

ORIGINAL ARTICLE

Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study

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ABSTRACT

Background: A breast cancer (BC) diagnosis can profoundly affect the sex life of patient and partner within a couple. The purpose of the present study is to examine whether individual and partner sexual functioning, affectionate behavior, emotional closeness and depressive symptoms are associated with change over time in satisfaction with sex life of sexually active heterosexual couples dealing with BC and to explore whether the associations differ between patients and partners after adjustment for basic sociodemographic characteristics, comorbidity and BC treatment.

Material and methods: Women with BC and their male partners participated in a longitudinal study (Time 1, ≤ 4 months after surgery; Time 2, 5 months later). Participants completed items from the PROMIS[®] Sexual Function and Satisfaction measure (version 1.0), two items measuring affectionate behavior, a single item measuring emotional closeness and the Center for Epidemiologic Studies–Depression Scale. Registers provided sociodemographic and medical information. Multilevel models were used, which take the interdependency of couples' scores into account.

Results: A total of 287 sexually active couples were included in the analyses. Less vaginal discomfort and more vaginal lubrication were associated with increases in patients' satisfaction with sex life. Patients' and partners' satisfaction increased with higher ratings of their own orgasm ability and of partners' timing of ejaculation. Patients' reports of affectionate behavior were positively associated with their partners' satisfaction, and vice versa for partners. Patients' satisfaction increased the more emotional closeness their partner experienced. Partners' depressive symptoms were negatively associated with their satisfaction. Sociodemographic factors and BC treatment were not significantly associated with change in satisfaction.

Conclusion: Satisfaction with sex life in sexually active couples dealing with BC needs to be seen as a couple issue. Health professionals should take the partner into account when addressing sexuality issues. Couples' functioning and relationship-related factors may be promising targets for couple interventions.

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A diagnosis of breast cancer (BC) can profoundly affect a couple's sex life [1,2]. Sexual satisfaction has been found to be associated with higher relationship quality [3], which in turn predicts better individual wellbeing [4]. However, BC treatment and its side effects, emotional distress and changed roles in the relationship can deteriorate patients' and partners' satisfaction with sex life [1,2,5]. Moreover, couples' experiences with their sexuality and relationship in the challenging phase of active treatment might influence their satisfaction with sex life after treatment completion. A person's satisfaction with sex life involves the partner to an important extent [3,6,7], and may not only be affected by the

person's own sexual problems [5], but also by the partner's [2,6]. Emotional distress or depressive symptoms can further lower satisfaction, although findings are mixed [7–9]. Frequent affectionate behavior, such as kissing and caressing, seems to be beneficial [3,5]. Emotional closeness, which is an important determinant of couples' adaptation to cancer [10], possibly also positively affects satisfaction with sex life.

Observational studies have investigated aspects of sexuality and their interplay within couples dealing with cancer (e.g. [9]). However, to our knowledge no study has investigated factors associated with change in satisfaction with sex life of sexually active couples dealing with BC. To address

this gap the present study uses data from the Danish Couples and Breast Cancer Cohort (DCBCC). This nationwide cohort of BC women and their cohabiting male partners includes self-report data and data from Danish nationwide administrative, health- and disease-specific registries. We have previously examined trajectories of depressive symptoms [11] and dyadic coping [12] in this cohort. The purpose of the present study is to examine whether individual and partner sexual functioning, affectionate behavior, emotional closeness and depressive symptoms are associated with change over time in satisfaction with sex life of sexually active heterosexual couples dealing with BC and to explore whether the associations differ between patients and partners.

Material and methods

Procedure and participants

Couples were eligible for inclusion in the DCBCC if the patient was female, ≥ 18 years, Danish resident, had had surgery for primary invasive BC ≤ 4 months before invitation to the study, and was cohabiting with a male partner who was ≥ 18 years. The inclusion period ranged from July 2011 to August 2012. Couples were sent questionnaires including measures of individual wellbeing and relationship aspects by mail three times throughout one year. The procedure is described in detail elsewhere [13]. The study was reported to the Danish Data Protection Agency (ID: 2012-41-0901) and to The Regional Scientific Ethical Committee for Southern Denmark (ID: S-20110103). The present study focuses on the subgroup of sexually active couples at T1 (baseline, ≤ 4 months following BC surgery) and T2 (five months later) to examine change in satisfaction with sex life in the transitional period from active treatment to treatment completion. Couples were included if patient and partner reported sexual activity at T1 and T2 and at both time points completed the sexual satisfaction measure.

Measurements

The present study uses T1 assessments of all self-report measures and the T2 assessment of satisfaction with sex life. All measures were obtained for both patients and partners unless otherwise specified.

Satisfaction with sex life and sexual functioning

Satisfaction with sex life and sexual functioning were measured with ten items from the Patient-Reported Outcomes Measurement Information System (PROMIS)[®] Sexual Function and Satisfaction measure (SexFS) version 1.0 [14]. We assessed global satisfaction with sex life, orgasm ability, patients' vaginal lubrication, patients' vaginal discomfort, partners' erectile function and partners' timing of ejaculation (see Appendix 1). All items have a 30-day recall period and a five-point response scale. All subdomain scores are expressed as T scores [$\bar{x}=50$, standard deviation (SD)=10]. We converted the raw scores to T scores based on scores obtained

in the testing of the items for the PROMIS[®] SexFS version 2.0 [15]. In version 2.0, scores are centered around norms for sexually active US adults [15]. For the two items timing of ejaculation and orgasm ability raw scores are used (range 1–5). Higher scores indicate higher satisfaction or function, except for vaginal discomfort, where higher scores indicate more discomfort. Participants could choose a 'not applicable' option, if they did not engage in the activity in question. This option is not used to calculate a score [15]. At both T1 and T2 we categorized participants as sexually inactive based on the response '*have not been sexually active in the past 30 days*' on the item '*When you were sexually active, how satisfying has it been?*'

A change score for satisfaction with sex life was calculated by subtracting the T1 score from the T2 score. A positive score thus indicates increased satisfaction at T2.

Affectionate behavior

Two items from the PROMIS[®] SexFS version 1.0 item pool on sexual activities were used to assess the frequency of holding and hugging and of kissing with another person on five-point scales [14]. We replaced '*another person*' by '*your partner*' to measure affectionate behavior within the couple (Appendix 1). The two items correlated highly (Spearman's rank correlation = 0.70 for patients and partners). The mean of the two items was computed as overall score of affectionate behavior.

Emotional closeness

One item assessed how close participants felt to their partner during the past 30 days (inspired by Manne et al. [16]). A five-point scale and 30-day recall were chosen, as consistent with the measure of affectionate behavior (Appendix 1).

These measures were translated from English into Danish in a forward-backward procedure and pilot-tested in the target population.

Depressive symptoms

Participants completed the Danish version of the Center for Epidemiologic Studies-Depression Scale (CES-D) [17]. The 20 items measure depressive symptoms in the last week on four-point scales (0 = *rarely or never*; 3 = *almost always*). Total scores range from 0 to 60. Higher scores indicate more depressive symptoms. Reliability and validity have been established, also in cancer patients [18]. In our sample, Cronbach's alpha was 0.89 for patients and 0.88 for partners.

Sociodemographic and health-related information

Age and marital status at time of study invitation were obtained through the Danish Civil Registration System. Information on highest education obtained was retrieved from the Integrated Database for Labor Market Research [19] for 2010. Relationship length was self-reported by the patient at T1. Clinical and treatment-related information on BC was derived from the database of the Danish Breast Cancer

Group (DBCg) [20]. The Charlson Comorbidity Index [21] was calculated on data from the Danish National Patient Register, covering all hospitalizations since 1977 and outpatient visits since 1995 [22]. The weighted index score considers the number and seriousness of 19 comorbid diseases, BC diagnosis excluded.

Statistical analyses

Frequency distributions and percentages or mean values with SDs and ranges were calculated for sample characteristics. The Spearman's rank correlations within couples were calculated for the scale scores that were rated by both patients and partners.

To test whether individual and partner-related characteristics were associated with change in satisfaction with sex life from T1 to T2 we used multilevel models, which take the interdependency of scores within couples into account. The data consisted of two levels: dyads (i.e. couples) at Level 2 and individuals (i.e. patients and partners) nested within dyads at Level 1. There were two types of predictor variables: (1) couple-level variables, i.e. the gender-specific variables vaginal lubrication, vaginal discomfort, erectile function and timing of ejaculation, for which both members of the couple received the same score; (2) individual-level variables, i.e. orgasm ability, affectionate behavior, emotional closeness and depressive symptoms, which could differ between individuals within the couple [23]. All predictors were examined in separate models. For couple-level predictors each model examined, whether the respective predictor was associated with change in satisfaction with sex life of couples. For individual-level predictors both actor effects (i.e. associations of a person's own score with her/his own outcome) and partner effects (i.e. associations of the person's partner's score with her/his own outcome) were examined [23]. To account for the correlation of the individual-level predictors within couples, actor and partner effects were tested within the same model.

All models were adjusted for the individual-level variables satisfaction with sex life at T1, age, education and Charlson Comorbidity Index (actor effects only) and for the major BC treatment-related variables type of surgery, chemotherapy and endocrine treatment. Radiotherapy was not included because of a causal relationship with type of surgery: lumpectomized women are allocated to radiotherapy.

To test whether the associations differed between patients and partners we tested for interactions between role and the predictor variables. Significant interactions were examined.

The significance level for all analyses was $\alpha < 0.05$. All analyses were conducted with STATA 13.0.

Results

Of 2254 eligible couples, 792 (35%) participated in the DCBCC study. Of these, 287 couples were included in the present analyses (Figure 1). A comparison of included ($n = 287$, 36%) and excluded couples ($n = 505$, 64%) on sociodemographic, health- and BC-related characteristics showed

significant differences: patients and partners in excluded couples were older and had longer relationship duration; patients in excluded couples were more likely to have basic school only and less likely to have received chemotherapy (all $ps < 0.05$; data not shown).

Patients' age averaged 56 years and partners' 58 years (Table 1). Average relationship duration was 29.0 years ($SD = 14.5$), and 90% of couples ($n = 258$) were married. Most women had no affected lymph nodes ($n = 166$, 58%); none had metastases. Some 91% ($n = 260$) were referred to radiotherapy and 14% ($n = 41$) to treatment with trastuzumab. Couples were mailed the T1 questionnaire on average 62 days after surgery ($SD = 24$). Satisfaction with sex life at T1 averaged 49.53 ($SD = 6.97$) for patients and 50.87 ($SD = 7.37$) for partners and was moderately correlated within couples ($r_s = 0.54$). Average change in satisfaction with sex life from T1 to T2 was -0.89 ($SD = 6.91$, range = -20.84 – 19.4) for patients and -1.05 ($SD = 6.81$, range = -23.64 – 18.99) for partners (Table 2).

Vaginal lubrication was significantly positively associated with change in satisfaction with sex life, whereas vaginal discomfort was negatively associated with such change (Table 3). There was significant interaction by role: the associations were significant only for patients (Table 4). Higher scores on timing of ejaculation were associated with increased sexual satisfaction in couples. A significant actor effect was observed for orgasm ability: a person's own score on orgasm ability was positively associated with her/his change in satisfaction (Table 3).

There were significant partner effects for affectionate behavior and emotional closeness with a person's partner's score being positively associated with the person's own change in satisfaction (Table 3). The partner effect of emotional closeness was significant only for patients (Table 4).

A significant actor effect was observed for depressive symptoms with a person's score being negatively associated with her/his change in satisfaction (Table 3). This association was significant only for partners (Table 4).

A significant interaction by role was observed for the association of severe comorbidity and change in satisfaction (Table 3); the association was neither significant for patients nor for partners (Table 4). Exploratory analyses of the marginally significant interaction term for type of surgery (Table 3) revealed no significant association for patients ($p = 0.12$) and partners ($p = 0.57$), respectively (data not shown). No other significant associations or interactions were observed.

Discussion

The present study found that sexual functioning, affectionate behavior, emotional closeness and depressive symptoms of sexually active couples significantly contributed to change in their satisfaction with sex life, whereas no significant associations were found for sociodemographic factors and BC treatment. Both individual characteristics and the respective partner's characteristics played a role, suggesting mutual

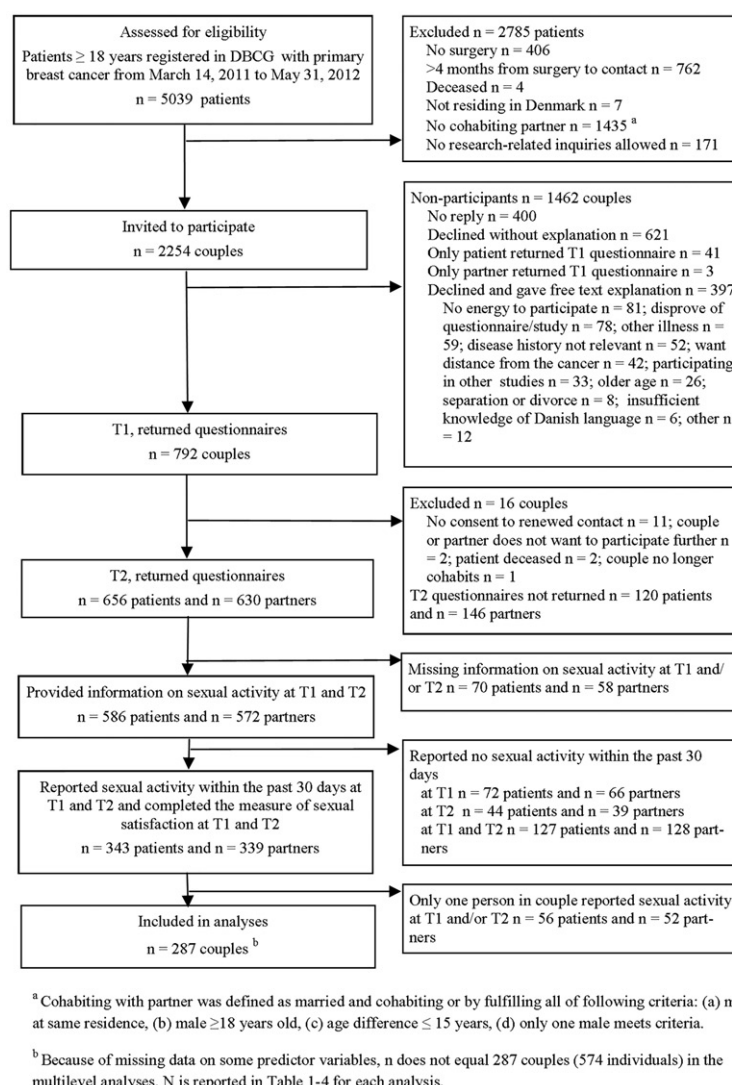


Figure 1. Flowchart of a Danish nationwide longitudinal study of satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer.

DBCG: Danish Breast Cancer Group, a nationwide clinical database for breast cancer in Denmark; T1: baseline, ≤4 months after surgery for breast cancer; T2: 5 months after T1.

^aCohabiting with partner was defined as married and cohabiting or by fulfilling all of following criteria: (a) male at same residence, (b) male ≥18 years old, (c) age difference ≤15 years, (d) only one male meets criteria. ^bBecause of missing data on some predictor variables, n does not equal 287 couples (574 individuals) in the multilevel analyses. N is reported in Tables 1-4 for each analysis.

Table 1. Sociodemographic, health-related and breast cancer-related information of 287 sexually active heterosexual couples dealing with breast cancer.

Characteristic	Patients	Male partners
Sociodemographic information	Mean (SD)	Mean (SD)
Age (in years)	55.77 (10.01)	57.75 (10.47)
Education ^a	n (%)	n (%)
Basic education	18 (6)	33 (11)
Vocational training	150 (52)	158 (55)
Higher education	114 (40)	92 (32)
Health-related information		
Charlson Comorbidity Index		
No comorbidity (0)	215 (75)	191 (67)
Mild comorbidity (1)	45 (16)	57 (20)
Severe comorbidity (≥2)	27 (9)	39 (14)
Breast cancer treatment		
Type of surgery		
Lumpectomy	216 (75)	
Mastectomy	71 (25)	
Allocated to chemotherapy		
No	125 (44)	
Yes	162 (56)	
Allocated to endocrine treatment		
No	76 (26)	
Yes	211 (74)	

^a5 patients missing, 4 partners missing.
SD: standard deviation.

influences; yet, some associations differed significantly between patients and partners.

The findings for sexual functioning suggest that a person's change in satisfaction with sex life is more affected by her/his own experience of sexual functioning than by the partner's experience: Patients' and partners' satisfaction increased with higher ratings of their own orgasm ability; less vaginal discomfort and more lubrication were associated with increases in patients' satisfaction only. An exception was premature ejaculation, which negatively affected partners and patients. Contrary to this, a cross-sectional study of 1009 mid-life couples found that men's sexual satisfaction but not women's was affected by their partner's sexual functioning [3]. However, Fisher et al. [3] used a sum score including different dimensions of functioning, whereas we measured selected dimensions separately. This impedes a comparison.

Satisfaction of patients and partners increased the more affectionate behavior their respective partner reported. This confirms previous findings [3] that affectionate behavior,

Table 2. Mean values with standard deviations, range and within-couple correlations of self-report measures for 287 sexually active heterosexual couples in the Danish Couples and Breast Cancer Cohort (DCBCC).

Scale	Patient Mean (SD)	Range	n	Male partner Mean (SD)	Range	n	Couple r_s
Satisfaction with sex life, T1	49.53 (6.97)	30.53–62.28	287	50.87 (7.37)	30.53–62.28	287	0.54 ^a
Change in satisfaction with sex life, T1-T2	−0.89 (6.91)	−20.84–19.4	287	−1.05 (6.81)	−23.64–18.99	287	0.28 ^a
Vaginal discomfort, T1	51.52 (8.46)	44.03–76.47	283	na	na	na	na
Vaginal lubrication, T1	48.20 (8.96)	27.8–58.92	285	na	na	na	na
Erectile functioning, T1	na	na	na	52.41 (7.14)	30.91–57.79	284	na
Timing of ejaculation, T1	na	na	na	3.78 (0.95)	1–5	282	na
Orgasm ability, T1	3.21 (1.20)	1–5	275	3.88 (1.06)	1–5	285	0.11
Affectionate behavior, T1	4.01 (0.96)	1.5–5	287	4.08 (1.03)	1–5	285	0.58 ^a
Emotional closeness, T1	4.66 (0.60)	2–5	286	4.69 (0.60)	2–5	287	0.33 ^a
Depressive symptoms, T1	10.79 (8.42)	0–39	286	7.70 (7.39)	0–35	287	0.24 ^a

^aSignificant at $p < 0.01$.na: not applicable; r_s : Spearman's rank correlation coefficient; SD: standard deviation; T1: Time 1 (baseline, ≤ 4 months following surgery for breast cancer); T2: Time 2 (5 months after T1).**Table 3.** Associations between predictors and change in satisfaction with sex life, and significance level of interactions by role in 287 sexually active heterosexual couples ($n = 574$) in the Danish Couples and Breast Cancer Cohort (DCBCC).

Predictor ^a	Associations between predictor and change in satisfaction with sex life ^d				Interactions by role p
	B	p	95% CI	n ^e	
Vaginal discomfort	−0.11	<0.01	−0.18–−0.03	557	0.03
Vaginal lubrication	0.10	<0.01	0.03–0.17	561	0.04
Erectile functioning	0.08	0.09	−0.01–0.16	559	0.14
Timing of ejaculation	0.72	0.02	0.10–1.33	555	0.77
Orgasm ability, actor effect ^b	1.02	<0.01	0.55–1.48	537	0.32
Orgasm ability, partner effect ^c	0.38	0.09	−0.06–0.81	537	0.74
Affectionate behavior, actor effect ^b	0.34	0.25	−0.23–0.91	561	0.67
Affectionate behavior, partner effect ^c	0.65	0.02	0.09–1.21	561	0.27
Emotional closeness, actor effect ^b	0.68	0.13	−0.19–1.56	563	0.06
Emotional closeness, partner effect ^c	0.90	0.03	0.07–1.73	563	0.03
Depressive symptoms, actor effect ^b	−0.11	<0.01	−0.18–−0.05	564	0.02
Depressive symptoms, partner effect ^c	−0.04	0.21	−0.10–0.02	564	0.14
Satisfaction with sex life, T1, actor effect ^b	−0.54	<0.01	−0.61–−0.47	565	0.94
Age, actor effect ^b	−0.01	0.84	−0.08–0.06	565	0.82
Level of education, actor effect ^b (reference: basic education)				565	
Vocational training	−0.60	0.49	−2.33–1.12		0.57
Higher education	−0.39	0.68	−2.23–1.46		0.43
Charlson Comorbidity Index, actor effect ^b [reference: no comorbidity (0)]				565	
Mild comorbidity (1)	1.08	0.09	−0.17–2.32		0.90
Severe comorbidity (≥ 2)	0.18	0.81	−1.32–1.69		0.02
Type of surgery [lumpectomy vs. mastectomy (reference)]	−0.43	0.54	−1.82–0.96	565	0.05
Allocated to chemotherapy [yes vs. no (reference)]	−1.13	0.12	−2.56–0.31	565	0.25
Allocated to endocrine therapy [yes vs. no (reference)]	0.25	0.71	−1.07–1.57	565	0.61

^aAll self-report measures are those obtained in questionnaires from T1;^b'Actor effect' denotes the association of a person's own score with her/his own outcome;^c'Partner effect' denotes the association of the person's partner's score with her/his own outcome;^dAll coefficients are adjusted for satisfaction with sex life at T1, age, education, Charlson Comorbidity Index, type of surgery, chemotherapy and endocrine therapy. In addition, actor and partner effects of orgasm ability, affectionate behavior, emotional closeness and depressive symptoms, respectively, are mutually adjusted for each other. Interaction effects are not included in the models;^e $n < 574$ is due to missing data on the education variable as shown in Table 1 and on the self-reported data as shown in Table 2.CI: confidence interval; T1: Time 1 (baseline, ≤ 4 months following surgery for breast cancer).

such as caressing and kissing, contributes to higher satisfaction with sex life. Interestingly, both patients and partners benefitted the more affectionate behavior their partner reported, whereas their own reports were unrelated to their change in satisfaction. Maybe receiving affectionate behavior is more important here than giving: when partners behave affectionately towards the other person the conveyed message of love and desire may influence the other person's satisfaction with sex life.

Patient's satisfaction increased the more emotional closeness her partner experienced, which may be related to gender differences: women's thoughts and feelings seem to be more interdependent than men's [24]. Women may also be

more sensitive to how the partner feels about emotional closeness, which may impact on their satisfaction with sex life. Maybe this female tendency towards relational interdependence is intensified by emotional vulnerability after BC diagnosis: patients may be searching for security and reassurance in the relationship and pay even more attention to their partners' views.

Higher scores on depressive symptoms were associated with a decrease in satisfaction with sex life only for partners. The lack of an association for patients is supported by findings of a longitudinal study of BC patients examining whether depressive symptoms predict sexual enjoyment [8]. Possibly, emotional distress in patients' partners generalizes

Table 4. Associations between predictors and change in satisfaction with sex life split up by role (patient vs. male partner) for the significant interactions in 287 sexually active heterosexual couples (n=574) in the Danish Couples and Breast Cancer Cohort (DCBCC).

Predictor ^a	Associations between predictors and change in satisfaction with sex life by role (patient vs. male partner) for the significant interactions ^d			
	B	p	95% CI	n ^e
Vaginal discomfort				557
Patient	−0.16	<0.01	−0.25–−0.07	
Male partner	−0.06	0.18	−0.15–0.03	
Vaginal lubrication				561
Patient	0.15	<0.01	0.07–0.23	
Male partner	0.06	0.16	−0.02–0.14	
Emotional closeness, partner effect ^b				563
Patient	1.97	<0.01	0.71–3.22	
Male partner	−0.07	0.91	−1.31–1.17	
Depressive symptoms, actor effect ^c				564
Patient	−0.04	0.35	−0.13–0.05	
Male partner	−0.19	<0.01	−0.29–−0.10	
Severe comorbidity (≥2) [reference: no comorbidity (0)]				565
Patient	−1.89	0.10	−4.15–0.38	
Male partner	1.51	0.12	−0.42–3.44	

^aAll self-report measures are those obtained in questionnaires from T1;

^bPartner effect^c denotes the association of the person's partner's score with her/his own outcome;

^cActor effect^c denotes the association of a person's own score with her/his own outcome;

^dAll coefficients are adjusted for satisfaction with sex life at T1, age, education, Charlson Comorbidity Index, type of surgery, chemotherapy and endocrine therapy. In addition, actor and partner effects of emotional closeness and depressive symptoms, respectively, are mutually adjusted for each other;

^en < 574 is due to missing data on the education variable as shown in Table 1 and on the self-reported data as shown in Table 2.

CI: confidence interval; T1: Time 1 (baseline, ≤4 months following surgery for breast cancer).

more to other areas of wellbeing than in patients, whereas cancer patients may attribute the distress they experience more to BC and deal with it differently.

The non-significant findings for age, education and BC treatment are generally supported by previous studies of women with BC [6–8]. Ganz et al. [6], however, found that using tamoxifen (vs. not using tamoxifen) and having stopped menstruating after diagnosis or a past history of hormone replacement therapy (vs. being already postmenopausal and not taking hormone replacement therapy at diagnosis) were associated with poorer satisfaction; having mastectomy without reconstruction (vs. lumpectomy) was associated with higher satisfaction. Yet, these associations were found inconsistently, i.e. in one out of two samples. Maybe treatment parameters have an indirect effect on satisfaction through their association with sexual functioning [6].

Previous findings regarding comorbidity are inconsistent [6,7]. We found a significant interaction by role for the association of severe comorbidity and change in satisfaction. This indicates that patients and partners were differentially affected by severe comorbidity. The coefficients suggest that severe comorbidity could possibly be associated with a decrease in patients' satisfaction and an increase in partners' satisfaction. Yet, only a minority had severe comorbidity and, although we do not know this, the large confidence intervals for both patients and partners may indicate that a larger study sample might have been needed to investigate this association.

The non-significant findings regarding BC treatment and comorbidity could be due to our selection criteria: we focused on the subgroup of couples who were sexually active at T1 and T2. This may have resulted in a homogeneous sample of sexually well functioning couples excluding those that stopped sexual activity because of problems

potentially related to BC treatment or comorbidity [1], thus reducing the likelihood of finding associations.

Satisfaction with sex life of patients and partners was close to US norm scores ($\bar{x}$ = 48.57 for women and 49.51 for men, age group 45–59) [15]. This may point to an overrepresentation of robust couples in our sample, as declines in satisfaction with sex life after cancer diagnosis have been reported [1]. However, the US norm scores do not necessarily apply to the Danish population. Average changes in satisfaction were small for both patients and partners, but there was large variation. Hence, while some patients' and partners' satisfaction is increasing, satisfaction of others is deteriorating.

This study has several strengths. To our knowledge, it is the first to examine factors associated with both BC patients' and their partners' satisfaction with sex life. The longitudinal design enabled capturing change over time. The analytic approach accounted for the interdependency of couples' scores and permitted analyzing mutual influences within couples. Population-based registers were used to identify eligible couples and to obtain sociodemographic and medical information, thus obviating problems due to recall bias. Validated self-report instruments measured satisfaction, sexual functioning and depressive symptoms, and the included sexual functioning dimensions covered the sexual dysfunctions most frequent in Denmark [25].

Limitations include the low baseline participation rate of 35% and attrition, possibly introducing non-response bias. However, high response rates are difficult to obtain in couple-based research [26], perhaps particularly when the sensitive topic sexuality is included. Of the examined socio-demographic, health- and BC-related characteristics, participation was reduced by older age, lower socioeconomic status and morbidity of the partner [13]; attrition was related

to older age, longer relationship duration, shorter education and not having received chemotherapy. These differences may partly reflect a natural decline in the frequency of sexual activity at older age. However, we do not know whether our findings can be generalized to populations with more diverse profiles in terms of sociodemography, chemotherapy treatment and partner morbidity. Further, information on satisfaction with sex life before diagnosis was unavailable; however, the longitudinal assessments permitted studying change over time. Measurement invariance of the Danish translations of the PROMIS® SexFS was not tested, but we applied a careful translation procedure and pilot-tested the Danish items. Finally, we do not know whether our results can be generalized to women with BC in same-sex relationships or those who do not cohabit with a partner.

In conclusion, our findings underscore that satisfaction with sex life after BC needs to be seen as a couple issue. Thus, health professionals should consider the patient's partner when addressing sexuality issues. Sociodemographic factors and BC treatment were not significantly associated with couples' satisfaction. Attention should be given to emotional closeness and affectionate behavior. Addressing these factors in couple-based interventions likely increases couples' satisfaction with sex life, potentially also in those who do not engage in genital sexual activity. Our study focused on sexually active couples. Future research could examine factors associated with not being sexually active in order to further understand couples' sexuality after cancer.

Disclosure statement

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Appendix 1.

Items used to measure satisfaction with sex life, sexual functioning, affectionate behavior and emotional closeness in the Danish study of sexually active heterosexual couples dealing with breast cancer

Satisfaction with sex life and sexual functioning^a

Satisfaction

1) In the past 30 days, how satisfied have you been with your sex life?

1 = Not at all; 2 = A little bit; 3 = Somewhat; 4 = Quite a bit; 5 = Very

2) In the past 30 days, when you have had sexual activity, how satisfying has it been?

0 = Have not had sexual activity in the past 30 days; 1 = Not at all; 2 = A little bit; 3 = Somewhat; 4 = Quite a bit; 5 = Very

Orgasm

3) In the past 30 days, how would you rate your ability to have a satisfying orgasm/climax?

0 = Have not tried to have an orgasm/climax in the past 30 days; 5 = Excellent; 4 = Very good; 3 = Good; 2 = Fair; 1 = Poor

Vaginal lubrication

4) In the past 30 days, how difficult has it been for your vagina to get lubricated ('wet') when you wanted it to?

0 = Have not tried to get lubricated in the past 30 days; 5 = Not at all; 4 = A little bit; 3 = Somewhat; 2 = Quite a bit; 1 = Very

5) In the past 30 days, how often have you had difficulty with sexual activity because your vagina was too dry?

0 = Have not had any sexual activity in the past 30 days; 5 = Never; 4 = Rarely; 3 = Sometimes; 2 = Often; 1 = Always

Vaginal discomfort

6) In the past 30 days, how often have you had difficulty with sexual activity because of discomfort or pain in your vagina?

0 = Have not had any sexual activity in the past 30 days; 1 = Never; 2 = Rarely; 3 = Sometimes; 4 = Often; 5 = Always

7) In the past 30 days, how often have you stopped sexual activity because of discomfort or pain in your vagina?

0 = Have not had any sexual activity in the past 30 days; 1 = Never; 2 = Rarely; 3 = Sometimes; 4 = Often; 5 = Always

Erectile function

8) In the past 30 days, how difficult has it been for you to get an erection when you wanted to? (If you use pills, injections, or a penis pump

to help you get an erection, please answer this question thinking about the times that you used these aids.)

0 = Have not tried to get an erection in the past 30 days; 5 = Not at all; 4 = A little bit; 3 = Somewhat; 2 = Quite a bit; 1 = Very

9) In the past 30 days, how difficult has it been to keep an erection (stay hard) when you wanted to? (If you use pills, injections, or a penis pump to help you get an erection, please answer this question thinking about the times that you used these aids.)

0 = Have not had an erection in the past 30 days; 5 = Not at all; 4 = A little bit; 3 = Somewhat; 2 = Quite a bit; 1 = Very

Timing of ejaculation

10) In the past 30 days, how often have you ejaculated ('come') more quickly than you would like?

0 = Have not tried to ejaculate in the past 30 days; 5 = Never; 4 = Rarely; 3 = Sometimes; 2 = Often; 1 = Always

Affectionate behavior^b

1) In the past 30 days how often have you and your partner spent time holding or hugging each other romantically?

1 = Have not done in the past 30 days; 2 = Once a week or less; 3 = Once every few days; 4 = Once a day; 5 = More than once a day

2) In the past 30 days how often have you kissed your partner romantically?

1 = Have not done in the past 30 days; 2 = Once a week or less; 3 = Once every few days; 4 = Once a day; 5 = More than once a day

Emotional closeness^c

1) How close did you feel to your partner during the past 30 days?

1 = Not at all; 2 = A little bit; 3 = Somewhat; 4 = Quite a bit; 5 = Very

^aThe items measuring satisfaction with sex life and sexual functioning stem from the Patient-Reported Outcomes Measurement Information System (PROMIS)[®] Sexual Function and Satisfaction measure (SexFS) version 1.0.

Reference: Flynn KE, Lin L, Cyranowski JM, et al. Development of the NIH PROMIS[®] Sexual Function and Satisfaction measures in patients with cancer. *J Sex Med*. 2013;10(Suppl 1):43–52.

For information on items eventually included in version 2.0 after testing please contact the developers of the measure.

^bThe items on affectionate behavior stem from the PROMIS[®] SexFS item pool on sexual activities (version 1.0). Note that we in the present study replaced the original wording 'another person' by 'your partner' to measure affectionate behavior within the couple.

Reference: Flynn KE, Lin L, Cyranowski JM, et al. Development of the NIH PROMIS[®] Sexual Function and Satisfaction measures in patients with cancer. *J Sex Med*. 2013;10(Suppl 1):43–52.

For information on items eventually included in version 2.0 after testing please contact the developers of the measure.

^cThe measure of emotional closeness was inspired by: Manne S, Ostroff J, Rini C, et al. The interpersonal process model of intimacy: the role of self-disclosure, partner disclosure, and partner responsiveness in interactions between breast cancer patients and their partners. *J Fam Psychol*. 2004;18:589–599.