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Sexual Well-Being Among Partnered Women With Breast Cancer Recurrence

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Abstract

Purpose— A woman's risk for sexual disruption after breast cancer recurrence has received little clinical or research attention.

Patients and Methods— Breast cancer patients recently diagnosed with recurrence (n = 60) were initially assessed at baseline and completed follow-ups at 4, 8, and 12 months. They were compared by age, stage, and duration and frequency of follow-up with matched patients who remained disease free (n = 120). Using linear mixed modeling, the groups were compared in their trajectories of change on measures of sexuality, relationship satisfaction, cancer-specific stress, and physical functioning. Recurrence subgroups, those with locoregional versus distant disease and those younger versus older than 52 years, were also compared.

Results— At baseline, the recurrence group had significantly lower intercourse frequency and physical functioning compared with the disease-free group and these differences were maintained. There were no significant differences in the frequencies of kissing or sexual and relationship satisfactions. For the recurrence group patients, the heightened stress of the diagnostic/early recurrence treatment period declined to the lower disease-free levels by 12 months. This effect was largely due to improvement of the patients with distant disease. Finally, sexual changes were most notable for younger patients.

Conclusion— To our knowledge, this is the first longitudinal, controlled study of sexuality—sexuality in the context of other quality of life domains—for women coping with recurrence. Despite disruption, patients maintained their sexual lives. Younger and distant recurrence patients, however, may have greatest risk of sexual disruption. The factors contributing to sexual disruption remain unknown, and studies investigating strategies to help patients maintain this aspect of quality of life are needed.

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INTRODUCTION

All cancer diagnoses, including recurrence,[1] are associated with significant psychological stress.[2] Up to 35% of patients may have mood, anxiety, or adjustment disorders.[3,4] Moreover, significant deficits in health-related quality of life—cancer-specific domains in particular—are evident in patients with breast cancer recurrence.[5,6] There is extensive literature on sexual morbidities associated with breast cancer; however, most studies are cross-sectional with newly diagnosed patients and focus on the impact of mastectomy[7] or adjuvant treatments.[8,9] In contrast, there have only been two studies of women with breast cancer recurrence. Silberfarb and colleagues[10] found that patients with recurrent disease were 50% more likely to experience significant disruptions in desire and intercourse frequency than their newly diagnosed counterparts. Hanson Frost et al[11] contrasted newly diagnosed women, undergoing chemotherapy, post-treatment, or with recurrent disease, and reported no group differences in sexuality or marital outcomes.

In sum, there are minimal data, and this may be related, in part, to the assumption that sexuality might be the least of a patient's concerns. Alternatively, after recurrence, the need for intimacy and support may be considerable as the stress is great. We conducted a controlled, longitudinal study of patients with newly diagnosed breast cancer recurrence. We monitored behavioral and subjective dimensions of sexuality, including sexual behavior (frequency of intercourse and kissing) and global sexual and relationship satisfaction for coincident change. Sexuality is examined in context, as measures of stress, functional status, and symptoms/signs were included. There are significant decrements in sexuality after an initial diagnosis of breast cancer.[5,12–16] As we were interested in determining any added burden of recurrence, a similar cohort of patients remaining disease free was selected as the referent group. The study aims were: to describe the trajectories of behavioral and subjective sexuality outcomes for those diagnosed with recurrence; to describe their stress and physical functioning trajectories for contextual reference; to compare these trajectories with those of patients remaining disease free and observed similarly; and to test for individual differences within the recurrence group, specifically patients differing in the extent of disease and age at recurrence diagnosis.

PATIENTS AND METHODS

An ongoing, randomized, clinical trial testing the efficacy of a psychological intervention for newly diagnosed breast cancer patients (N = 227) provided the context for this study. Details of accrual, procedures, and outcomes have been published.[2,17] Briefly, consecutive patients from a university-affiliated comprehensive cancer center were accrued. Study arms were assessment only or psychological intervention and assessment. Intervention sessions were conducted during the first 12 months after accrual and patients were monitored with assessments every 4 months. When a patient experienced a recurrence, she was approached and consented to the recurrence study, which had required a separate review and approval from the local human investigations committee in accordance with an assurance filed with and approved by the Department of Health and Human Services.

Patient Groups

Recurrence group—Eleven years after the start of the randomized trial, data analyses for this recurrence substudy began. By then, 55 of 227 patients (24%) had experienced a recurrence. Women without a significant other (ie, romantic partner), diagnosed with a second primary tumor, or who experienced a recurrence fewer than 12 months after the initial diagnosis were not eligible. The latter criterion effectively excludes women with rapid disease progression. Of the 55 patients, 20 (36%) were not eligible. Of the remaining 35, seven (20%) had withdrawn from the randomized trial before their recurrence and three (9%) declined

participation. Thus, 25 of 35 (71%) partnered, recurrent cancer patients were accrued. Of these patients, approximately one half (52%) were randomly assigned to the intervention arm.

During this same period, 59 other consecutive patients referred to the same medical oncology clinic for recurrent breast cancer were also accrued. Inclusion criteria were identical with one exception—eligibility in the randomized trial was restricted to women initially diagnosed with stage II or III disease, whereas women originally diagnosed with stage I-III were accrued from the clinic. Of the 59 accrued, 48 (81%) were partnered. In combination, 73 partnered patients with recurrence were enrolled.

After informed consent, patients completed face-to-face interviews and questionnaires. The baseline assessment was performed a median 10 weeks after diagnosis and then repeated 4, 8, and 12 months later. By the 12-month follow-up, six patients (8%) discontinued participation and seven (10%) had a second recurrence or died. Thus, data from 60 of 73 patients (82%) were analyzed.

Disease-free group—Patients from the randomized trial that had a partner, no evidence of disease, and no diagnosis of a second primary cancer were matched to the recurrence group patients. To increase the reliability of the estimates for the mixed-effects models and statistical power, each recurrence patient was matched to two disease-free patients. Patients were matched on age, follow-up duration, and, to the extent possible, initial stage. Of the patients identified as matches (n = 120), approximately one half (55%) were randomly assigned to the intervention arm.

Measures

Sexual behavior—Patients reported the frequency of sexual intercourse and kissing during the past 2 months, using an 8-point scale ranging from 0 (did not occur at all) to 7 (once/d for intercourse; 10-point scale ranging from 0 to 9 > 4 times/d for kissing).[18] Four-month test-retest reliability was 0.74 for intercourse and 0.85 for kissing.

Sexual satisfaction—Participants were asked to rate their current sexual life using a 9-point scale ranging from 0 (could not be worse) to 8 (could not be better).[19]

Relationship satisfaction—Using the satisfaction item from the dyadic adjustment scale,[20] participants rated their current overall satisfaction on a 7-point scale, ranging from 0 (extremely unhappy) to 3 (happy representing the degree of happiness in most relationships) to 6 (perfect). Correlations among the sexuality and relationship measures are provided in Table 1.

Cancer-Specific Stress

The impact of events scale (IES)[21] examines anxious cognitions and avoidant thoughts and behaviors related to traumatic stress. Items were slightly reworded for patients to focus on cancer-related stresses. Total scores can range from 0 to 75. Distinctions among scores have been made (<10 = low; 10 to 19 = moderate; and >19 = high stress levels) in studies contrasting nonclinic and clinic patients seeking treatment for stress disorders.[22] Internal consistency was 0.90.

Physical Functioning

Measures were completed by a nurse after a patient interview, with chart review and physician consultation as needed.

Functional status—The Karnofsky performance status (KPS)[23] 11-point scale ranges from 100 (normal) to 0 (dead). Inter-rater reliability ranges from 0.70 to 0.97.[24,25]

Symptoms, signs, illnesses, and toxicities—The type and severity of treatment toxicities and common symptoms/signs and illnesses (eg, fever, numbness) were rated.[26] Items are grouped in 19 body categories (eg, cardiovascular), rated on a 0 to 4 scale, and then averaged. Internal consistency ranges from 0.67 to 0.83.[1,17]

Analytic Strategy

Descriptive statistics are provided and one-way analysis of variance or χ^2 tests compare the groups on sociodemographic, disease, and treatment variables when initially diagnosed. Linear mixed-effects models[27] tested for group differences and changes over time in trajectories. Within this framework, the fixed effects (group-average effects) were estimated to test for group differences at baseline (recurrence *v* disease free), changes over time within the recurrence group, and group by time interaction effects. Specifically, four coefficients were estimated for each variable: an intercept and a linear slope for the reference group and differences in intercept and slope in the comparison group (disease free) when contrasted with the recurrence group. The repeated assessments were coded as 0, 4, 8, and 12 so that the time elapsed in months between assessments is reflected in the estimations.

As there are individual differences in patients' risk for sexual disruption,[28,29] we used the same procedures in follow-up analyses with the recurrence group, contrasting the trajectories of patients with local (n = 21) versus distant (n = 39) metastatic disease and patients younger (n = 30; mean, 43 years; range, 29 to 51) versus older (n = 30; mean, 60 years; range, 52 to 81) when diagnosed with recurrence. We note that the age data were distributed normally with an equal mean and median of 51.5 and the median (52) was used to create the two groups. Thus, we contrasted women generally younger and older when in midlife (ie, 43 *v* 60 years). The following variables were controlled: age, education, original surgery (lumpectomy *v* mastectomy), location of recurrent disease (local *v* distant), and any therapies at recurrence (surgery, chemotherapy, and radiation therapy).

RESULTS

Preliminary Analyses and Description of the Groups

Table 2 presents sociodemographic, disease, and treatment characteristics. The groups did not differ on any sociodemographic variable ($P > .07$). The average disease-free interval for the recurrence group was 52 months (median, 33) and the average time since initial diagnosis for the disease-free group was 45 months (median, 37). As described, imbalance between groups in disease stage at initial diagnosis was anticipated ($\chi^2_2 = 38.6$; $P < .001$). Approximately 30% of the recurrence group had been initially diagnosed with stage I disease. Consistent with this, fewer of the recurrence group patients had been originally treated with chemotherapy (χ^2_1, 7.2; $P = .007$) and/or hormone therapies (χ^2_1, 4.4; $P = .04$).

Comparison of Trajectories: Recurrence Versus Disease-Free Groups

Table 3 provides the observed means and standard deviations for all measures at baseline. Table 4 summarizes the results from the fixed-effects models comparing the mean trajectories of the groups. For each outcome, the values in the first row are the estimates of intercept and linear slope for the reference group (recurrence), and those in the second row are the estimates of differences in intercept and slope of the comparison group (disease free) from the reference group.

For the sexual outcomes, the recurrence group had a significantly lower intercourse frequency at baseline than the disease-free group ($P = .03$; corresponding to intercourse once per month *v* once to twice per month, respectively; Fig 1A). This difference between groups remained, as there was no significant change over time for the recurrence group and the rate of change for the disease-free group was not significantly different from that of the recurrence group. In contrast, the groups were equivalent in their reports of partner kissing (once per day) and their global evaluations of their current sexual life (somewhat inadequate) and relationship (very happy).

Regarding cancer-specific stress, the recurrence group had significantly higher stress at baseline than the disease-free group ($P = .001$). According to normative IES estimates,[22] values were high for the recurrence group and moderate for the disease-free group. This heightened stress among recurrence group patients significantly declined ($P = .008$) to the moderate range (estimated mean, 14.87) by 12 months. The interaction was not significant. For physical functioning, the recurrence group had significantly more symptoms/signs (symptoms, signs, illnesses, and toxicities) and lower functional status (KPS) at baseline than the disease-free group ($P < .02$; Fig 1B), and these differences remained stable. For KPS, the mean value at baseline for the recurrence group corresponded to normal activity with effort (some signs/symptoms of disease), whereas the disease-free group corresponded to be able to carry on normal activity (minor signs/symptoms).

Comparison of Trajectories: Local Versus Distant Recurrence Groups

With regards to intercourse frequency, there were no group differences at baseline, with a frequency equivalent to intercourse once per month (Table 3); however, there were both significant time ($P = .04$) and interaction effects ($P = .02$; Fig 1C). While frequency of intercourse increased among the local recurrence group to once to twice per month, it declined further for the distant recurrence group to 0.5/month. Also, while the groups did not differ in the frequency of kissing at baseline (once per day), there was a significant decline for the distant group ($P = .03$; 4 to 6/week). Despite these behavioral differences, the groups did not differ in their global evaluations of sexual life or relationship satisfaction.

An interesting pattern was observed for the stress measure: there was a significant time effect for the distant group ($P = .048$). Their cancer-specific stress (IES) declined from a high (mean, 19.2) to a moderate level (mean, 14.1).[22] There were no significant effects with regard to symptoms/signs (symptoms, signs, illnesses, and toxicities); however, there was a significant interaction effect for functional status ($P = .01$; Fig 1D). KPS of the local group improved (from 80 at initial to 88 at 12 months), whereas for the distant group it remained at a lower, stable level (from 80 at initial to 79 at 12 months).

Comparison of Trajectories: Younger Versus Older Patients at Recurrence

Table 3 presents the baseline data. The younger recurrence group had significantly higher intercourse frequency at baseline ($P = .01$; 1 to 2/month) versus the older recurrence group (0.5/month). However, this higher frequency of intercourse declined significantly across time ($P = .01$) and did so differentially ($P = .01$). By 12 months, intercourse frequency for the younger group declined to the stable level of the older group (0.5/month; Fig 1E). Also, the frequency of kissing significantly declined among the younger group from once per day to four to six times per week by 12 months ($P = .03$); the four to six times per week level of the older group remained stable. There were no significant effects for sexual and relationship satisfaction.

Regarding cancer-specific stress, the younger group had significantly higher cancer-specific stress at baseline than the older group ($P = .03$) and this difference remained stable. For physical

functioning, there was a marginally significant interaction effect for both symptoms/signs (P = .06) and functional status (P = .09; Fig 1F). For the younger group, there were no changes, but symptoms/signs declined and functional status improved for the older group.

DISCUSSION

Currently, metastatic breast cancer is considered incurable, and the goals of treatment are generally palliative.[30] Nevertheless, with the development of newer, more effective agents, such as trastuzumab[31] and bevacizumab in combination with chemotherapy, improvements in time to progression are realized.[32] While long-term survival rates remain modest, many patients are living longer with minimal disease-related symptoms. Thus, quality of life issues are salient.

To our knowledge, this is the first longitudinal, controlled study of sexuality, and sexuality in the context of physical health and other quality of life domains, for women coping with their recent recurrence diagnosis. Overall, both disease-free and recurrence group patients rated their sexual lives as somewhat inadequate. How these patients viewed their sexual lives before the diagnosis of breast cancer is unknown; however, data does show that sexuality declines after a cancer diagnosis and does not improve over time.[14] The only significant difference between the groups was on the frequency of intercourse, suggesting that is the aspect of sexuality most vulnerable to disruption after recurrence diagnosis. An important correlate of sexual well-being is the characteristics of one's relationship, and the patients in both groups reported, on average, that they were very happy with their partner. To what extent a women's positive view of her relationship is a buffer to further deteriorations in her sexual life or that of the couple is unknown, but raises an interesting hypothesis that could be tested in future studies.

The results of this study demonstrate the resilience of patients as they cope with recurrence. The recurrence diagnosis produces substantial stress and quality of life disruption.[1,5,6] However, during the 12 months after diagnosis stress declined to eventually match that of the disease-free survivors—an effect occurring in large measure because of the emotional improvement for those with distant metastases. Unfortunately, there was no salutary effect on sexuality; both the frequency of intercourse and kissing declined significantly. While negative psychological effects of all kinds—depression, anxiety, stress—disrupt sexual desire, reduce the frequency of activities, and produce sexual problems and dysfunctions,[33] these data suggest that psychological improvement does not necessarily prevent sexual behaviors from declining. This occurs even for the frequency of kissing, which is strongly correlated (r = 0.71) with patients' reports of relationship satisfaction. Because of the limited focus of these data, we do not know if these declines mirror those of embracing, hand holding, and related affectionate behaviors. Finally, comparison of recurrence patients differing in age at diagnosis—patients in their 40s versus their 60s—suggests sexual activity changes most notably for younger women. The change is equivalent to having intercourse once or twice per month to once every 2 months. This change is also unwelcome, as trends (P = .10) in the observed data show their view of their sexual life declines from average to somewhat inadequate.

A strength of the study is the addition of time-equivalent assessments from a matched, disease-free sample, providing comparison analyses of patients' trajectories across sexuality, stress, and health domains. Both behavioral and subjective aspects of sexuality were included. The primary measures were brief, but they are commonly used, robust indicators.[18,34] The pattern of correlations among variables provided evidence for their separate consideration, with correlations in the moderate range with kissing most strongly related to relationship satisfaction and intercourse most strongly related to sexual satisfaction. With this foundation, future research might consider measures sampling a range of behavioral sexual expression that contribute to global satisfaction, such as sexual responsiveness, partner sexual functioning, and

quality of communication, among others. Also, participation of sexual partners would provide additional insights as to how couples cope and attempt to maintain sexual activity when their partners have symptoms, are recovering from treatment, and/or have stress regarding body changes.[35]

The limitations of study were the restricted ethnic and educational sampling, and we are uncertain of the applicability of the findings to lesbian couples. Regarding generalizability, these findings may represent the best case scenario, as the patients' relationships were predominantly long-term (20+ years) ones in which women reported being happy. Future studies should also include unpartnered women. Having limited these data to only partnered women may implicitly suggest to the reader that we view a woman's sexual life as equivalent to that which she shares with a partner. We do not; indeed, women view themselves as the same sexual person whether or not they have a current partner,[29] and future research needs to address the sexual needs of all patients, whether they happen to have a partner or not.

This study provides an important, although preliminary, view of the impact of breast cancer recurrence on women's sexual activity and satisfaction. The presence of symptoms from the illness or treatment may play an influential role in the extent to which women can maintain (or recover) their sexual life during the first year after recurrence diagnosis. Younger patients may be most vulnerable to sexual disruption. Women coping with recurrence are attempting to maintain their quality of life—including their sexual life—as they undergo cancer treatment and re-establish emotional equilibrium.

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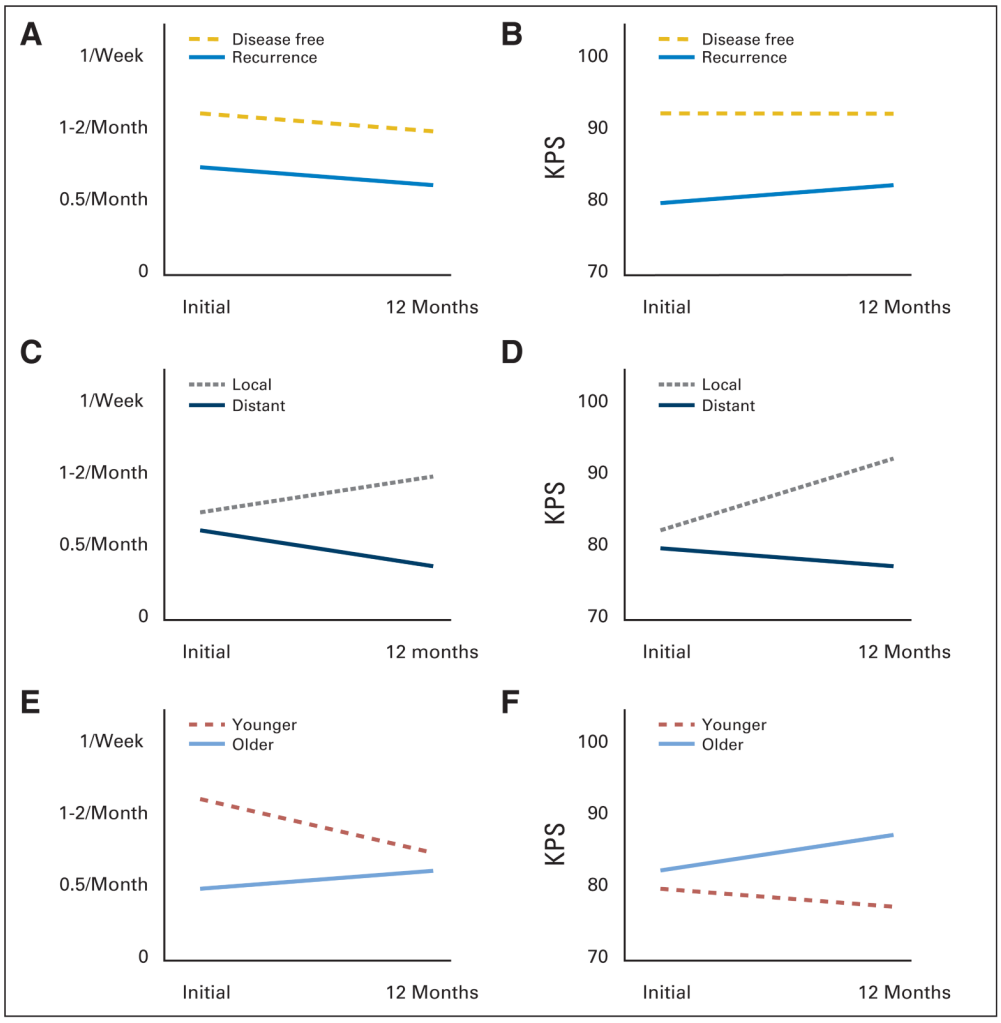

Fig 1.

Comparison of group trajectories from initial to 12-month follow-up for (A, C, E) frequency of intercourse and (B, D, E) functional status (Karnofsky performance status [KPS]) outcomes.

Table 1

Correlations Among Sexuality and Relationship Variables at Initial Assessment for the Recurrence and Disease-Free Groups

Group	1	2	3	4
Recurrence				
Intercourse frequency	—			
Kissing frequency	0.19	—		
Sexual satisfaction	0.58*	0.31†	—	
Relationship satisfaction	0.35†	0.71*	0.33†	—
Disease free				
Intercourse frequency	—			
Kissing frequency	0.44*	—		
Sexual satisfaction	0.65*	0.36*	—	
Relationship satisfaction	0.42*	0.48*	0.52*	—

*Correlation is significant at the .01 level (two tailed).

†Correlation is significant at the .05 level (two tailed).

Table 2

Sociodemographic, Prognostic, and Treatment Variables for the Recurrence and Disease-Free Groups

Variable	Recurrence (n = 60)		Disease Free (n = 120)	
	Mean (%)	SD	Mean (%)	SD
Sociodemographic				
Age, years	51.7	10.0	51.4	9.2
Race, white	92		93	
Education, years	14.8	3.0	15.4	2.9
Marital status, married	91		81	
Relationship duration, years	26.8	12.4	25.4	12.2
Family income, thousand $/year	75.3	67.5	82.8	87.1
Initial diagnosis				
Stage, %				
I	28		0	
II	60		90	
III	12		10	
No. of positive nodes	2.9	5.1	2.9	4.6
ER/PR, % positive	70		73	
Initial treatment				
Surgery, % modified radical mastectomy	53		49	
Radiation therapy, % yes	54		60	
Chemotherapy, % yes	77		92	
Hormone therapy, % yes	61		77	
Recurrence diagnosis				
Disease-free interval, months	51.6	49.4		
Location of recurrent disease				
Local	25			
Regional	10			
Distant	65			
Bone	47			
Viscera	27			
Treatments for recurrence*				
Surgery, % yes	33			
Radiation therapy, % yes	33			
Chemotherapy, % yes	75			
Hormone therapy, % yes	62			
Bone marrow transplantation, % yes	7			

Abbreviations: SD, standard deviation; ER, estrogen receptor status; PR, progesterone receptor status.

* Refers to treatments received during the first 12 months after recurrence diagnosis.

Table 3

Observed Means and Standard Deviations for Sexuality, Stress, and Physical Functioning at Recurrence Diagnosis for Disease-Free and Recurrence Subgroups

	Outcome											
	Disease Free (n =120)		Recurrence (n = 60		Local Recurrence (n =21)		Distant Recurrence (n =39)		Younger Recurrence (n =30)		Older Recurrence (n =30)	
Measure	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Sexuality												
Intercourse frequency	2.03	1.52	1.55	1.52	1.67	1.45	1.48	1.57	2.05	1.61	1.13	1.33
Kissing frequency	6.14	2.52	6.61	2.58	6.27	2.25	6.79	2.76	7.20	2.07	6.13	2.89
Sexual satisfaction	3.44	2.07	3.34	2.07	3.53	1.60	3.24	2.29	4.00	2.10	2.79	1.91
Relationship satisfaction	3.80	1.19	4.07	1.23	3.90	1.17	4.17	1.28	4.41	0.98	3.70	1.38
Cancer-specific stress												
IES	13.30	13.04	20.60	14.86	20.60	15.17	20.61	14.89	22.61	13.93	18.73	15.67
Physical functioning												
SymS/Tox	0.22	0.11	0.26	0.11	0.25	0.11	0.26	0.12	0.24	0.12	0.27	0.11
KPS	90.88	8.47	78.98	10.45	80.00	8.37	78.42	11.51	77.59	12.44	80.33	8.09

Abbreviations: SD, standard deviation; IES, impact of events scale; SymS/Tox, symptoms, signs, illnesses, and toxicities; KPS, Karnofsky performance status.

Table 4

Significance Tests for Recurrence Versus Disease-Free Groups on Intercept and Slope Estimates and Their Differences

	Intercept				Slope			
Measure	**Estimate**	**SE**	***t***	***P***	**Estimate**	**SE**	***t***	***P***
Sexuality								
Intercourse frequency								
Recurrence	1.59	0.19	8.22	.00	−0.02	0.01	−1.21	.23
Disease free	0.50	0.24	2.13	.03*	0.00	0.01	0.27	.79
Kissing frequency								
Recurrence	6.80	0.34	19.92	.00	−0.04	0.03	−1.57	.12
Disease free	−0.81	0.42	−1.95	.053	0.06	0.03	1.83	.07
Sexual satisfaction								
Recurrence	3.27	0.25	12.84	.00	−0.01	0.02	−0.36	.72
Disease free	0.26	0.31	0.86	.39	0.02	0.02	0.69	.49
Relationship satisfaction								
Recurrence	3.94	0.14	27.41	.00	0.00	0.01	0.31	.76
Disease free	−0.24	0.18	−1.33	.19	−0.02	0.01	−1.36	.18
Cancer-specific stress								
IES								
Recurrence	19.23	1.70	11.29	.00	−0.36	0.14	−2.68	.01†
Disease free	−7.06	2.09	−3.38	.00*	0.18	0.17	1.09	.28
Physical functioning								
SymS/Tox								
Recurrence	0.26	0.01	18.51	.00	0.00	0.00	−1.85	.07
Disease free	−0.04	0.02	−2.45	.02*	0.00	0.00	0.84	.40
KPS								
Recurrence	80.29	1.01	79.78	.00	0.11	0.13	0.88	.38
Disease free	10.50	1.23	8.56	.00*	−0.18	0.15	−1.18	.24

Abbreviations: IES, impact of events scale; SymS/Tox, symptoms, signs, illnesses, and toxicities; KPS, Karnofsky performance status.

*Significant group difference at baseline.

†Significant change over time within recurrence group.