potential mediators of the hypothesized relationship between a history of breast cancer and sexual functioning. This discussion will review the findings, consider the limitations of the current study, and discuss clinical implications and future research directions.

Contrary to predictions, women who completed treatment for breast cancer within the past five years did not report higher levels of sexual dysfunction when compared to women with no history of breast cancer. These groups of women did not differ significantly on an overall measure of sexual function or on any of the eight individual subscales examining the sexual phases. The variables of depression, fatigue, marital satisfaction, body image, and vaginal problems did correlate with sexual functioning in the predicted directions for this sample as a whole. Specifically, as scores on the scales of depression, fatigue, body dissatisfaction, and vaginal problems increased, scores on a measure of sexual functioning decreased. Likewise, as scores on measures of marital satisfaction and body satisfaction increased, scores on a measure of sexual functioning increased. However, when the breast cancer patients and the non-cancer comparison participants were compared on these psychological and physical variables, they differed significantly only on reported number of vaginal concerns. The lack of significant differences on these variables based on breast cancer status was contrary to initial hypotheses.

Based on previous research suggesting that treatment with chemotherapy may have a more damaging effect on women's sexual functioning (Schover et al., 1995), we

preformed additional analyses comparing only women treated with chemotherapy to the non-cancer comparison group. This new grouping based on treatment received yielded similar non-significant results. Finally, analyses were performed to look at the potential interactive effects of age and breast cancer status on sexual functioning. This interaction was not found to contribute significantly to differences in sexual functioning.

At first glance, these results do not appear to fit neatly into the current body of literature that posits a prevalence of sexual dysfunction in breast cancer survivors of anywhere from 15-37% (Schover et al., 1997) to 96% (Barni & Mondin, 1997). However, the current literature has known problems with sample selection and make-up (Ganz et al., 1998; Yurek et al., 2000; Gilbar et al., 1997), as well as measurement variability (Kiebert, et al., 1991). Specifically, measurements of sexual functioning used often vary in their format, reliability, and validity oftentimes with researchers developing their own measures of sexual functioning.

The current study did find evidence that vaginal problems were more common in cancer survivors. This result may reflect the effects of tamoxifen that many of the women were receiving, as well as the high percentage (96%) of postmenopausal women. Most breast cancer patients are postmenopausal due to age at diagnosis or treatment effects (Ganz et al., 2000). These vaginal problems included vaginal dryness, genital itching/irritation, and pain with intercourse. While difficulties with menopausal symptoms are not exclusive to breast cancer patients they may be intensified to due to tamoxifen use and effects of chemotherapy. Previous research has shown that menopausal symptoms and sexual functioning can be improved with proper symptom assessment, education, counseling, and pharmacologic and behavioral interventions (Ganz et al., 2000).

Limitations

This study has several limitations that need to be addressed. The samples for the current study consisted primarily of Caucasian, well-educated, higher income women. This feature may limit the generalizability of the findings to populations more diverse with regard to race/ethnicity, education, and socioeconomic status. The relatively low response rate of 28% for breast cancer patients and 59% for non-cancer comparisons is another major limitation. A systematic bias may have existed connected with whether or

not a woman agreed to participate. For example, it is possible that women with more severe problems in sexual functioning may have declined to participate. The use of cross-sectional design that includes a sample of patients with considerably varied time since diagnosis is another limitation. This feature limits the ability to make conclusions about the time course of problems in sexual functioning. Statistical power is yet another limitation. Although the sample size had power adequate to detect a medium effect, sexual functioning may have been a smaller than medium effect. Finally, all data was collected via self-report without any corroborating objective measures of sexual functioning. Ideally, corresponding data would also have been collecting from spouses and partners.

Future Directions

Whenever possible, future research should strive to include a non-patient comparison group in order to identify any needs that set cancer patients apart from those with no cancer history. Longitudinal research employing pre-treatment baseline assessments, as well as larger and more demographically diverse samples would allow for a better understanding of sexual functioning over time, as well as any potential cultural and demographic differences. Comparison studies between cancer patients by age of diagnosis, disease stage, and treatment type also may shed light on how these medical variables affect sexual functioning outcomes. In addition, new procedures should be employed to increase participation. With the use of websites and e-mails versus telephone and mail, faster and more efficient recruitment may be possible.

The number of breast cancer patients who did report vaginal problems warrants more intervention studies. The Ganz et al. (2000) intervention study was able to reduce menopausal symptoms and improve sexual functioning. Future research should seek to continue to study interventions that could better educate, inform, and normalize this experience for breast cancer survivors.

Table 1
Demographic Characteristics of Breast Cancer Patients and Non-Cancer Comparison Participants

	Breast Cancer Patients		Non-Cancer Participants			
	N	(%)	N	(%)	χ^2	p
Race					1.74	.18
White	68	(96%)	40	(100%)		
Non-White	3	(4%)	0	(0%)		
Marital Status					.30	.58
Married	66	(93%)	36	(90%)		
Not Married	5	(7%)	4	(10%)		
Education					1.78	.18
$\leq$ 12 years	14	(20%)	4	(10%)		
> 12 years	57	(80%)	36	(90%)		
Employment					3.63	.06*
Employed	40	(56%)	15	(38%)		
Not employed	31	(44%)	25	(62%)		
Household Income					2.2	.33
< $40,000	10	(14%)	4	(10%)		
$\geq$ $40,000	51	(72%)	26	(65%)		
Did not answer	10	(14%)	10	(25%)		
Menopausal Status					7.13	.008**
Pre- or perimenopausal	3	(4%)	8	(20%)		
Postmenopausal	68	(96%)	32	(80%)		

*p < .1
**p < .05

Table 2
Medical Characteristics of Breast Cancer Patients (N = 71)

	N	(%)
Stage		
0	10	14%
I	29	41%
II	32	45%
Surgery Type		
Lumpectomy	59	84%
Mastectomy	10	14%
Bilateral Lumpectomy	1	1%
Bilateral Mastectomy	1	1%
Reconstructive Surgery		
None	63	88%
Immediate	4	6%
Delayed	4	6%
Treatment Received		
Chemo only	7	10%
Chemo and XRT	26	37%
XRT only	38	53%
Time Since Diagnosis		
1 - 2 years	2	3%
2 – 3 years	10	14%
3 – 4 years	30	42%
4 – 5 years	29	41%

Table 3

Comparison Between Breast Cancer Patients and Non-Cancer Participants on Sexual Functioning Questionnaire

	Breast Cancer Patients SFQ M (SD)	Non-Cancer Participants SFQ M (SD)	t	p
Overall Score	2.41 (0.88)	2.50 (0.89)	-0.47	.64
Interest Subscale	1.50 (1.05)	1.49 (0.87)	0.05	.96
Desire Subscale	2.80 (1.21)	2.84 (1.43)	-0.17	.86
Arousal Subscale	1.77 (1.19)	1.69 (1.14)	0.33	.74
Orgasm Subscale	3.39 (1.68)	3.80 (1.68)	-1.24	.22
Satisfaction Subscale	3.04 (1.68)	3.44 (1.83)	-1.18	.24
Activity Subscale	2.63 (1.46)	2.60 (1.34)	0.10	.92
Relationship Subscale	3.07 (1.08)	3.24 (1.11)	-0.78	.44
Masturbation Subscale	0.62 (0.99)	0.57 (1.02)	0.26	.80

Table 4

Correlational Analyses of Psychological and Physical Variables with Sexual Functioning Questionnaire (SFQ) Overall Score

	SFQ Overall Score
Depressive Symptomatology (CES-D)	-0.31**
Fatigue (FSI)	-0.23*
Marital Satisfaction (DAS Marital Satisfaction Subscale)	0.56***
Emotional Expression (DAS Affectional Expression Subscale)	0.44***
Body Image (BESAQ)	-0.41***
Body Image (BSRQ)	0.26*
Vaginal Problems (BCPT Vaginal Subscale)	-0.24*

* $p<.05$
** $p\leq.001$
*** $p<.0001$

Table5

Comparison Between Breast Cancer Patients and Non-Cancer Participants on Psychological and Physical Variable Scores

	Breast Cancer Patients	Non-Cancer Participants		
	M (SD)	M (SD)	t	*p*
CES-D (depression)	9.23 (8.78)	6.73 (7.94)	1.90	.06
FSI (fatigue)	1.41 (1.67)	1.37 (1.88)	0.12	.91
DAS—Marital Satisfaction Subscale	8.60 (2.20)	8.62 (2.84)	-0.09	.93
DAS—Affectional Expression Subscale	38.42 (5.15)	38.19 (4.84)	0.23	.82
BESQ (body image)	36.11 (21.53)	34.92 (21.15)	0.26	.80
BSRQ (body image)	2.23 (0.95)	2.41 (0.73)	-1.03	.31
BCPT—Vaginal Subscale	3.69 (2.65)	2.21 (2.53)	2.82	.0057*

Table 6

Comparison Between Breast Cancer Patients Treated with Chemotherapy and Non-Cancer Comparison Participants on Sexual Functioning Questionnaire

	Breast Cancer Patients SFQ M (SD)	Non-Cancer Participants SFQ M (SD)	t	*p*
Overall Score	2.17 (0.90)	2.50 (0.89)	-1.50	.14
Interest Subscale	1.47 (1.05)	1.49 (0.87)	- 0.08	.94
Desire Subscale	2.57 (1.26)	2.84 (1.43)	-0.87	.39
Arousal Subscale	1.58 (1.05)	1.69 (1.14)	-0.44	.66
Orgasm Subscale	3.10 (1.68)	3.80 (1.68)	-1.75	.08
Satisfaction Subscale	2.69 (1.64)	3.44 (1.83)	-1.84	.07
Activity Subscale	2.40 (1.51)	2.60 (1.34)	- 0.62	.54
Relationship Subscale	2.90 (1.12)	3.24 (1.11)	-1.27	.21
Masturbation Subscale	0.65 (0.95)	0.57 (1.02)	0.34	.74

Table 7

Significance of Interaction of Age and Group Membership for Each Scale of the SFQ

	β	F	p
Overall Score	-.72	1.11	.30
Interest Subscale	-.57	.77	.38
Desire Subscale	-.87	1.86	.18
Arousal Subscale	-.37	.33	.57
Orgasm Subscale	.33	.27	.60
Satisfaction Subscale	-.07	.01	.92
Activity Subscale	-.22	.12	.73
Relationship Subscale	-.53	.66	.42
Masturbation Subscale	-.37	.33	.57

Figure 1. Flow chart of recruitment for breast cancer patients

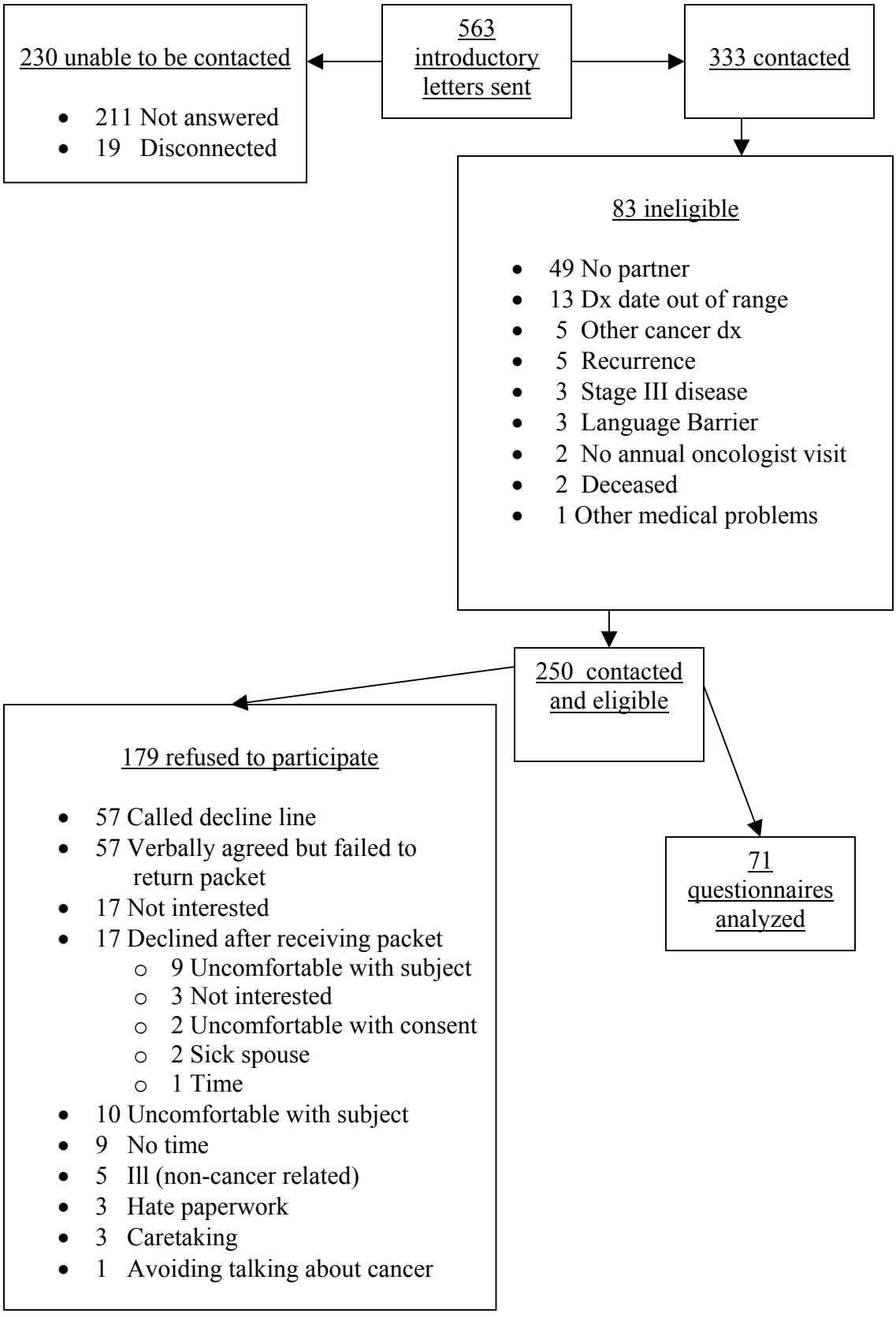
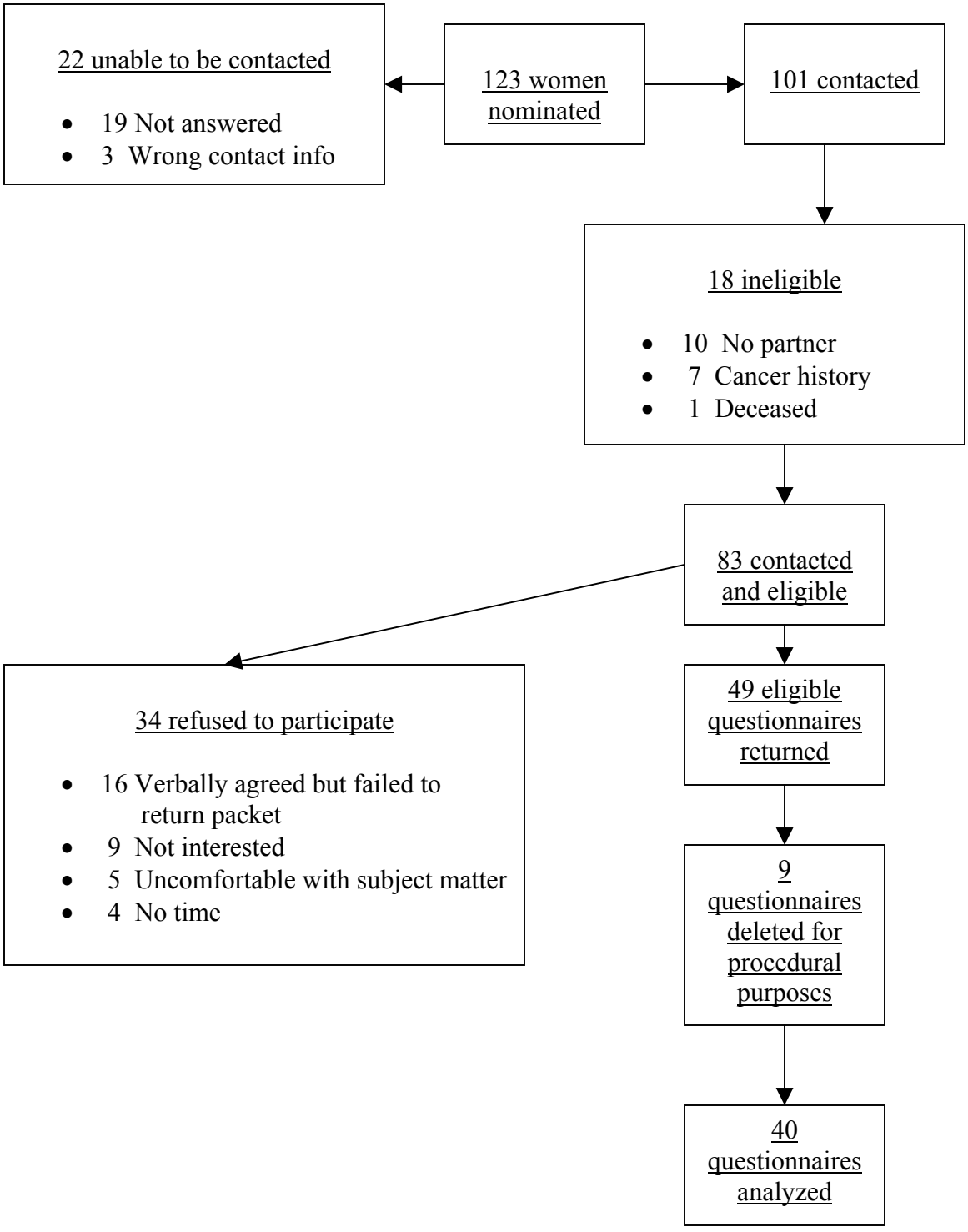


Figure 2. Flow chart of recruitment for non-cancer participants



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Appendices

Appendix A: Introductory Letter for Breast Cancer Patients

To Our Patients,

As part of our continuing efforts to improve patient care, we are asking selected patients treated by the Breast Program at Moffitt Cancer Center and their friends to participate in a research study. This study is being conducted in collaboration with Heidi Grenke, B.A. and Paul Jacobsen, Ph.D. from Moffitt's Psychosocial and Palliative Care Program. They are interested in assessing quality of life, including sexual functioning, in women with and without a past history of breast cancer. In order to do so, they need to collect information from women with a history of breast cancer, as well as women of the same age without a history of breast cancer. Although sexual functioning is a sensitive topic, it is an important concern for many breast cancer survivors. Only through research in this area, will we be able to better assess and treat the concerns of breast cancer survivors.

Participation would entail completing a brief packet of questionnaires that takes approximately 25 minutes to finish. The information you can provide will be important in helping us better assess the types of changes women with breast cancer experience, so that we might better plan for their care.

If you do not wish to learn more about this study, please call (813) 903-4606 or 1-800-456-3434 x4606 and you will not be contacted further. Otherwise, within the next week, you will receive a phone call from Heidi Grenke in order to provide additional information about how to participate in this study.

I greatly appreciate your taking the time to consider this request.

Sincerely,

Karen Fields, M.D.
Program Leader, Breast Program

Appendix B: Telephone Script for Breast Cancer Participants

Hello, my name is Heidi Grenke and I am a graduate student at the University of South Florida doing research at the Moffitt Cancer Center. Currently, I am doing a study along with Dr. _____ and the other doctors in the Breast Program. Last week, you should have received a letter from us describing a study we are currently doing on the quality of life of women who have been diagnosed with cancer in the past 5 years.

Did you receive that letter?

Is now a good time to tell you a little bit more about the study?

We are most interested in finding out how you are feeling both physically and emotionally now that treatment has ended and time has passed. If you agree to participate, we will be asking for some of your time and input. We will be mailing you out a questionnaire packet that will include questions about your mood, level of fatigue, body image, and sexual functioning. This packet will take approximately 45 minutes to complete. While some of the questions about sexual functioning will seem quite personal, I want to guarantee you that all information will be kept strictly confidential. The information you provide will help us to learn more about how to assist patients in coping with possible side effect of cancer treatment over time.

We will also be asking you to nominate female friends within 5 years of your age that would also be willing to complete a questionnaire for this study. We are asking women without a breast cancer diagnosis to also complete the questionnaire so that we can determine whether or not the quality of life of women treated for breast cancer differs from that of the quality of life of women of similar age and circumstances NOT diagnosed with breast cancer.
Does this sound like something you might be interested in?

I have a few questions to ask you, to ensure that this study is a good fit for you.

1. When were your first diagnosed with breast cancer? _____
2. Have you seen your oncologist in the past year?
3. What did he/she say?
4. Have you ever been diagnosed with any other type of cancer (r/o if other than basal cell)?
5. Do you have any other medical conditions that we should be aware of?
6. Do you have a spouse or partner with whom you are currently sexually active?

Appendix C: Recruitment Invitation for Non-Cancer Participants

Dear _____,

I am taking part in a research study that looks at the impact of breast cancer treatment on quality of life. This study is being done through the H. Lee Moffitt Cancer Center and Research Institute, where I received my care, and focuses on sexual functioning in breast cancer survivors. One important aspect of the study is to compare the reports of women who received breast cancer treatment with those women without cancer ('healthy controls'). This information will help the researchers at Moffitt identify the specific needs of women treated for breast cancer.

I have nominated you to be invited to take part in this study as a 'healthy control'. One of the researchers at Moffitt, Heidi Grenke, will call you within the next week to further explain the study. Taking part in this study would involve completing a questionnaire packet (which should take about 25 minutes to complete) by mail on one occasion.

This type of research is needed so that doctors can improve their skills in helping women manage the effects of breast cancer treatment and experience better quality of life. I encourage you to take part in the study and I hope you will agree to participate.

Sincerely, _____

Appendix D: General Background Information Form for Breast Cancer Patients

We appreciate your participation in this project; we could not complete it without you. Your answers will remain completely confidential. Thank you for your time.

1. Today's date: ☐☐/ ☐☐ /☐☐ (month/day/year)

2. Your birth date: ☐☐ /☐☐/ ☐☐ (month/day/year)

3. Height ☐ (ft) ☐☐ (in)

4. Weight ☐☐☐ (pounds)

5. Which of the following best describes your ethnic background?

☐ 1 Spanish/Hispanic/Latino
☐ 2 Not Spanish/Hispanic/Latino

6. What is your race? (check one box)

☐ 1 White/Caucasian
☐ 2 Black/African American
☐ 3 Asian/Pacific Islander
☐ 4 American Indian/Alaska Native
☐ 5 Other: _____

7. What is the highest grade or level of education you have completed? (check one box)

☐ 1 8th grade or less
☐ 2 Some high school (grade 9 to 12)
☐ 3 High school graduate or GED
☐ 4 Vocational school or some college
☐ 5 College or university graduate
☐ 6 Professional or graduate school

8. What category best describes **your** usual occupation? If you are not currently employed, which category best describes your **LAST** job? (check one box)

☐ 1 Professional (e.g., teacher/professor, nurse, lawyer, physician, engineer)
☐ 2 Manager/Administrator (e.g., sales managers)
☐ 3 Clerical (e.g., secretaries, clerks, or mail carriers)
☐ 4 Sales (e.g., sales persons, agents, and brokers)
☐ 5 Service (e.g., police, cooks, waitress, or hairdressers)
☐ 6 Skilled Crafts, Repairer (e.g., carpenters)
☐ 7 Equipment or Vehicle Operator (e.g., truck drivers)

Appendix D: General Background Information Form for Breast Cancer Patients (Continued)

☐ 8 Laborer (e.g., maintenance factory workers)
☐ 9 Farmer (e.g., owners, managers, operators, or tenants)
☐ 10 Member of the military
☐ 11 Homemaker (with no job outside the home)
☐ 12 Other (please describe)_____

9. Which category best describes your **spouse/partner's** usual occupation? If your spouse/partner is notcurrently employed, which category best describes his/her **LAST** job? (check one box)

☐ 1 Professional (e.g., teacher/professor, nurse, lawyer, physician,engineer)
☐ 2 Manager/Administrator (e.g., sales managers)
☐ 3 Clerical (e.g., secretaries, clerks, or mail carriers)
☐ 4 Sales (e.g., sales persons, agents, and brokers)
☐ 5 Service (e.g., police, cooks, waitress, or hairdressers)
☐ 6 Skilled Crafts, Repairer (e.g., carpenters)
☐ 7 Equipment or Vehicle Operator (e.g., truck drivers)
☐ 8 Laborer (e.g., maintenance factory workers)
☐ 9 Farmer (e.g., owners, managers, operators, or tenants)
☐ 10 Member of the military
☐ 11 Homemaker (with no job outside the home)
☐ 12 Other (please describe)_____

10. Which of the following best describes **your** current employment situation? (check one box)

☐ 1 Paid full-time employment
☐ 2 Paid part-time employment
☐ 3 Self-employed
☐ 4 On leave with pay
☐ 5 On leave without pay
☐ 6 Not employed - disabled
☐ 7 Not employed – retired
☐ 8 Student full-time
☐ 9 Student part-time
☐ 10 Homemaker
☐ 11 Volunteer
☐ 12 Unemployed-looking for work
☐ 13 Unemployed-not looking for work

11. What is **your** approximate annual gross income? (check one box)

☐ 1 Less than $ 10,000
☐ 2 $10,000 - $19,999
☐ 3 $20,000 - $ 39,999
☐ 4 $40,000 - $74,999
☐ 5 $75,000 or more
☐ 6 Prefer not to answer

Appendix D: General Background Information Form for Breast Cancer Patients (Continued)

12. What was your total **household** income (from all sources) before taxes in the last calendar year? Your answer will remain completely confidential. (check one box)

☐ 1 Less than $ 10,000
☐ 2 $10,000 - $19,999
☐ 3 $20,000 - $ 39,999
☐ 4 $40,000 - $74,999
☐ 5 $75,000 or more
☐ 6 Prefer not to answer

13. When were you first diagnosed with breast cancer?

☐☐ /☐☐ (month/year)

14. Which of the following have you received? (check all that apply)

☐ 1 Lumpectomy to remove the cancer
☐ 2 Mastectomy to remove the cancer
☐ 3 Lumpectomy + mastectomy to remove the cancer
☐ 4 Bilateral Mastectomy to remove the cancer
☐ 5 Breast reconstruction
☐ 6 Radiation therapy
☐ 7 Chemotherapy before your breast cancer surgery
☐ 8 Chemotherapy after your breast cancer surgery
☐ 9 Hormonal therapy to shrink or reduce the cancer (ex: Tamoxifen)
☐ 10 Hormonal therapy to prevent another cancer (ex: Tamoxifen)
☐ 11 Other (describe_____)

15. When did you finish chemotherapy treatments?

☐ 1 I did not receive chemotherapy treatment.

☐ 2 I finished chemotherapy treatments on ☐☐ /☐☐ (month/year)

16. When did you finish radiation treatments?

☐ 1 I did not receive radiation treatment.

☐ 2 I finished radiation treatments on ☐☐ /☐☐ (month/year)

Appendix D: General Background Information Form for Breast Cancer Patients (Continued)

17. Which of the following best describes how you presently function? (check one box)

- ☐ 1 I am able to carry on normal activity or do work and I have no physical complaints or problems.
- ☐ 2 I am able to carry on normal activity or do work even with minor physical complaints.
- ☐ 3 I am able to carry on normal activity or do work but it takes effort because of physical problems.
- ☐ 4 I am unable to carry on normal activity but I care for myself.
- ☐ 5 I am unable to carry on normal activity and I require occasional help from others, but I am able to care for most of my personal needs.
- ☐ 6 I require considerable help from others and I require frequent medical care.
- ☐ 7 I am disabled and I require special care and help.

18. Do you take prescription medication regularly?

- ☐ 1 Yes
- ☐ 2 No

19. Are you currently taking Tamoxifen?

- ☐ 1 Yes
- ☐ 2 No

If yes:
Dose: Since:

_____ _____

Appendix D: General Background Information Form for Breast Cancer Patients
(Continued)

20. What medications, other than Tamoxifen, do you currently take?

Drug:	Dose:	Since:	Reason:
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

21. Please indicate your sexual orientation (check one box).

☐ 1 Heterosexual
☐ 2 Homosexual
☐ 3 Bisexual
☐ 4 Prefer not to answer

22. What is your current marital status? (check one box)

☐ 1 Single, never married
☐ 2 Married
☐ 3 Living in a marriage-like relationship
☐ 4 Divorced
☐ 5 Widowed
☐ 6 Separated

23. Length of time you have been with your current partner (check one box):

☐ 1 Less than 6 months
☐ 2 Six months to 1 year
☐ 3 One to 2 years
☐ 4 Two to 5 years
☐ 5 More than 5 years

24. Were you with this current partner before your breast cancer diagnosis?

☐ 1 Yes
☐ 2 No

25. Does your partner have any difficulty with sexual desire, becoming sexually aroused, or achieving orgasm?

☐ 1 Yes (Go to question 26)
☐ 2 No (Go to question 27)

Appendix D: General Background Information Form for Breast Cancer Patients (Continued)

26. When did your partner start having difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐☐ /☐☐ (month/year)

27. Prior to your breast cancer diagnosis, did you have any difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐ 1 Yes (Go to question 28)
☐ 2 No (Go to question 29)

28. When did you start having difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐☐ /☐☐ (month/year)

29. Current living arrangement (check one box):

☐ 1 Live alone
☐ 2 Live with spouse/partner
☐ 3 Live with spouse/partner and children
☐ 4 Live with children (no spouse/partner)
☐ 5 Live with roommate who is not partner
☐ 6 Live with parents
☐ 7 Other (specify:_____)

30. How long in current living arrangement (check one box):

☐ 1 Less than 1 month
☐ 2 One to 6 months
☐ 3 Seven months to 2 years
☐ 4 Between 2 to 5 years
☐ 5 More than 5 years

31. Number of children under 18 living at home: ☐☐

Appendix E: General Background Information Form for Non-Cancer Participants

We appreciate your participation in this project; we could not complete it without you. Your answers will remain completely confidential. Thank you for your time.

1. Today's date: ☐☐/ ☐☐ /☐☐ (month/day/year)

2. Your birth date: ☐☐ /☐☐/ ☐☐ (month/day/year)

3. Height ☐ (ft) ☐☐ (in)

4. Weight ☐☐☐ (pounds)

5. Which of the following best describes your ethnic background?

☐ 1 Spanish/Hispanic/Latino
☐ 2 Not Spanish/Hispanic/Latino

6. What is your race? (check one box)

☐ 1 White/Caucasian
☐ 2 Black/African American
☐ 3 Asian/Pacific Islander
☐ 4 American Indian/Alaska Native
☐ 5 Other: _____

7. What is the highest grade or level of education you have completed? (check one box)

☐ 1 8th grade or less
☐ 2 Some high school (grade 9 -12)
☐ 3 High school graduate or GED
☐ 4 Vocational school or some college
☐ 5 College or university grad
☐ 6 Professional or graduate school

Appendix E: General Background Information Form for Non-Cancer Participants (Continued)

8. What category best describes **your** usual occupation? If you are not currently employed, which category best describes your **LAST** job? (check one box)

☐ 1 Professional (e.g., teacher/professor, nurses, lawyer, physician, engineer)
☐ 2 Manager/Administrator (e.g., sales managers)
☐ 3 Clerical (e.g., secretaries, clerks, or mail carriers)
☐ 4 Sales (e.g., sales persons, agents, and brokers)
☐ 5 Service (e.g., police, cooks, waitress, or hairdressers)
☐ 6 Skilled Crafts, Repairer (e.g., carpenters)
☐ 7 Equipment or Vehicle Operator (e.g., truck drivers)
☐ 8 Laborer (e.g., maintenance factory workers)
☐ 9 Farmer (e.g., owners, managers, operators, or tenants)
☐ 10 Member of the military
☐ 11 Homemaker (with no job outside the home)
☐ 12 Other (please describe)_____

9. Which category best describes your **spouse/partner's** usual occupation? If your spouse/partner is not currently employed, which category best describes his/her **LAST** job? (check one box)

☐ 1 Professional (e.g., teacher/professor, nurse, lawyer, physician, engineer)
☐ 2 Manager/Administrator (e.g., sales managers)
☐ 3 Clerical (e.g., secretaries, clerks, or mail carriers)
☐ 4 Sales (e.g., sales persons, agents, and brokers)
☐ 5 Service (e.g., police, cooks, waitress, or hairdressers)
☐ 6 Skilled Crafts, Repairer (e.g., carpenters)
☐ 7 Equipment or Vehicle Operator (e.g., truck drivers)
☐ 8 Laborer (e.g., maintenance factory workers)
☐ 9 Farmer (e.g., owners, managers, operators, or tenants)
☐ 10 Member of the military
☐ 11 Homemaker (with no job outside the home)
☐ 12 Other (please describe)_____

10. Which of the following best describes **your** current employment situation? (check one box)

☐ 1 Paid full-time employment
☐ 2 Paid part-time employment
☐ 3 Self-employed
☐ 4 On leave with pay
☐ 5 On leave without pay
☐ 6 Not employed - disabled
☐ 7 Not employed – retired
☐ 8 Student full-time
☐ 9 Student part-time
☐ 10 Homemaker
☐ 11 Volunteer
☐ 12 Unemployed-looking for work
☐ 13 Unemployed-not looking for work

Appendix E: General Background Information Form for Non-Cancer Participants (Continued)

11. What is **your** approximate annual gross income? (check one box)

☐ 1 Less than $ 10,000
☐ 2 $10,000 - $19,999
☐ 3 $20,000 - $ 39,999
☐ 4 $40,000 - $74,999
☐ 5 $75,000 or more
☐ 6 Prefer not to answer

12. What was your total **household** income (from all sources) before taxes in the last calendar year? (check one box)

☐ 1 Less than $ 10,000
☐ 2 $10,000 - $19,999
☐ 3 $20,000 - $ 39,999
☐ 4 $40,000 - $74,999
☐ 5 $75,000 or more
☐ 6 Prefer not to answer

13. Which of the following best describes how you presently function? (check one box)

☐ 1 I am able to carry on normal activity or do work and I have no physical complaints or problems.
☐ 2 I am able to carry on normal activity or do work even with minor physical complaints.
☐ 3 I am able to carry on normal activity or do work but it takes effort because of physical problems.
☐ 4 I am unable to carry on normal activity but I care for myself.
☐ 5 I am unable to carry on normal activity and I require occasional help from others, but I am able to care for most of my personal needs.
☐ 6 I require considerable help from others and I require frequent medical care.
☐ 7 I am disabled and I require special care and help.

14. Do you take prescription medication regularly?

☐ 1 Yes (Go to question 15)
☐ 2 No (Go to question 16)

Appendix E: General Background Information Form for Non-Cancer Participants (Continued)

15. What medications do you currently take?

Drug:	Dose:	Since:	Reason:
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

16. Please indicate your sexual orientation. (check one box)

☐ 1 Heterosexual
☐ 2 Homosexual
☐ 3 Bisexual
☐ 4 Prefer not to answer

17. What is your current marital status? (check one box)

☐ 1 Single, never married
☐ 2 Married
☐ 3 Living in a marriage-like relationship
☐ 4 Divorced
☐ 5 Widowed
☐ 6 Separated

18. Length of time you have been with your current partner (check one box):

☐ 1 Less than 6 months
☐ 2 Six months to 1 year
☐ 3 One to 2 years
☐ 4 Two to 5 years
☐ 5 More than 5 years

19. Does your partner have difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐ 1 Yes (Go to question 20)
☐ 2 No (Go to question 21)

20. When did your partner start having difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐☐ /☐☐ (month/year)

Appendix E: General Background Information Form for Non-Cancer Participants
(Continued)

21. Do you have any difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐ 1 Yes (Go to question 22)
☐ 2 No (Go to question 23)

22. When did you start having difficulties with sexual desire, becoming sexually aroused, or achieving orgasm?

☐☐ /☐☐ (month/year)

23. Current living arrangement (check one box):

☐ 1 Live alone
☐ 2 Live with spouse/partner
☐ 3 Live with spouse/partner and children
☐ 4 Live with children (no spouse/partner)
☐ 5 Live with roommate who is not partner
☐ 6 Live with parents
☐ 7 Other (specify:_____)

24. How long in current living arrangement (check one box):

☐ 1 Less than 1 month
☐ 2 One to 6 months
☐ 3 Seven months to 2 years
☐ 4 Between 2 to 5 years
☐ 5 More than 5 years

25. Number of children under 18 living at home: ☐☐

Appendix F: Center for Epidemiologic Studies, Depression Scale

For each statement below, make an **"X"** in the box which best describes how often you felt or behaved this way-- **DURING THE PAST WEEK, INCLUDING TODAY.**

		None of the Time	A Little of the Time	A Moderate Amount of Time	Most of the Time
DURING THE PAST WEEK:					
1.	I was bothered by things that usually don't bother me	☐	☐	☐	☐
2.	I did not feel like eating; my appetite was poor.	☐.....	☐	☐	☐
3.	I felt that I could not shake off the blues even with help from my family or friends	☐.....	☐	☐	☐
4.	I felt that I was just as good as other people	☐.....	☐	☐	☐
5.	I had trouble keeping my mind on what I was doing	☐.....	☐	☐	☐
6.	I felt depressed	☐.....	☐	☐	☐
7.	I felt that everything I did was an effort	☐.....	☐	☐	☐
8.	I felt hopeful about the future	☐.....	☐	☐	☐
9.	I thought my life had been a failure	☐.....	☐	☐	☐
10.	I felt fearful	☐.....	☐	☐	☐
11.	My sleep was restless	☐.....	☐	☐	☐
12.	I was happy	☐.....	☐	☐	☐
13.	I talked less than usual	☐.....	☐	☐	☐
14.	I felt lonely	☐.....	☐	☐	☐
15.	People were unfriendly	☐.....	☐	☐	☐
16.	I enjoyed life	☐.....	☐	☐	☐
17.	I had crying spells	☐.....	☐	☐	☐
18.	I felt sad	☐.....	☐	☐	☐
19.	I felt that people disliked me	☐.....	☐	☐	☐
20.	I could not "get going"	☐.....	☐	☐	

Appendix G: Fatigue Symptom Inventory

For each of the following, circle the one number that best indicates how that item applies to you.

1. Rate your level of fatigue on the day you felt **most** fatigued during the past week.

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										As fatigued as I could be

2. Rate your level of fatigue on the day you felt **least** fatigued during the past week.

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										As fatigued as I could be

3. Rate your level of fatigue on the **average** in the last week.

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										As fatigued as I could be

4. Rate your level of fatigue **right now**.

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										As fatigued as I could be

5. Rate how much, in the past week, fatigue interfered with your **general level of activity**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

6. Rate how much, in the past week, fatigue interfered with your **ability to bathe and dress yourself**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

7. Rate how much, in the past week, fatigue interfered with your **normal work activity (includes both work outside the home and housework)**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

8. Rate how much, in the past week, fatigue interfered with your **ability to concentrate**

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

9. Rate how much, in the past week, fatigue interfered with your **relations with other people**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

10. Rate how much, in the past week, fatigue interfered with your **enjoyment of life**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										Extreme interference

11. Rate how much, in the past week, fatigue interfered with your **mood**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No										Extreme

12. Indicate **how many days**, in the past week, you felt fatigued for any part of the day:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*
Days							Days

13. Rate **how much of the day**, on average, you felt fatigued in the past week:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
None of the day										The entire day

14. Indicate which of the following best describes the **daily pattern** of your fatigue in the past week:

0	*1*	*2*	*3*	4
Not at all fatigued	Worse in the morning	Worse in the afternoon	Worse in the evening	No consistent daily pattern of fatigue

Appendix H: Body Exposure in Sexual Activities Questionnaire

If you have <u>not</u> engaged in sexual activity in the last six months, please mark an "X" in this box ☐ and proceed on to the next questionnaire.

We are interested in the thoughts and behaviors that an individual may experience or enact during sexual encounters. Read each statement carefully and identify how characteristic it is of you and your experience using the following code:

	Never	Rarely	Sometimes	Often	Always
1. During sexual activity I am constantly thinking that my partner will notice something about my body that is a turnoff…….	☐	☐	☐	☐	☐
2. During sexual activity I worry that my partner will find aspects of my physique unappealing…….	☐	☐	☐	☐	☐
3. During sexual activity I am aware of how my body looks……	☐	☐	☐	☐	☐
4. During sexual activity something about the way my body looks makes me feel inhibited…….	☐	☐	☐	☐	☐
5. I am uncomfortable when undressed by my partner……	☐	☐	☐	☐	☐
6. I prefer to keep my body hidden under a sheet or blanket during sexual activity…	☐	☐	☐	☐	☐
7. I am comfortable with my partner looking at my genitals during sexual activity……..	☐	☐	☐	☐	☐
8. During sexual activity I worry that my partner will find my body repulsive……	☐	☐	☐	☐	☐
9. During sexual activity I worry that my partner will think the size and shape of my sex organs are in-adequate or unattractive	☐	☐	☐	☐	☐

Appendix H: Body Exposure in Sexual Activities Questionnaire (Continued)

	Never	Rarely	Sometimes	Often	Always
10. When it comes to my partner seeing me naked, I have nothing to hide……	☐	☐	☐	☐	☐
11. During sexual activity I have thoughts that my body looks sexy……	☐	☐	☐	☐	☐
12. I don't like my partner to see me completely naked during sexual activity…	☐	☐	☐	☐	☐
13. During sexual activity I expect my partner to be excited by seeing me without my clothes……	☐	☐	☐	☐	☐
14. I prefer to keep certain articles of clothing on during sexual activity……	☐	☐	☐	☐	☐
15. I am self-conscious about my body during sexual activity…….	☐	☐	☐	☐	☐
16. During sexual activity I worry that my partner will find the appearance or odor of my genitals repulsive …..	☐	☐	☐	☐	☐
17. During sexual activity I try to hide certain areas of my body from my partner's view…	☐	☐	☐	☐	☐
18. During sexual activity I keep thinking that parts of my body are too unattractive to be sexy…….	☐	☐	☐	☐	☐
19. There are parts of my body that I don't want my partner to see during sexual activity……	☐	☐	☐	☐	☐
20. During sexual activity I worry about what my partner thinks about how my body looks……..	☐	☐	☐	☐	☐
21. During sexual activity I worry that my partner could be turned off by the way parts of my body feel to his/her touch…	☐	☐	☐	☐	☐

Appendix H: Body Exposure in Sexual Activities Questionnaire (Continued)

	Never	Rarely	Sometimes	Often	Always
22. During sexual activity it is hard for me not to think about my weight……	☐	☐	☐	☐	☐
23. I feel self-conscious if the room is too well lit during sexual activity	☐	☐	☐	☐	☐
24. I am generally comfortable having parts of my body exposed to my\ partner during sexual activity…….	☐	☐	☐	☐	☐
25. During sexual activity I enjoy having my partner look at my body……	☐	☐	☐	☐	☐
26. During sexual activity there are certain poses or positions I avoid because of the way my body would look to my partner …	☐	☐	☐	☐	☐
27. During sexual activity I am distracted by thoughts of how certain parts of my body look……..	☐	☐	☐	☐	☐
28. I am comfortable with my partner looking at my breast area during sexual activity……	☐	☐	☐	☐	☐
29. During sexual activity I worry that my partner will find my breast area repulsive	☐	☐	☐	☐	☐
30. During sexual activity I worry that my partner will think the size and shape of my breasts are inadequate or unattractive	☐	☐	☐	☐	☐
31. During sexual activity I worry about what my partner thinks about how my breast area looks…….	☐	☐	☐	☐	☐

Appendix I: The Body-Self Relations Questionnaire: Appearance Evaluation Subscale

Using the scale below, please check one box that best matches your agreement with the following statements.

	Definitely Disagree	Mostly Disagree	Neither Agree nor Disagree	Mostly Agree	Definitely Agree
1. My body is sexually appealing……..	☐	☐	☐	☐	☐
2. I like my looks just the way they are….	☐	☐	☐	☐	☐
3. Most people would consider me good looking……	☐	☐	☐	☐	☐
4. I like the way I look Without my clothes	☐	☐	☐	☐	☐
5. I like the way my clothes fit me…….	☐	☐	☐	☐	☐
6. I dislike my physique…	☐	☐	☐	☐	☐
7. I'm physically unattractive.…	☐	☐	☐	☐	☐

Would you be interested in receiving a free copy of the American Cancer Society booklet entitled, "Sexuality and Cancer: For the Woman Who Has Cancer, and Her Partner"?

☐ Yes ☐ No

Appendix J: Dyadic Adjustment Scale

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	Almost Always Agree	Occasion-ally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Demonstrations of affection	☐	☐	☐	☐	☐	☐
2. Sex relations	☐	☐	☐	☐	☐	☐
	All the time	Most of the time	More often than not	Occasion-ally	Rarely	Never
3. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	☐	☐	☐	☐	☐	☐
4. How often do you or your mate leave the house after a fight?	☐	☐	☐	☐	☐	☐
5. In general, how often do you think that things between you and your partner are going well?	☐	☐	☐	☐	☐	☐
6. Do you confide in your mate?……	☐	☐	☐	☐	☐	☐
7. Do you everregret that you married? *(or lived together).*	☐	☐	☐	☐	☐	☐
8. How often do you and your partner quarrel?	☐	☐	☐	☐	☐	☐
9. How often do you and your mate "get on each other's nerves?"	☐	☐	☐	☐	☐	☐

	Every Day	Almost Every Day	Occasionally	Rarely	Never
10. Do you kiss your mate?…..	☐	☐	☐	☐	☐

There are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Mark an "X" in the box.)

	Yes	No
11. Being too tired for sex	☐	☐
12. Not showing love	☐	☐

13. The descriptors on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the descriptor that best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

14. Which of the following statements best describes how you feel about the future of your relationship? (Check one box.)

☐ I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.

☐ I want very much for my relationship to succeed, and *will do all I can* to see that it does.

☐ I want very much for my relationship to succeed, and *will do my fair share* to see that it does.

☐ It would be nice if my relationship succeeded, but *I can't do much more than I am doing* now to help it succeed.

☐ It would be nice if it succeeded, but I *refuse to do any more than I am doing* now to keep the relationship going.

☐ My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

Appendix K: The Breast Cancer Prevention Trial Symptom Checklist

We are interested in knowing whether you have had any of the following problems during the PAST FOUR WEEKS.

	Not at all	Slightly	Moderately	Quite a bit	Extremely
1. Hot flashes……	☐	☐	☐	☐	☐
2. Headaches……	☐	☐	☐	☐	☐
3. Blind spots, fuzzy vision……...	☐	☐	☐	☐	☐
4. Nausea……	☐	☐	☐	☐	☐
5. Vomiting…….	☐	☐	☐	☐	☐
6. Diarrhea…….	☐	☐	☐	☐	☐
7. Constipation……	☐	☐	☐	☐	☐
8. Difficulty with bladder control (when laughing or crying)…….	☐	☐	☐	☐	☐
9. Difficulty with bladder control (at other times)……	☐	☐	☐	☐	☐
10. Vaginal discharge……	☐	☐	☐	☐	☐
11. Vaginal bleeding or spotting……	☐	☐	☐	☐	☐
12. Genital itching/irritation…	☐	☐	☐	☐	☐
13. Vaginal dryness……	☐	☐	☐	☐	☐
14. Pain with intercourse……	☐	☐	☐	☐	☐
15. Cramps……	☐	☐	☐	☐	☐

Appendix K: The Breast Cancer Prevention Trial Symptom Checklist (Continued)

		Not at all	Slightly	Moderately	Quite a bit	Extremely
16.	Breast sensitivity/tenderness…	☐	☐	☐	☐	☐
17.	Ringing in ears……	☐	☐	☐	☐	☐
18.	General aches and pains..	☐	☐	☐	☐	☐
19.	Joint pains……	☐	☐	☐	☐	☐
20.	Chest pains……	☐	☐	☐	☐	☐
21.	Swelling of hands or feet..	☐	☐	☐	☐	☐
		Not at all	Slightly	Moderately	Quite a bit	Extremely
22.	Muscle stiffness……	☐	☐	☐	☐	☐
23.	Difficulty breathing……	☐	☐	☐	☐	☐
24.	Dry mouth……	☐	☐	☐	☐	☐
25.	Weight gain……	☐	☐	☐	☐	☐
26.	Weight loss……	☐	☐	☐	☐	☐
27.	Unhappy with the appearance of my body..	☐	☐	☐	☐	☐
28.	Decreased appetite……	☐	☐	☐	☐	☐
29.	Feelings of suffocation…	☐	☐	☐	☐	☐
30.	Forgetfulness……	☐	☐	☐	☐	☐
31.	Excitability……	☐	☐	☐	☐	☐
32.	Short temper……	☐	☐	☐	☐	☐

Appendix K: The Breast Cancer Prevention Trial Symptom Checklist (Continued)

		Not at all	Slightly	Moderately	Quite a bit	Extremely
33.	Tendency to take naps; stay in bed……	☐	☐	☐	☐	☐
34.	Night sweats……	☐	☐	☐	☐	☐
35.	Cold sweats……	☐	☐	☐	☐	☐
36.	Tendency toward accidents…….	☐	☐	☐	☐	☐
37.	Avoidance of social affairs……..	☐	☐	☐	☐	☐
38.	Difficulty concentrating..	☐	☐	☐	☐	☐
39.	Easily distracted……	☐	☐	☐	☐	☐
40.	Dizziness, faintness……	☐	☐	☐	☐	☐
41.	Numbness, tingling……	☐	☐	☐	☐	☐
42.	Early awakening……	☐	☐	☐	☐	☐
43.	Any other problems? (Please specify.)_____	☐	☐	☐	☐	☐

Appendix L: Sexual Functioning Questionnaire

These next questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects your self and your body. Some questions ask about your own experiences, thoughts, and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. *Be assured that your responses are totally confidential.*

1. In the PAST MONTH, how frequently have you had sexual thoughts, urges, fantasies, or erotic dreams? (*Please make an "X" in the one box that is closest to your experience.)*

   ☐ Not at all
   ☐ Once
   ☐ 2 or 3 times
   ☐ Once a week
   ☐ 2 or 3 times per week
   ☐ Once a day
   ☐ More than once a day

2. Using the scale below, how frequently have you felt an **interest or desire to engage in** the following specific activities in the PAST MONTH? (*This question is about your interest and desires, <u>not</u> about how often you have engaged in sexual activity. For each item, please make an "X" in the one box that is closest to your experience):*

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per wk	Once a Day	More than once a day
a Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b Masturbation	☐	☐	☐	☐	☐	☐	☐
c Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d Petting and foreplay	☐	☐	☐	☐	☐	☐	☐
e Vaginal intercourse	☐	☐	☐	☐	☐	☐	☐
f Other sexual activity *please specify:*	☐	☐	☐	☐	☐	☐	☐

3. Using the scale below, how frequently have you become **aroused by** the following sexual activity in the PAST MONTH? (By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual. This question is about your arousal, not about how often you have engaged in sexual activity):

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b Masturbation	☐	☐	☐	☐	☐	☐	☐
c Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d Petting and foreplay	☐	☐	☐	☐	☐	☐	☐
e Vaginal intercourse.	☐	☐	☐	☐	☐	☐	☐
f Other sexual activity *please specify:* _____	☐	☐	☐	☐	☐	☐	☐

4. In the PAST MONTH, have you **felt pleasure** from any sexual activity? (Please mark one box.)

☐ 1 I have had no sexual activity in the past month
☐ 2 I have not felt any pleasure
☐ 3 Seldom, less than 25% of the time
☐ 4 Sometimes, about 50% of the time
☐ 5 Usually, about 75% of the time
☐ 6 Always felt pleasure

5. Using the scale below, how frequently have you **engaged in** the following sexual activity in the PAST MONTH?

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b Masturbation	☐	☐	☐	☐	☐	☐	☐
c Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d Petting and foreplay	☐	☐	☐	☐	☐	☐	☐
e Vaginal intercourse.	☐	☐	☐	☐	☐	☐	☐
f Other sexual activity *please specify:* _____	☐	☐	☐	☐	☐	☐	☐

6. In the PAST MONTH, how often have you **reached orgasm** (climax) during sexual activity? (Please mark one box.)

☐ 1 I have had no sexual activity in the past month
☐ 2 I have not experienced orgasm
☐ 3 Seldom, less than 25% of the time
☐ 4 Sometimes, about 50% of the time
☐ 5 Usually, about 75% of the time
☐ 6 I always experienced orgasm

7. When you have **orgasms** (climax), how intense have they been in the PAST MONTH?

☐ 1 I have had no sexual activity in the past month
☐ 2 I have had no orgasms in the last month
☐ 3 My orgasms were **very mild**
☐ 4 My orgasms were **fairly mild**
☐ 5 My orgasms were **fairly strong**
☐ 6 My orgasms were **very strong**

8. How **easy or difficult** has it been for you to have **orgasms** (climax) in the PAST MONTH?

- ☐ 1 I have had no sexual activity in the past month
- ☐ 2 I have had no orgasms in the last month
- ☐ 3 It was **very difficult** to have orgasms; it took a long time and a lot of concentration
- ☐ 4 It was **fairly difficult**; it took a while
- ☐ 5 It was **fairly easy**
- ☐ 6 It was **very easy**

Appendix L: Sexual Functioning Questionnaire (Continued)

How frequently in the PAST MONTH have you had the problems listed below?	Not at all	Seldom, less than 25% of the time	Sometimes Less than 50% of the time	Usually, about 75% of the time	Always	If you have checked anything other than "not at all", has it stopped or reduced your sexual activity? Yes	No
a. Problems with dreams or fantasies……..	☐	☐	☐	☐	☐	……☐	☐
b. Problems with masturbation……	☐	☐	☐	☐	☐	……☐	☐
c. Problems with touching, hugging, holding, kissing……	☐	☐	☐	☐	☐	……☐	☐
d. Problems with petting and foreplay…….…….	☐	☐	☐	☐	☐	……☐	☐
e. Problems with vaginal intercourse……	☐	☐	☐	☐	☐	……☐	☐
f. Problems with other sexual activity *Please specify:* _____	☐	☐	☐	☐	☐	……☐	☐
g. Vaginal bleeding or irritation after penetration or intercourse……..	☐	☐	☐	☐	☐	……☐	☐
h. Sharp pain inside or outside your vagina…	☐	☐	☐	☐	☐	……☐	☐
i. Increased sensitivity of your skin to intimate touching…….	☐	☐	☐	☐	☐	……☐	☐
j. Other problem with sexuality *Please specify:* _____	☐	☐	☐	☐	☐	……☐	☐

10. Please rate how interested you have been in sexual thoughts, feelings, or actions in the PAST MONTH by circling a number from 0 to 10.

0	1	2	3	4	5	6	7	8	9	10
Not at all Interested										Extremely Interested

11. Please rate the extent to which sexual activity has been satisfying for you in the PAST MONTH by circling a number from 0 to 10.

0	1	2	3	4	5	6	7	8	9	10
Not at all Interested										Extremely Interested

12. How often did the following factors influence your sexual activity in the PAST MONTH?

	Not at all	Seldom, less than 25% of the time	Sometimes, about 50% of the time	Usually, about 75% of the time	Always
a My own health	☐	☐	☐	☐	☐
b My partner's health	☐	☐	☐	☐	☐
c Conflict in my relationship	☐	☐	☐	☐	☐
d Other *please specify:* _____	☐	☐	☐	☐	☐

13. How frequently have you been able to communicate your sexual desires or preferences to your partner in the PAST MONTH?

☐ 1 I have not had a partner
☐ 2 I was always able to communicate my desires or preferences
☐ 3 Usually, about 75% of the time
☐ 4 Sometimes, about 50% of the time
☐ 5 Seldom, less than 25% of the time
☐ 6 I have been unable to communicate my desires or preferences

Appendix L: Sexual Functioning Questionnaire (Continued)

14. Overall, how satisfied have you been with your sexual relationship with your partner?

- ☐ 1 Very satisfied
- ☐ 2 Somewhat satisfied
- ☐ 3 Neither satisfied nor dissatisfied
- ☐ 4 Somewhat dissatisfied
- ☐ 5 Very dissatisfied

15. Overall, how satisfied do you think your partner has been with your sexual relationship?

- ☐ 1 Very satisfied
- ☐ 2 Somewhat satisfied
- ☐ 3 Neither satisfied nor dissatisfied
- ☐ 4 Somewhat dissatisfied
- ☐ 5 Very dissatisfied

16. Please rate how satisfied you have been with your ability to share warmth and intimacy with your partner in the PAST MONTH by circling the number below from 0 to 10.

0	1	2	3	4	5	6	7	8	9	10
Not at all Satisfied										Extremely Satisfied

17. Please rate how comfortable you are with touching, hugging or holding your partner in the PAST MONTH by circling the number below from 0 to 10.

0	1	2	3	4	5	6	7	8	9	10
Not at all Comfortable										Extremely Comfortable

18. Please rate how well you think you have adjusted to changes in your sex life since your breast cancer diagnosis by circling a number from 0 to 10.

0	1	2	3	4	5	6	7	8	9	10
Not at all Well										Extremely Well

Appendix L: Sexual Functioning Questionnaire (Continued)

19. What **impact** has your breast cancer and its treatment had on your sex life?

- ☐ 1 My sex life is a lot better than before
- ☐ 2 My sex life is a little better than before
- ☐ 3 My sex life is no different than before
- ☐ 4 My sex life is a little worse than before
- ☐ 5 My sex life is a lot worse than before

20. What impact has your breast cancer and its treatment had on your **interest** or **desire** for sex? (*This question is about your thoughts, fantasies or wishes, <u>not</u> about how you feel during sexual activity.)*

- ☐ 1 My interest is stronger
- ☐ 2 My interest is about the same
- ☐ 3 My interest is a little less
- ☐ 4 My interest is somewhat less
- ☐ 5 My interest is a lot less
- ☐ 6 I have lost all of my interest

21. What impact has your breast cancer and its treatment had on your **sexual arousal** during sexual activity? (*By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexual.)*

- ☐ 1 I am aroused more easily than ever
- ☐ 2 Arousal is about the same
- ☐ 3 It takes longer to get aroused, but the level of arousal is about the same
- ☐ 4 It takes longer to get aroused, and the level of arousal is not as intense
- ☐ 5 It is quite a bit more difficult for me to get aroused
- ☐ 6 I do not seem able to get aroused al all

22. What impact has your breast cancer and its treatment had on your **orgasms** during sex?

- ☐ 1 They are stronger than ever
- ☐ 2 They are about the same
- ☐ 3 It takes longer to get orgasm, but the intensity is about the same
- ☐ 4 It takes longer to get orgasm, and they are less intense than before the illness and treatment
- ☐ 5 Since the treatment, I am unable to orgasm
- ☐ 6 I have never experienced orgasm

23. Is there anything you would like to add about how sex has changed for you **since your breast cancer and its treatment**? Please describe below, as well as on the back of this sheet.