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## Sexual Functioning Among Early Post-Treatment Breast Cancer Survivors

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### Abstract

**Purpose**—1) To estimate percentages of partnered women who are sexually active over the first 2 years post breast cancer diagnosis; 2) to identify factors related to sexual inactivity; and 3) to evaluate separately, among both sexually active and inactive survivors, the relation between sexual problems and treatment-related variables, symptoms, and psychosocial factors.

**Methods**—Longitudinal observational study of breast cancer survivors recruited within 8 months of cancer diagnosis and followed for 18 months. The main outcome measures were: 1) being sexually active/inactive in the past month, and 2) sexual problems assessed with the 4-item sexual problems domain of the Quality of Life in Adult Cancer Survivors (QLACS) scale.

**Results**—At baseline, 52.4% of women reported being sexually active in the past month. This percentage increased to 60.7% 18 months later. In multivariable repeated-measures analyses, age, past chemotherapy, depressive symptoms, and lower perceived attractiveness were related to inactivity. Sexually inactive women reported more problems on the QLACS than sexually active women. In stratified multivariable analyses, depressive symptoms were related to greater sexual problems for both sexually active and inactive women, as was vaginal dryness. Among the sexually active women, younger age at diagnosis, less illness intrusiveness, and lower perceived attractiveness were related to more problems.

**Conclusions**—Research has shown that sexual functioning/sexual health are key aspects of quality of life for many cancer survivors, **and are often not addressed by health care providers**. Future studies should examine how such topics are handled by clinicians in their interactions with survivors.

### Keywords

sexual problems; breast cancer; quality of life; cancer survivorship

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**Conflict of interest.** The authors declare that they have no conflict of interests. We have full control of all primary data and we agree to allow the journal to review our data if requested.

## Introduction

Breast cancer is the most common cancer in women worldwide (and is the second most common cancer overall, after lung cancer), with nearly 1.7 million new cases diagnosed around the world in 2012 [1]. It is currently estimated that there are more than 3.5 million breast cancer survivors in the U.S. alone [2]. Further, with increased early detection and improved treatment, the number of breast cancer survivors continues to increase [2].

As a result of both diagnosis and treatment, sexual problems are common and distressing among breast cancer survivors and thus are important quality of life issues [3–8]. The most frequently reported sexual problems include diminished sexual interest [9, 10] or desire [3, 6, 11], decreased arousal and lubrication [3, 6, 10], and painful intercourse [3, 12] or vaginal penetration [11]. Survivors have been found to have a greater prevalence and persistence of sexual problems than women of the same age without a history of cancer [3, 10, 11, 13]. Previous research has shown that younger age [14], past chemotherapy use [6, 9, 14–16], and vaginal dryness [13, 14, 16] are associated with greater sexual problems among breast cancer survivors. Body image disturbance [10, 15, 16], and depression [17, 18] have also been related to more sexual problems.

The vast majority of research in this area has focused on younger women (i.e., those aged 50 years or younger) [9, 10, 12, 15, 18], newly diagnosed breast cancer survivors within 1 year of diagnosis [e.g., 3, 10, 13, 15], or only women who are sexually active [10, 13]. There have been few longitudinal studies and even fewer with samples of more than 200 survivors [e.g., 9, 12, 19].

The present exploratory study is based on a large sample of married/partnered breast cancer survivors across a wide age range. The goal of this research is to gain a better understanding of factors that impact being sexual active and sexual problems among recently diagnosed breast cancer survivors. The primary objectives are: 1) to estimate percentages of partnered women who are sexually inactive over the first 2 years post-breast cancer diagnosis; 2) to identify factors related to being sexually inactive; and 3) to evaluate separately, among both the sexually active and inactive survivors, the relationship between sexual problems and cancer treatment-related variables, symptoms, and psychosocial factors.

## Methods

### Participants and Procedure

The data reported in these analyses are based on secondary analyses derived from a prospective, observational study conducted among women who were newly diagnosed (within 8 months) with stage I, II, or III breast cancer [20, 21]. Study eligibility criteria included first-time breast cancer diagnosis, cancer stage I–III, at least 18 years of age, and the ability to read and understand English. Recruitment was conducted at Memorial Sloan Kettering Cancer Center and the University of Texas – Southwestern Center for Breast Care from 2002 to 2006 with follow-up assessments from 2002–2008. Women were recruited through hospital clinics and advertisements and were screened for eligibility. A total of 740 surveys were mailed to women deemed eligible from chart reviews or telephone screening;

653 women completed the baseline survey, for **an initial** response rate of 88%. The Institutional Review Boards at each of the participating institutions approved this study. Consent was implied for participants who returned questionnaires. All study protocols conformed to the Declaration of Helsinki.

Eligible women were mailed a baseline questionnaire to complete and return to the Coordinating Center at Wake Forest School of Medicine. Baseline questionnaires (T0) were completed within 8 months of diagnosis. Follow-up surveys were completed 6 (T1), 12 (T2), and 18 (T3) months following completion of the baseline survey. **Retention rate was high with 86.5% of the sample (N=565) remaining in the study at T3.** Only women who reported that they were married or “living in a marriage-type relationship” at T0 and who remained in such a relationship throughout follow-up were included in these analyses. Data on cancer surgeries and treatments were obtained from medical charts completed following primary treatment.

### Primary Outcomes

**Being Sexually Active**—Women were considered to be sexually active if they responded “yes” to a question “Have you been sexually active in the past month?” This question was asked at each time point.

**Sexual Problems**—Sexual problems were assessed with the sexual problems domain of the Quality of Life in Adult Cancer Survivors (QLACS) scale [7, 22]. The QLACS is a quality-of-life measure containing 47 items and 12 domains specifically designed for cancer survivors. The QLACS has previously been shown to have excellent psychometric properties for both short- and long-term cancer survivors [7, 22]. The sexual problems domain consists of 4 items: “*You were bothered by being **unable** to function sexually,*” “*You were dissatisfied with your sex life,*” “*You lacked interest in sex,*” and “*You avoided sexual activity.*” Items are scored on a 1 (never) to 7 (always) scale, where a higher score indicates more problems. A total domain score is calculated by summing each item for a range of 4 to 28 (coefficient alpha, 0.83). The QLACS was added to the protocol at T2 and T3.

### Independent Variables

Independent variables in the analysis included sociodemographics, cancer-related variables, symptoms, and psychosocial variables.

**Sociodemographic variables** included age at diagnosis (continuous, in years), race (non-Hispanic white/other), college (yes/no), and financial strain based on the question: “how difficult is it to pay for basics like food, housing, medical care, and heating?” (very or somewhat hard versus not hard), and children under the age of 18 living at home (yes/no). These sociodemographic variables were assessed at baseline and were not time-varying.

**Cancer-related variables** included time since cancer diagnosis, cancer stage at diagnosis (I vs II/ III), chemotherapy (coded as none/current/past in repeated-measures analyses using all survey time points, and as ever/never in analyses at T2 only), radiation therapy (treated the same as chemotherapy), hormonal treatment (coded as current/not current, and so updated in

repeated measures analyses), and surgery type (lumpectomy only, mastectomy with no reconstruction, mastectomy with reconstruction).

**Symptoms** previously found to be associated with sexual problems were included in analyses: severity of vasomotor symptoms and vaginal dryness (both coded on a four-point (0–3) ordinal scale corresponding to “none” to “severe”), as used in the Women's Health Initiative [23]. Symptom scores were assessed at each survey and thus were time-varying in repeated measures analyses.

**Psychosocial variables** included depressive symptoms, as assessed by the Beck Depression Inventory (BDI) [24], and perceived attractiveness, as assessed by the Lasry body image scale [25]. Also included was the Illness Intrusiveness Scale that assesses the degree to which breast cancer diagnosis and treatment interfered with 13 life areas: health, diet, paid work, active recreation, passive recreation, financial situation, relationship with spouse, sex life, family relations, other social relations, self-expression, religious expression, and community [26]. Three items were added to the standard scale that especially impact younger women: family responsibilities, social activities, and work around the house. For each item, respondents rated the degree that their illness or its treatment interfered with that area, based on a 7-point scale, ranging from 1 (not very much) to 7 (very much). The overall illness intrusiveness score is the sum of the 16 items (Cronbach's alpha, 0.93). The illness intrusiveness sex life question was removed for the analyses where illness intrusiveness was a predictor in regression models of the sexual problems score. All psychosocial variables were assessed at each survey and thus were time-varying in repeated measures analyses.

We also included baseline menopausal status (pre- or peri-menopausal versus postmenopausal).

### Statistical analyses

To describe the sample at baseline, we computed means and standard errors for continuous variables and proportions for categorical variables. For our first objective, we used data from all survey time points to evaluate associations with sexual activity status (active versus inactive) throughout follow-up. For our second objective, which focused on sexual problems of cancer survivors, we used data on problems reported on the T2 survey, when the women were 12–20 months post-diagnosis. We selected this time period to allow us to focus on the period immediately after completion of primary treatment. Our analyses of sexual problems at T2 were conducted separately among the sexually active and the sexually inactive.

For our first objective, we modeled the association between the dichotomous outcome of sexually active versus inactive at all four survey time points using a repeated-measures **logistic regression model that predicted sexually active versus inactive status at each time point**. Independent variables in this model included age at diagnosis, race, presence of children under 18 years of age in the home, difficulty paying for basics, postmenopausal status, stage at diagnosis, surgery type, chemotherapy status, radiation therapy status, hormone therapy status, vasomotor symptoms and vaginal dryness, depressive symptoms, perceived attractiveness, and illness intrusiveness.

To address the second objective related to sexual problems, we focused on the QLACS sexual problems scores from the T2 interview, which was completed between 12–20 months post-diagnosis. We first examined differences by sexual activity status in mean scores on the various QLACS sexual problems items and the overall sexual problems score, using independent sample t-tests. We then examined multivariable associations with the overall sexual problems domain score, stratifying these analyses by sexual activity status (active and inactive) at T2. In the multivariable linear regression models, we used the same list of predictor variables as listed above, though only baseline levels of these variables were used. We also included time since diagnosis (in months).

All analyses except the repeated measures **logistic model (done in PROC GENMOD)** were complete-case analyses; GENMOD assumes data are missing at random and utilizes full information maximum-likelihood methods with respect to missing data.

We used a two-tailed alpha level of 0.05 throughout. All analyses were conducted using SAS 9.4 (SAS Institute, Inc., Cary, N.C).

## Results

### Sample characteristics

The analytic sample for the present analyses consists of 457 breast cancer survivors who reported throughout the study that they were married (n=438; table 1) or “living in a marriage type relationship” (n=19). We restricted our sample to married/partnered women because they have an “opportunity” for sexual activity, and lack of a sexual partner is a primary reason women report for being sexually inactive use [14, 27]. The women in our sample were predominantly white (94%), reported little difficulty paying for basics (89%), and were predominantly college-educated (65%). Just over half (53.4%) were diagnosed with stage I disease and in terms of type of surgery, the majority (64.6%) had a lumpectomy only. Sixty-nine percent reported receiving chemotherapy (69%). The mean age at diagnosis was 54.4 years.

### Being sexually active

At T0, 52.4% of women reported being sexually active in the past month. This percentage increased to 59.3% at T1, and then increased only slightly after that, to 59.8% at T2, and 60.7% at T3 (Table 2). The sample size declined modestly over time, and a small number of women at each time point did not answer this question. There was considerable variability in sexual activity status by age, with women under age 45 (75% at T0 to 80% at T3) and women aged 45–54 (60% at T0 to 66% at T3) being more likely to be sexually active than were women over age 64. However, women aged 55–64 years showed the greatest increase over time; only 41.8% were sexually active at T0, but 60.4% reported being sexually active by T3.

In a multivariable repeated-measures logistic regression analysis on the dichotomous outcome of sexually active (yes/no) assessed at each of the four time points, the following variables were significantly predictive of inactivity: older age ( $p<0.001$ ), past chemotherapy

(compared to none;  $p=0.03$ ), depressive symptoms ( $p<.0001$ ), and lower perceived attractiveness ( $p=0.002$ ) (Table 3).

### Sexual problems

Table 4 shows the mean scores on the QLACS sexual problems items and total sexual problems domain score at T2 by sexually active/inactive status at T2. Women who were not active reported significantly more problems than did those who were active for all areas except for being unable to function sexually. For both groups, a lack of sexual interest had the highest problem rating. The total problems domain score was significantly higher for inactive women (14.1) than for sexually active women (10.1). To place these domain scores in context, it is worth pointing out that among the sexually active women, the sexual problems domain was rated more problematic than **some of the** other problem domains of the QLACS: negative feelings (9.8), cognitive problems (9.6), and pain (8.4). Among the inactive women, the sexual problems domain score was higher than the cognitive problems (10.3), pain (9.4), fatigue (12.7), and negative feelings (10.5) domains. Out of 47 individual items on the QLACS, the “lack interest in sex” item scored as the fourth most problematic area for the sexually active women and was the most problematic item among the inactive women.

In stratified multivariable linear modeling analyses with sexual problems domain score at T2 as the outcome and containing all covariates, depressive symptoms were significantly related to greater sexual problems among both sexually active ( $p<.001$ ) and inactive ( $p=0.002$ ) women, as was vaginal dryness ( $p<.001$  for both groups; Table 5). Among the sexually active women, younger age at diagnosis ( $p=0.02$ ), less illness intrusiveness ( $p=0.04$ ), and lower perceived attractiveness ( $p=0.009$ ) were related to more problems. Among those who were not sexually active, being on hormone therapy was significantly associated ( $p=0.03$ ) with fewer predicted sexual problems. Hormone therapy was the only cancer treatment-related variable that was significantly related to sexual problems score for either group.

### Discussion

This is perhaps the largest longitudinal study to date that has examined sexual activity and sexual functioning problems among breast cancer survivors over a 2-year period following diagnosis. Among married/partnered women, 52% reported being sexually active in the past month within the first 8 months of diagnosis. This percentage increased to 59% at T1 and 61% at T3, which was 18–24 months post-diagnosis.

Although our study did not have a comparison group of women *without* cancer, several other studies provide indirect comparative data, **suggesting that a lower percentage of breast cancer survivors are sexually active 2 years post diagnosis compared to women without cancer**. Dorval and colleagues reported that 83.3% of partnered women without cancer reported being sexually active in the past year [28]. Another study found that 71% of women aged 40–69 who were in a significant relationship reported being sexual active in the past year [29]. Although we found that 29% of sexually active women and 62% of inactive women reported that lack of interest occurred more than sometimes, Broekel and colleagues

found that only 13% of women without cancer reported that lack of sexual interest was at least somewhat of a problem [30].

In addition to being older, inactive women reported more depressive symptoms and lower perceived attractiveness and were less likely to have had chemotherapy. They also reported that they had less interest in sex and were more likely to avoid sexual activity than women who were sexually active. Although inactive women were not asked the extent to which they *wanted* to be sexually active, this group reported at least sometimes being dissatisfied with their sex life. Among the items on the illness intrusiveness measure, sex life had the highest mean score out of 16 life areas for the active and inactive women under age 54 (**the mean was 5.6 on a 7-point scale for the inactive women under age 45 and 4.1 for those age 45-54**). These findings suggest that sexual functioning is a potential concern among partnered breast cancer survivors who have *not* been sexually active and that studies of sexually active women only are missing this important group of women.

For both active and inactive women, vaginal dryness and depressive symptoms were related to greater sexual functioning problems. Similar findings have been observed among other studies of breast cancer survivors [13, 14, 16–18], as well as in women without cancer [31], but these factors pose a particular problem for breast cancer survivors [32]. Although estrogen therapy can help reduce vaginal dryness, this treatment is generally contraindicated for cancer survivors [33]. Breast cancer survivors are also at higher risk for depressive symptoms [32].

In addition to the above factors, among those survivors who were sexually active, we also found that younger age and lower perceived attractiveness were related to more problems, findings that are consistent with other studies [9, 10, 15, 16]. **Psychosocial counseling and/or** educational programs, such as the American Cancer Society sponsored program “Look Good Feel Better,” might help women with body image concerns. One recent study found that internet-based cognitive behavioral therapy improved body image and sexual functioning among breast cancer survivors aged 18–65 [34].

### Implications for Practice

Responses to the QLACS sexual problems measure and the **relatively** high ranking of sex life on the illness intrusiveness measure, particularly for women aged 54 and under, emphasize the importance of sexual functioning **relative to other life areas**, among many breast cancer survivors. Previous studies, however, have found that sexual functioning often is not discussed between patients and providers [8, 35]. One study found that 70% of breast and gynecological cancer patients expressed concerns about sexual function and 66% had unmet needs for consultation with a sexual health expert [35]. **Recent guidelines from the American Society of Clinical Oncology (ASCO) recommend that health care team members should initiate a discussion with all cancer patients regarding sexual health and dysfunction resulting from cancer or its treatment [36]. These guidelines further recommend that psychosocial and/or psychosexual counseling be offered to all patients over age 18 with cancer.** Clinician decisions about broaching the topic of sexual health can sometimes be based on erroneous assumptions about the relevance of sexual health concerns [5, 37].

**Clinicians should also recognize that** the relationship between sexual inactivity/problems and depression can be complicated and is likely reciprocal. A diagnosis of breast cancer and its subsequent treatment can lead to depressive symptoms which can contribute to the avoidance of sexual activity [17, 18]. On the other hand, cancer treatments can also have a direct impact on vaginal dryness and painful sex leading to sexual problems, which may in turn lead to depressive symptoms [4, 38]. To address these problems, products such as vaginal rings and moisturizers are available to help alleviate vaginal dryness which may in turn help reduce depression. Behavioral or pharmaceutical treatments of depression may in turn improve sexual functioning. **The ASCO guidelines provide a brief summary of the effective treatments for these and other specific types of sexual problems** [36].

### Limitations

There are several limitations of this study. The sample was relatively homogeneous (mostly white, educated, and partnered women), which limits its generalizability. Although the QLACS items can be answered regardless of sexual orientation (since no male-specific sexual acts are referred to), we do not know if results would differ by sexual orientation, which was not assessed in this study. A few studies have concluded that sexual minority breast cancer survivors and heterosexual survivors are similar in sexual frequency and sexual satisfaction, while lesbian breast cancer survivors report less disruption in their sexual relationships [39, 40] **although research on sexual minority women is quite limited** [41]. Second, like most studies, we did not have a measure of sexual activity/functioning prior to diagnosis and are unable to examine the impact of cancer diagnosis and treatment on change in sexual activity and functioning. Third, relationships with sexual partners and perceived partner dysfunction can be important factors [16], but they were not explored. Additionally, menopausal status was only obtained at baseline, and previous studies have shown that change in menopausal status can influence sexual functioning [10, 19]. Lastly, the sample data were collected approximately 10 years ago and may not reflect advances in treatment regimens since this time. However chemotherapy, endocrine therapy, surgeries and radiation continue to have a large effect on woman's sexual health and function [38, 42, 43].

Strengths of the analyses include a large sample of breast cancer survivors of all ages, a wide range of potential predictors, and a focus on the newly post treatment survivorship time period. Our findings suggest that sexual functioning is a concern for many (though not all) women who are partnered but *not* currently sexually active, a group that group is often understudied. Our data suggest that assumptions about the relative importance of sexual health cannot be based only on a woman's sexual activity status. Sexual inactivity among partnered women has important implications for intimate relationships. As sexual activity stops, other forms of intimacy and affection such as touching and physical contact may also decline [4, 43]. Both survivors and partners have reported that these changes can lead to isolation and sadness, and are often accompanied by poor communication [44]. Although other quality of life issues may improve after primary treatment, sexual health concerns are among the complications that can worsen over time [33, 45]. Moving forward, providers from a variety of clinical specialties need to be prepared to address sexual health discussions and offer appropriate resources and referrals.



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## References

1. [Accessed 29, 2017] World Cancer Research Fund International, Breast Cancer Statistics. 2012. <http://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/breast-cancer-statistics>
2. Miller KD, Siegel RL, Lin CC, et al. Cancer treatment and survivorship statistics, 2016. *CA Cancer J Clin.* 2016; 66:271–289. DOI: 10.3322/caac.21349 [PubMed: 27253694]
3. Aerts L, Christiaens MR, Enzlin P, et al. Sexual functioning in women after mastectomy versus breast conserving therapy for early-stage breast cancer: A prospective controlled study. *Breast.* 2014; doi: 10.1016/j.breast.2014.06.012
4. Bober SL, Varela VS. Sexuality in adult cancer survivors: Challenges and intervention. *J Clin Oncol.* 2012; 30:3712–3719. DOI: 10.1200/JCO.2012.41.7915 [PubMed: 23008322]
5. Dizon DS, Suzin D, McIlvenna S. Sexual health as a survivorship issue for female cancer survivors. *The Oncologist.* 2014; 19:202–210. DOI: 10.1634/theoncologist.2013-0302 [PubMed: 24396051]
6. Gilbert E, Ussher JM, Perz J. Sexuality after breast cancer: a review. *Maturitas.* 2010; 66:397–407. DOI: 10.1016/j.maturitas.2010.03.027 [PubMed: 20439140]
7. Sohl SJ, Levine B, Avis NE. Evaluation of the Quality of Life in Adult Cancer Survivors (QLACS) scale for early post-treatment breast cancer survivors. *Qual Life Res.* 2015; 24:205–212. DOI: 10.1007/s11136-014-0749-x [PubMed: 24996392]
8. Flynn KE, Reese JB, Jeffery DD, et al. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology.* 2012; 21:594–601. DOI: 10.1002/pon.1947 [PubMed: 21394821]
9. Avis NE, Crawford S, Manuel J. Psychosocial problems among younger women with breast cancer. *Psychooncology.* 2004; 13:295–308. DOI: 10.1002/pon.744 [PubMed: 15133771]
10. Burwell SR, Case LD, Kaelin C, Avis NE. Sexual problems in younger women after breast cancer surgery. *J Clin Oncol.* 2006; 24:2815–2821. DOI: 10.1200/JCO.2005.04.2499 [PubMed: 16782919]
11. Boehmer U, Ozonoff A, Timm A, et al. After breast cancer: Sexual functioning of sexual minority survivors. *J Sex Res.* 2014; 51:681–689. DOI: 10.1080/00224499.2013.772087 [PubMed: 23730713]
12. Fobair P, Stewart SL, Chang S, et al. Body image and sexual problems in young women with breast cancer. *Psychooncology.* 2006; 15:579–594. DOI: 10.1002/pon.991 [PubMed: 16287197]
13. Boquiren VM, Esplen MJ, Wong J, et al. Sexual functioning in breast cancer survivors experiencing body image disturbance: Sexual function and body image disturbance. *Psychooncology.* 2016; 25:66–76. DOI: 10.1002/pon.3819 [PubMed: 25916689]
14. Ganz PA, Rowland JH, Desmond K, et al. Life after breast cancer: Understanding women's health-related quality of life and sexual functioning. *J Clin Oncol.* 1998; 16:501–514. DOI: 10.1200/JCO.1998.16.2.501 [PubMed: 9469334]
15. Rosenberg SM, Tamimi RM, Gelber S, et al. Treatment-related amenorrhea and sexual functioning in young breast cancer survivors. *Cancer.* 2014; 120:2264–2271. DOI: 10.1002/cncr.28738 [PubMed: 24891236]
16. Ganz PA, Desmond KA, Belin TR, et al. Predictors of sexual health in women after a breast cancer diagnosis. *J Clin Oncol.* 1999; 17:2371–2371. DOI: 10.1200/JCO.1999.17.8.2371 [PubMed: 10561299]
17. Speer JJ, Hillenberg B, Sugrue DP, et al. Study of sexual functioning determinants in breast cancer survivors. *Breast J.* 2005; 11:440–447. DOI: 10.1111/j.1075-122X.2005.00131.x [PubMed: 16297089]
18. Lee M, Kim YH, Jeon MJ. Risk factors for negative impacts on sexual activity and function in younger breast cancer survivors: Sexual activity and dysfunction in cancer survivors. *Psychooncology.* 2015; 24:1097–1103. DOI: 10.1002/pon.3772 [PubMed: 25690696]

19. Ganz PA, Greendale GA, Petersen L, et al. Breast cancer in younger women: Reproductive and late health effects of treatment. *J Clin Oncol.* 2003; 21:4184–4193. DOI: 10.1200/JCO.2003.04.196 [PubMed: 14615446]
20. Avis NE, Levine B, Naughton MJ, et al. Explaining age-related differences in depression following breast cancer diagnosis and treatment. *Breast Cancer Res Treat.* 2012; 136:581–591. DOI: 10.1007/s10549-012-2277-0 [PubMed: 23053661]
21. Avis NE, Levine B, Naughton MJ, et al. Age-related longitudinal changes in depressive symptoms following breast cancer diagnosis and treatment. *Breast Cancer Res Treat.* 2013; 139:199–206. DOI: 10.1007/s10549-013-2513-2 [PubMed: 23588951]
22. Avis NE, Smith KW, McGraw S, et al. Assessing quality of life in adult cancer survivors (QLACS). *Qual Life Res.* 2005; 14:1007–1023. [PubMed: 16041897]
23. Barnabei VM, Cochrane BB, Aragaki AK, et al. Menopausal symptoms and treatment-related effects of estrogen and progestin in the Women's Health Initiative. *Obstet Gynecol.* 2005; 105:1063–1073. DOI: 10.1097/01.AOG.0000158120.47542.18 [PubMed: 15863546]
24. Beck AT, Steer RA, Ball R, Ranieri WF. Comparison of Beck Depression Inventories-IA and-II in psychiatric outpatients. *J Pers Assess.* 1996; 67:588–597. DOI: 10.1207/s15327752jpa6703\_13 [PubMed: 8991972]
25. Lasry JC, Margolese RG, Poisson R, et al. Depression and body image following mastectomy and lumpectomy. *J ChronicDis.* 1987; 40:529–534.
26. Devins GM. Using the Illness Intrusiveness Ratings Scale to understand health-related quality of life in chronic disease. *J Psychosom Res.* 2010; 68:591–602. DOI: 10.1016/j.jpsychores.2009.05.006 [PubMed: 20488277]
27. Oberguggenberger A, Martini C, Huber N, et al. Self-reported sexual health: Breast cancer survivors compared to women from the general population – an observational study. *BMC Cancer.* 2017; 17doi: 10.1186/s12885-017-3580-2
28. Dorval M, Maunsell E, Deschênes L, et al. Long-term quality of life after breast cancer: comparison of 8-year survivors with population controls. *J Clin Oncol.* 1998; 16:487–494. DOI: 10.1200/JCO.1998.16.2.487 [PubMed: 9469332]
29. Addis IB, Van Den Eeden SK, Wassel-Fyr CL, et al. Sexual activity and function in middle-aged and older women. *Obstet Gynecol.* 2006; 107:755–764. DOI: 10.1097/01.AOG.0000202398.27428.e2 [PubMed: 16582109]
30. Broeckel JA, Thors CL, Jacobsen PB, et al. Sexual functioning in long-term breast cancer survivors treated with adjuvant chemotherapy. *Breast Cancer Res Treat.* 2002; 75:241–248. DOI: 10.1023/A:1019953027596 [PubMed: 12353813]
31. Avis NE, Colvin A, Karlamangla AS, et al. Change in sexual functioning over the menopausal transition: Results from the Study of Women's Health Across the Nation. *Menopause.* 2017; 24:379–390. DOI: 10.1097/GME.0000000000000770 [PubMed: 27801705]
32. Krebber AM, Buffart LM, Kleijn G, et al. Prevalence of depression in cancer patients: A meta-analysis of diagnostic interviews and self-report instruments. *Psychooncology.* 2014; 23:121–130. DOI: 10.1002/pon.3409 [PubMed: 24105788]
33. de Villiers TJ, Gass MLS, Haines CJ, et al. Global consensus statement on menopausal hormone therapy. *Climacteric.* 2013; 16:203–204. DOI: 10.3109/13697137.2013.771520 [PubMed: 23488524]
34. Hummel SB, van Lankveld JJDM, Oldenburg HSA, et al. Efficacy of internet-based cognitive behavioral therapy in improving sexual functioning of breast cancer survivors: Results of a randomized controlled trial. *J Clin Oncol.* 2017; 35:1328–1340. DOI: 10.1200/JCO.2016.69.6021 [PubMed: 28240966]
35. Goldfarb SB, Abramsohn E, Andersen BL, et al. A national network to advance the field of cancer and female sexuality. *J Sex Med.* 2013; 10:319–325. DOI: 10.1111/jsm.12061 [PubMed: 23350613]
36. Carter J, Lacchetti C, Andersen BL, et al. Interventions to address sexual problems in people with cancer: American Society of Clinical Oncology clinical practice guideline adaptation of Cancer Care Ontario guideline. *J Clin Oncol.* 2017; JCO.2017.75.899. [Epub ahead of print]. doi: 10.1200/JCO.2017.75.8995

37. Canzona M, Ledford CJW, Fisher CL, et al. Clinician barriers to initiating sexual health conversations with breast cancer survivors: The influence of assumptions and situational constraints. *Fam Syst Health*. In Press.
38. Boswell EN, Dizon DS. Breast cancer and sexual function. *Transl Androl Urol*. 2015; 4:160–168. DOI: 10.3978/j.issn.2223-4683.2014.12.04 [PubMed: 26816822]
39. Arena PL, Carver CS, Antoni MH, et al. Psychosocial responses to treatment for breast cancer among lesbian and heterosexual women. *Women Health*. 2007; 44:81–102. DOI: 10.1300/J013v44n02\_05
40. Fobair P, O'Hanlan K, Koopman C, et al. Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. *Psychooncology*. 2001; 10:40–51. DOI: 10.1002/1099-1611(200101/02)10:1<40::AID-PON480>3.0.CO;2-S [PubMed: 11180576]
41. Boehmer U, Potter J, Bowen DJ. Sexual functioning after cancer in sexual minority women. *Cancer J*. 2009; 15:65–69. DOI: 10.1097/PPO.0b013e31819587cc [PubMed: 19197176]
42. Marino JL, Saunders CM, Emery LI, et al. How does adjuvant chemotherapy affect menopausal symptoms, sexual function, and quality of life after breast cancer? *Menopause*. 2016; 23:1000–1008. DOI: 10.1097/GME.0000000000000664 [PubMed: 27272225]
43. Tay R, Gibney T, Antill YC. Sexual dysfunction after breast cancer: A review of treatments and strategies. *Cancer Forum*. 2017; 41:25–31.
44. Hawkins Y, Ussher J, Gilbert E, et al. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: The experience of partners in a sexual relationship with a person with cancer. *Cancer Nurs*. 2009; 32:271–280. DOI: 10.1097/NCC.0b013e31819b5a93 [PubMed: 19444088]
45. Ligibel JA, Denlinger CS. New NCCN guidelines for survivorship care. *J Natl Compr Canc Netw*. 2013; 11:640–644.

**Table 1**  
**Sample characteristics of women who were married or partnered throughout follow-up**  
**(N=457)**

Characteristic	M (SD)	N (%)
Age at diagnosis (years)	54.4 (11.6)	
Partner status		
Married		438 (95.8%)
Living in a marriage-type relationship		19 (4.2%)
White race		431 (94.3)
Children under 18 years in home		146 (32.0)
Difficulty paying for basics		
Somewhat/very hard		52 (11.4)
Not hard		405 (88.6)
Completed 4-year college education		295 (64.6)
Postmenopausal		230 (50.3)
Cancer stage		
I		244 (53.4)
II or III		213 (46.6)
Radiation		332 (72.7)
Chemotherapy		313 (68.5)
Surgery		
Lumpectomy only		295 (64.6)
Mastectomy with reconstruction		104 (22.8)
Mastectomy without reconstruction		58 (12.7)
Hormonal therapy		337 (73.9)

**Table 2**  
**Partnered women who report being sexually active in the past month by age group and time point**

Time point	Age group (years)				
	All	20-44	45-54	55-64	65+
T0	52.4% (232)	75.0% (66)	60.4% (96)	41.8% (46)	27.9% (24)
T1	59.3% (255)	75.6% (62)	65.8% (102)	55.2% (58)	38.0% (33)
T2	59.8% (245)	77.0% (57)	64.0% (96)	54.9% (56)	42.0% (36)
T3	60.7% (242)	80.0% (56)	65.5% (95)	60.4% (61)	35.0% (30)

Data are presented as % (n).

T0: 0-8 months post diagnosis (n=457; 14 women missing on sexual activity status).

T1: 6-14 months post diagnosis (n=434; 4 women missing on sexual activity status.).

T2: 12-20 months post diagnosis (n=418; 8 women missing on sexual activity status).

T3: 18-26 months post diagnosis (n=401; 2 women missing on sexual activity status).

**Table 3**  
**Results of the multivariable logistic regression analysis of sexually active versus non-active status**

Variable	Parameter	SE	p-value
Age at diagnosis	-0.06	0.01	<b>&lt;0.001</b>
White race	0.30	0.33	0.37
Children under 18 in home	-0.02	0.23	0.94
Difficulty paying for basics	0.25	0.27	0.35
College education	0.31	0.18	0.08
Postmenopausal	-0.25	0.26	0.35
Stage I (compared to II and III)	0.22	0.20	0.29
Surgery <sup>a</sup>			
Mastectomy with reconstruction	0.26	0.23	0.27
Mastectomy w/out reconstruction	0.23	0.29	0.42
Hormonal therapy	0.23	0.15	0.12
Chemotherapy <sup>b</sup>			
Past	-0.47	0.22	<b>0.03</b>
Current	-0.39	0.24	0.11
Radiation therapy <sup>c</sup>			
Past	0.02	0.18	0.93
Current	0.25	0.33	0.46
Vaginal dryness	0.34	0.06	<b>&lt;0.001</b>
Depressive symptoms	-0.04	0.01	<b>&lt;0.001</b>
Perceived attractiveness	0.09	0.03	<b>0.002</b>
Illness intrusiveness	-0.01	0.004	0.07

<sup>a</sup>Reference group is lumpectomy only.

<sup>b</sup>Reference group is chemotherapy never.

<sup>c</sup>Reference group is radiation never.

**Table 4**  
**Mean responses on the sexual problems domain of the QLACS at T2 by sexually active versus non-active status**

<b>Sexual Problems Items<sup>a</sup></b>	<b>Sexually Active N=245<sup>b</sup></b>	<b>Sexually Inactive N=165<sup>c</sup></b>	<b>P value</b>
You were bothered by being <b>unable</b> to function sexually	2.5 (1.6)	2.7 (1.8)	0.159
You were dissatisfied with your sex life	2.7 (1.7)	3.3 (2.1)	0.006
You lacked interest in sex	3.1 (1.7)	4.3 (2.0)	<0.001
You avoided sexual activity	2.5 (1.6)	3.7 (2.2)	<0.001
Sexual Problems total score	10.7 (5.3)	14.1 (6.5)	<0.001

<sup>a</sup>A higher score indicates more problems. Data are presented as mean (SD).

<sup>b</sup>1-3 women were missing on different QLACS sexual problems items.

<sup>c</sup>2 women were missing on all QLACS sexual problems items.

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**Table 5**  
**Results of the multivariable regression analysis of the QLACS sexual problems domain score at T2, stratified by sexually active versus non-active status**

Variable	Sexually Active			Sexually Inactive		
	Estimate	SE	p-value	Estimate	SE	p-value
Age at diagnosis (years)	-0.09	0.04	0.02 <sup>a</sup>	-0.01	0.06	0.86
Time since diagnosis (months)	0.01	0.20	0.94	0.26	0.36	0.47
White race	1.44	1.26	0.25	-0.98	1.88	0.60
Difficulty paying for basics	-0.31	0.93	0.74	-1.09	1.49	0.47
College education	-0.16	0.62	0.80	0.17	0.94	0.86
Postmenopausal	1.36	0.85	0.11	-0.13	1.34	0.92
Stage I	-0.17	0.68	0.81	-0.28	1.05	0.79
Mastectomy no reconstruction <sup>b</sup>	0.54	0.99	0.59	1.29	1.56	0.41
Mastectomy w/reconstruction <sup>b</sup>	-0.22	1.08	0.84	-0.22	1.46	0.88
Hormonal therapy	0.01	0.69	0.99	-2.23	1.02	0.03 <sup>a</sup>
Radiation	0.21	0.92	0.82	1.96	1.31	0.14
Chemotherapy	-0.70	0.72	0.33	-1.40	1.13	0.22
Vasomotor symptoms (0–3 scale)	0.34	0.30	0.26	0.32	0.50	0.52
Vaginal dryness (0–3 scale)	2.01	0.30	<0.001 <sup>a</sup>	1.76	0.50	<0.001 <sup>a</sup>
Depressive symptoms	0.40	0.08	<0.001 <sup>a</sup>	0.27	0.09	0.002 <sup>a</sup>
Perceived attractiveness	-0.38	0.14	0.009	-0.21	0.24	0.38
Illness intrusiveness	-0.05	0.03	0.04 <sup>a</sup>	0.05	0.04	0.19

<sup>a</sup> Statistically significant at  $p < 0.05$ . SE, standard error.

<sup>b</sup> Relative to lumpectomy only