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ORIGINAL ARTICLE

Prevalence and risk factors for sexual dysfunction in young women following a cancer diagnosis – a population-based study

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ABSTRACT

Background: Self-reported sex problems among women diagnosed with reproductive and nonreproductive cancers before the age of 40 are not fully understood. This study aimed to determine sexual dysfunction in young women following a cancer diagnosis in relation to women of the general population. Furthermore, to identify factors associated with sexual dysfunction in women diagnosed with cancer.

Materials and Methods: A population-based cross-sectional study with 694 young women was conducted 1.5 years after being diagnosed with cancer (response rate 72%). Potential participants were identified in national quality registries covering breast and gynecological cancer, lymphoma and brain tumors. The women with cancer were compared to a group of women drawn from the general population ($N = 493$). Sexual activity and function were assessed with the PROMIS® SexFS. Logistic regression was used to assess differences between women with cancer and the comparison group, and to identify factors associated with sexual dysfunction.

Results: The majority of the women with cancer (83%) as well as the women from the comparison group (87%) reported having had sex the last month (partner sex and/or masturbation). More than 60% of the women with cancer (all diagnoses) reported sexual dysfunction in at least one of the measured domains. The women with cancer reported statistically significantly more problems than women of the comparison group across domains such as decreased interest in having sex, and vaginal and vulvar discomfort. Women with gynecological or breast cancer and those receiving more intense treatment were at particular high risk of sexual dysfunction (≥2 domains). Concurrent emotional distress and body image disturbance were associated with more dysfunction.

Conclusion: The results underscore the need to routinely assess sexual health in clinical care and follow-up. Based on the results, development of interventions to support women to cope with cancer-related sexual dysfunction is recommended.

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Neoplasms; population based; sexual dysfunction; women; young adults

Background

Worldwide, more than half a million women are diagnosed with cancer yearly before reaching age 40 [1], a period typically including intimate relationships and family building. It is well-known that cancer and cancer therapies are associated with a number of early and late consequences including a negative impact on sex life [2]. Sexual problems are caused, directly or indirectly, by changes in body functions and responses related to sex and intimacy [3]. According to the integrative biopsychosocial model presented by Bober and Valera [4], sexual problems following cancer are associated with biological factors (e.g. hormonal alterations [5], change/loss of body part [2,6]) as well as psychological (e.g. emotional distress [6,7], body image [6–8]), interpersonal (communication barriers [9]) and social/cultural (social norms) factors.

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Some studies report that approximately half of young women report sexual dysfunction in the first years after being diagnosed with cancer [2,9]. The reported problems include lack of desire and interest in sex [10,11], vaginal discomfort and dyspareunia [11], difficulties related to orgasm as well as lower satisfaction with sex life [9,10,12]. How prevalence of sexual problems in young patients varies by cancer type and treatment modality is not fully understood. The studies that include young women have typically not analyzed this age group separately, making it difficult to draw firm conclusions about the situation of women with reproductive and nonreproductive cancers. Additionally, studies comparing their results to corresponding general population samples are scarce. Therefore, the present study aims to determine sexual activity and dysfunction in young women following a cancer diagnosis in relation to women of the general population. Furthermore, we aim to identify factors associated with sexual dysfunction among young women diagnosed with cancer.

Material and methods

Study setting and design

This population-based cross-sectional study is part of the Fex-Can Cohort study, mapping sexual and reproductive health in young adults (YAs) the first five years after being diagnosed with cancer, described in a study protocol [13]. The present study reports on sexual activity and function among the women at the baseline assessment, 1.5 years after diagnosis, and includes a general population sample described in detail elsewhere [14]. The study combines registry and survey data for women with cancer outlined in accordance to the STROBE guidelines [15].

Participants and procedure

All women in Sweden at the age of 18–39 years who were diagnosed with breast cancer, cervical cancer, lymphoma, ovarian cancer or a brain tumor during the period January 2016 through August 2017 were identified in national quality registries ($N = 977$). Among the identified patients, ten women were excluded due to being deceased ($n = 4$), lack of valid postal address ($n = 2$), self-reported cognitive impairment ($n = 1$), and administrative failure ($n = 3$). The remaining 967 women were approached for possible participation during 2017–2018 (1.5 years after diagnosis).

A random sample of women ($n = 1000$) from the general population in the same age span (19–40 years) were identified by the Swedish population registry to constitute a comparison group [14]. The same exclusion criteria as for the women with cancer were applied for the comparison group ($n = 17$). Additionally, women who reported having received treatment for cancer were excluded ($n = 13$).

Potential participants received a letter describing the study together with the survey package, which was possible to complete on paper, online or over the phone; nonresponders received two reminders. Informed consent was obtained from all participants. Ethical approval for the study procedures was obtained from the Regional Ethical Review Board in Stockholm (Registration number: 2013/1746-31/4; 2014/2244-32; 2015/2042-32/4; 2016/1848-32, 2017/916-32, 2017/1416-32).

Data collection

From the survey package, we selected variables measuring sexual activity and function, body image, emotional distress and socio-demographics, for the present study. In addition to collection of patient-reported outcomes from the women with cancer and the general population sample, we retrieved clinical data from national quality registries for the women with cancer.

Measures

Primary outcomes

Sexual activity and function were assessed with the Patient-Reported Outcomes Measurement Information System® (PROMIS) Sexual Function and Satisfaction measure (SexFS) version 2.0 [16]. For the present study the following domains were selected: Satisfaction with Sex Life, Interest in Sexual Activity, Vaginal Lubrication, Vaginal Discomfort, Vulvar Discomfort –Labial, Vulvar Discomfort – Clitoral, Orgasm – Pleasure, Orgasm – Ability, as well as sexual screeners (sexual activity, reasons for not having had sex with a partner). The domains were completed by individuals who had been sexually active the past 30 days with the exception of the domain Interest of Sexual Activity which was completed regardless of having had sex the past 30 days or not. Sexual activity is defined as sex with a partner and/or solo sex (masturbation). Item response theory was used to estimate each respondent's item responses which are transformed to a t-score metric (Mean = 50, standard deviation = 10). The mean of 50 corresponds to the mean of U.S. adults who have been sexually active in the past 30 days [16]. One standard deviation below or above 50 (depending on the direction of scale) is considered indicative of dysfunction in respective domain (http://www.nihpromis.org/). The PROMIS SexFS has shown adequate validity and reliability [16]. The items were translated into Swedish and linguistically validated in accordance with the procedures of FACITrans and PROMIS [17]. Missing data were handled according to the established PROMIS methodology for the SexFS [16]. In addition to SexFS, a study-specific question to retrospectively assess satisfaction with sex life before cancer was included (rated on a 5-point scale from 'not at all' to 'very much').

Secondary outcomes

Emotional distress was assessed with the Hospital Anxiety and Depression Scale (HADS) [18] including two subscales that assess symptoms of anxiety (7 items) and depression (7 items). Ratings are combined to an overall score of emotional distress (range 0–42), with higher scores indicating

greater distress. The HADS has shown satisfactory internal consistency and validity [19,20].

Bodily concerns associated with the cancer experience were assessed using the 10-item Body Image Scale (BIS) [21]. A total score (range 0–30) is calculated by summarizing the items, with higher scores indicating greater body image disturbance. BIS has shown clinical validity as well as test-retest reliability and satisfactory internal consistency [21].

Registry data

Clinical data were collected from the Swedish national cancer quality registries including cancer type and stage, date of diagnosis, treatment, and relapse [22–25]. Based on diagnosis, stage and received treatment, patients' treatment intensity was classified (least, moderately, very, or most intensive/extensive treatment) according to an adapted version of the Intensity of Treatment Rating scale (ITR-3.0) [26,27], the ITR-YA [28].

Statistical analyses

Analyses were performed using SPSS Statistics version 27. Sociodemographic and clinical characteristics of groups were compared using Student's *t*-test and chi-square tests. Possible differences in sexual dysfunction between women with cancer and the comparison group were tested by logistic regression, adjusted for socio-demographics (age, education, country of birth, relationship status, having children). Prevalence of sexual dysfunction is presented for all selected domains. To identify factors associated with dysfunction in women with cancer, logistic regression models were conducted for a subset of five SexFS domains (to enable comparison with previous reports [14,29], and for having dysfunction in two or more domains. Associated factors were selected *a priori*: age (continuous), education (university degree/no university degree), country of birth (Sweden/outside Sweden), relationship status (partnered/not partnered), having children (yes/no), sexual orientation (heterosexual/nonheterosexual), cancer diagnosis, treatment intensity (less intensive/more intensive), body image disturbance (continuous), and emotional distress (continuous). First, each factor was examined in bivariate analyses, using simple logistic regression and chi-square tests as appropriate. Factors associated with dysfunction in the respective domain were thereafter analyzed using multivariable logistic regression. All models were adjusted for the retrospective assessment of prediagnosis satisfaction with sex life (low/medium/high). All tests were two-tailed and *p*-values $<.05$ were considered statistically significant.

Results

Of the total of 967 women with cancer that were approached, 694 (response rate 72%) completed the survey a mean of 465 days after diagnosis (SD 79, range 216–695). Responders did not differ from nonresponders with regard to age at diagnosis or intensity of the received treatment, but participation rates differed by cancer type (Supplementary Table 1).

The final cohort of women had a mean age of 35 years at cancer diagnosis with the majority being partnered, sociodemographic characteristics of participants presented in Table 1. Study participants were compared to women drawn from the general population ($n = 493$, 51% response rate). The women with cancer were older, were to a lesser extent working or studying and more frequently had children, than the comparison group (Table 1). For clinical characteristics of the women with cancer, see Table 2. Half of the women had breast cancer and more than half of the total sample (53%) had received treatment rated as very or most intensive/extensive (Table 2).

Sexual activity

The majority of the women with cancer (83%) as well as the women from the comparison group (87%) reported having had sex the last month (partner sex and/or masturbation). During the same period, around two-thirds of the women with cancer (67%) reported that they had been sexually active with a partner, which did not differ from the women in the comparison group (69%). The most common reasons given for not having had sex with a partner the past 30 days are shown in Supplementary Table 2. Women with cancer differed statistically from the comparison group with a higher number of complaints given for six of the eleven prespecified reasons for not having had sex with a partner. Additionally, women in the comparison group to a higher extent than the women with cancer, recorded that they had not had time for sex.

Table 1. Socio-demographic characteristics of the women with cancer and the comparison group.

	Women with cancer ($n = 694$) *n* (%)	Comparison group ($n = 493$) *n* (%)	*p* Value
Age at survey, years			
Mean (SD)[a]	34.5 (4.9)	29.7 (6.1)	<.001
Country of birth			
Sweden	579 (84)	422 (86)	.322
Outside Sweden	114 (17)	71 (14)	
Highest Education[b]			
University degree	417 (60)	283 (58)	.401
No university degree[c]	275 (40)	207 (42)	
Occupation[b]			
Working/studying	530 (77)	440 (89)	<.001
Unemployed, sick-leave, other[d]	162 (23)	52 (11)	
Relationship status[b]			
Partnered	585 (85)	394 (81)	.071
Not partnered	106 (15)	95 (19)	
Have children[b]			
Yes	473 (69)	230 (47)	<.001
No	214 (31)	261 (53)	
Sexual orientation[b]			
Heterosexual	633 (93)	454 (93)	.726
Non-heterosexual[e]	45 (7)	35 (7)	

Numbers do not sum up to total due to missing data.
[a]Difference tested by Student's *t*-test.
[b]Differences tested by Chi-square test.
[c]Includes elementary school, upper secondary school, folk high school.
[d]Parental leave, retired.
[e]Nonheterosexual includes homosexual, bisexual, polysexual.

Table 2. Clinical characteristics of the women with cancer ($n = 694$).

	Breast $n = 349$ No. (%)	Cervical $n = 190$ No. (%)	CNS $n = 66$ No. (%)	Lymphoma $n = 57$ No. (%)	Ovarian $n = 32$ No. (%)	All women $n = 694$ No. (%)
Treatment intensity[a]						
Least intensive/extensive	11 (3)	128 (73.6)	5 (7.7)	3 (5.3)	16 (51.6)	163 (24)
Moderately intensive/extensive	73 (21)	7 (4.0)	44 (67.7)	17 (29.8)	10 (32.3)	151 (22)
Very intensive/extensive	256 (74)	37 (21.3)	15 (23.1)	33 (57.9)	4 (12.9)	345 (51)
Most intense/extensive	6 (2)	2 (1.1)	1 (1.5)	4 (7.0)	1 (3.2)	14 (2)
Type of treatment						
Surgery	340 (97)	153 (80)	61 (92)	0	31 (97)	585 (84)
(Immuno-)[b] Chemotherapy	305 (87)	39 (21)	13 (20)	55 (96)	10 (31)	422 (61)
Radiotherapy	260 (74)	36 (19)	12 (18)	23 (40)	0	331 (48)
Chemotherapy and radiotherapy	233 (67)	36 (19)	10 (15)	23 (40)	0	302 (43)
Endocrine treatment	217 (62)	0	0	0	0	217 (31)
Antibody treatment	98 (28)	1 (1)	0	0	2 (6)	101 (15)
Stem cell transplantation	0	0	0	1	0	1 (<1)

[a]Patients classified according to an adapted version of the Intensity of Treatment Rating Scale (ITR) 3.0.
[b]Nine women treated for lymphoma received immunotherapy in addition to chemotherapy.
Numbers do not sum up to total due to missing data ($n = 21$).

Table 3. Differences in prevalence of sexual dysfunction[a] between women with cancer and a comparison group.

Dysfunction related to domains	Brain tumor *n* (%)	Breast cancer *n* (%)	Cervical cancer *n* (%)	Lymphoma *n* (%)	Ovarian cancer *n* (%)	All diagnoses *n* (%)	Comparison group *n* (%)	OR (95% CI)	^{Adj}p Value
	$n = 66$	$n = 349$	$n = 190$	$n = 57$	$n = 32$	$n = 694$	$n = 493$		
Satisfaction with Sex Life	9 (16)	71 (26)	33 (20)	6 (13)	9 (33)	128 (22)	51 (12)	**1.93 (1.31–2.85)**	**.001**
Interest in Sexual Activity	24 (37)	181 (53)	78 (41)	15 (27)	12 (38)	310 (45)	156 (32)	**1.41 (1.08–1.84)**	**.012**
Orgasm – Ability	12 (23)	103 (40)	50 (32)	11 (24)	8 (31)	184 (34)	117 (28)	**1.44 (1.05–1.96)**	**.022**
Orgasm – Pleasure	1 (2)	29 (11)	9 (6)	2 (5)	1 (4)	42 (8)	21 (5)	1.30 (0.72–2.36)	.387
Vaginal Lubrication	3 (6)	65 (24)	37 (23)	5 (11)	6 (22)	116 (21)	30 (7)	**3.10 (1.96–4.91)**	**<.001**
Vaginal Discomfort	3 (6)	52 (20)	39 (24)	4 (8)	4 (15)	102 (18)	35 (8)	**3.02 (1.92–4.76)**	**<.001**
Vulvar Discomfort-Clitoral	7 (13)	72 (26)	32 (20)	7 (15)	4 (17)	122 (22)	66 (16)	**1.83 (1.26–2.76)**	**.002**
Vulvar Discomfort-Labial	9 (17)	96 (36)	32(20)	14 (29)	6 (23)	157 (28)	80 (19)	**1.55 (1.11–2.18)**	**.010**
Dysfunction ≥ 1 domain[b]	37 (56)	240 (69)	116 (61)	24 (42)	21 (66)	438 (63)	263 (53)	**1.37 (1.06–1.78)**	**.017**
Dysfunction ≥ 2 domains[b]	9 (16)	110 (40)	54 (33)	9 (19)	9 (33)	191 (33)	77 (18)	**1.97 (1.42–2.74)**	**<.001**

CI: Confidence interval.
Valid percentages for women having had sexual activity (partner/solo sex) during the past 30 days.
Statistically significant ($p < 0.05$) differences in the logistic regression multivariable models indicated in bold; regression models adjusted for socio-demographics (age at study, education, relationship status, having children and country of birth).
[a]Sexual dysfunction defined as cut-off = 1 SD above/below the t-score mean of the norm population.
[b]Based on reports for the domains: Satisfaction with Sex Life, Interest in Sexual Activity, Orgasm – Ability, Orgasm – Pleasure, Vaginal Lubrication.

Prevalence of sexual dysfunction

More than 60% of the women with cancer (all diagnoses) reported sexual dysfunction in at least one of eight of the measured domains, see Table 3. Women with cancer reported most problems with regard to lack of interest in sexual activity (45%), ability to reach orgasm (34%), satisfaction with one's sex life (22%), and vulvar discomfort (22 and 28%, clitoral and labial respectively). Women with cancer were more likely to report dysfunction in each of the measured domains with the exception of Orgasm – Pleasure, than women in the comparison group (Table 3). The analyses comparing women with cancer to the general population sample were adjusted for age, education, relationship status, having children and country of birth. Additional comparative analyses showed that women with reproductive cancers (breast, cervical, ovarian) reported more sexual dysfunction than the general population, while women with brain tumors and lymphoma did not differ from the comparison group, Table 4. The descriptive results of sexual function are also presented with mean values (Supplementary Table 3).

Factors associated with sexual dysfunction in women with cancer

Factors associated with sexual dysfunction are shown in Table 5. The included clinical variables, treatment intensity and cancer type, both showed to be associated with rating low interest in sexual activity, and reporting dysfunction ≥ 2 domains. Additionally, when lymphoma was used as reference group, women with cervical and ovarian cancer were three and almost five times, respectively, more likely to report low satisfaction with their sex life. Furthermore, those diagnosed with breast and gynecological cancers were more likely than those with lymphoma to report sexual dysfunction in ≥ 2 domains. Regarding psychological factors, ratings of emotional distress and body image disturbance were related to dysfunction in most of the investigated domains.

Table 4. Differences in prevalence of sexual dysfunction[a] between women with reproductive cancers (breast, cervical, ovarian) and non-reproductive cancers (brain tumor, lymphoma) and a comparison group, respectively.

Dysfunction related to domains	Reproductive cancers $n = 571$ *n* (%)	Comparison group $n = 493$ *n* (%)	OR (95% CI)	Non-reproductive cancers $n = 123$ *n* (%)	Comparison group $n = 493$ *n* (%)	OR (95% CI)
Satisfaction with Sex Life	113 (24)	51 (12)	**2.47 (1.62–3.77)**	15 (15)	51 (12)	1.26 (0.67–2.38)
Interest in Sexual Activity	271 (48)	156 (32)	**1.62 (1.22–2.16)**	39 (32)	156 (32)	0.92 (0.59–1.43)
Orgasm – Ability	161 (36)	117 (28)	**1.74 (1.24–2.44)**	23 (23)	117 (28)	0.81 (0.48–1.36)
Orgasm – Pleasure	39 (9)	21 (5)	1.72 (0.91–3.28)	3 (3)	21 (5)	0.61 (0.17–2.16)
Vaginal Lubrication	108 (23)	30 (7)	**4.25 (2.60–6.96)**	8 (8)	30 (7)	1.18 (0.51–2.70)
Vaginal Discomfort	95 (21)	35 (8)	**4.27 (2.60–7.01)**	7 (7)	35 (8)	0.91 (0.39–2.15)
Vulvar Discomfort-Clitoral	108 (23)	66 (16)	**2.43 (1.60–3.68)**	14 (14)	66 (16)	0.92 (0.54–1.97)
Vulvar Discomfort-Labial	134 (29)	80 (19)	**1.72 (1.19–2.46)**	23 (22)	80 (19)	1.32 (0.77–2.25)
Dysfunction ≥1 domain[b]	377 (66)	263 (53)	**1.69 (1.27–2.24)**	61 (50)	263 (53)	0.81 (0.54–1.22)
Dysfunction ≥2 domains[b]	173 (37)	77 (18)	**2.50 (1.76–3.54)**	18 (18)	77 (18)	0.87 (0.54–1.69)

CI: Confidence interval.
Valid percentages for those women having had sexual activity (partner/solo sex) the past 30 days.
Statistically significant ($p < 0.05$) differences in the logistic regression multivariable models indicated in bold; regression models adjusted for socio-demographics (age at study, education, relationship status, having children and country of birth).
[a]Sexual dysfunction defined as cut-off = 1 SD above/below the t-score mean of the norm population.
[b]Based on reports for the domains: Satisfaction with Sex life, Interest in Sexual Activity, Orgasm – Ability, Orgasm – Pleasure, Vaginal Lubrication.

Finally, higher age among women with cancer was related to dysfunction in the domains Satisfaction with Sex Life and Vaginal Lubrication, as well as rating dysfunction in ≥2 domains.

Discussion

This is one of the largest population-based studies of sexual function ever conducted in young women following cancer. More than 60% of the approximately 700 participants reported sexual dysfunction in at least one domain about 1.5 years post-diagnosis. Comparing them to a group of women of similar age with no history of cancer, the women with cancer reported significantly more problems across domains, while being equally sexually active. Women with gynecological or breast cancer and those receiving more intense treatment were at particular high risk of sexual dysfunction (≥2 domains). Concurrent emotional distress and body image disturbance were associated with more dysfunction.

There is a limited body of knowledge about womens' sex life following a diagnosis with cancer in young adulthood and the existing research is dominated by breast cancer studies. Our number of women with cancer (all diagnoses) that were sexually active (83%) are in line with [5] or slightly higher [6,7] than those reported for large samples of women with breast cancer, during the first three years following diagnosis. Among those who had not been sexually active with a partner, the women with cancer were more likely than the women of the comparison group to associate this with vaginal dryness or pain, and feeling unattractive; all three reasons potentially related to cancer treatment. While our results of overall high sexual activity are reassuring, the high prevalence of problems among sexually active women, as well as potentially cancer-related reasons for not having partner sex, emphasize the need for support and information from health care providers [30].

More than half of the women with cancer (63%) reported sexual dysfunction in at least one domain and close to half rated low interest in having sex (Table 3). With the exception of women with lymphoma, mean values for all diagnoses indicated problems of clinical relevance (>0.5 SD) [31] for the domain Interest in Sexual Activity (Supplementary Table 3). In all but one of the measured domains, the total group of women with cancer rated more sexual dysfunction than the comparison group randomly drawn from the general population and approached for this specific study (Table 3). This is related to cancer type; women with gynecological and breast cancers reported more sexual dysfunction than the general population, while women with brain tumors and lymphoma did not differ from the comparison group (Table 4).

Women with breast cancer in the present study rated slightly less sexual dysfunction than previously reported from Sweden [11] but higher when compared to results from the United States [6]. Our results of women with cervical cancer show problems in line with previous results even though previous studies have predominately investigated early disease stages [32,33]. A majority of our population-based sample of women with cervical and ovarian cancer, experienced a negative impact on their sex life as indicated by more than 60% reporting sexual dysfunction (≥1 domain). As our results of women with brain tumors and lymphoma were based on small samples the findings should be interpreted with some caution, but they clearly indicate that these groups have less problems with regard to sexual function. This appears to be particularly true for young women diagnosed with lymphoma who did not demonstrate a higher risk of a negative impact on sex life in the measured domains than women in general. This contrasts to previous findings of young as well

Table 5. Factors associated with sexual dysfunction in 5 domains among 694 women with cancer.

Factors	Satisfaction with Sex life		Interest in Sexual Activity		Orgasm – Ability		Orgasm – Pleasure		Vaginal Lubrication		≥2 domains above cutoff	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Age at study[a]	**1.07**	**1.02–1.14**	1.04	1.00–1.08					**1.06**	**1.01–1.11**	**1.08**	**1.03–1.13**
Country of birth												
Other vs. Sweden (ref)			1.35	0.85–2.12								
Relationship status												
No partner vs. partnered (ref)	**2.23**	**1.16–4.27**										
Treatment intensity												
Very/most vs. least/moderately (ref)	1.50	0.88–2.57	**1.78**	**1.20–2.64**					1.22	0.77–1.93	**2.13**	**1.33–3.93**
Type of cancer												
Lymphoma (ref)												
Breast cancer	2.31	0.85–6.25	**2.62**	**1.31–5.26**	**2.80**	**1.32–5.92**					**2.62**	**1.10–6.20**
Cervical cancer	**3.08**	**1.06–8.92**	**2.99**	**1.41–6.35**	1.98	0.88–4.42					**4.15**	**1.64–10.50**
Ovarian cancer	**4.84**	**1.24–18.98**	2.79	1.00–7.78	1.69	0.54–5.23					**3.55**	**1.03–12.28**
Brain tumors	2.37	0.70–8.09	2.14	0.91–5.03	1.19	0.44–3.21					1.57	0.51–4.80
Emotional distress	**1.07**	**1.03–1.10**	**1.04**	**1.01–1.07**	**1.07**	**1.03–1.10**	**1.09**	**1.03–1.14**	**1.04**	**1.00–1.04**	**1.07**	**1.04–1.11**
Body image disturbance	**1.06**	**1.02–1.10**	**1.04**	**1.01–1.07**	1.02	0.99–1.05	1.03	0.99–1.05	**1.05**	**1.02–1.08**	**1.05**	**1.02–1.08**

OR: Odds Ratio.
CI: Confidence Interval.
[a]Age is treated as a continuous variable in the models.
Statistically significant ($p < .05$) factors in the multivariable models indicated in bold; models only include the factors associated with sexual dysfunction in the specific domain in bivariate analyses.
All models were adjusted for self-reported assessment of satisfaction with sex life prediagnosis.

as older women with lymphoma [34] and points to the need for more research in this group. Few studies have investigated sexual function in young women diagnosed with brain tumors and those published have small selected samples, still, they all indicate that sexual dysfunction is highly prevalent among patients with low-grade glioma [35]. We recommend future studies of sexual health to focus on young women with brain tumors for increased understanding of their possible problems and needs.

The present finding that intensity of treatment was related to sexual dysfunction is in line with some studies [11,36], while another study reports no such relation [8]. Our finding is not surprising as more intensive treatment can trigger menopause and thereby impact on sexual function [4,37]. Additionally, radiotherapy for cervical cancer may damage the vaginal mucosa leading to persistent vaginal changes (fibrosis, shortening and dryness) contributing to sexual dysfunction. Within the group of women diagnosed with cancer before the age of 40, those of higher age reported more dysfunction, as previously reported [8,9].

Emotional distress and body image disturbance were associated with sexual dysfunction in most domains and also for rating dysfunction in more than one domain. These specific psychological factors have repeatedly shown to be associated with negative impact on sexual function in young women with cancer [8,9,11].

The predictors and factors associated with sexual dysfunction were all in line with the elements described in Bober's and Valera's conceptual model [4]. The biological factors, in our study reflected by clinical diagnosis and treatment intensity, the psychological factors assessed as emotional distress and body image concerns, and interpersonal factors illustrated in our study by partnership and perception of one's sex life before getting cancer, were all associated with sexual dysfunction.

Clinical implications

Our results with two out of three women experiencing sexual dysfunction and the problems being related to the received cancer treatment and emotional distress, underscore the need for the healthcare to routinely address these issues in women with cancer. In a collaborative discussion with each patient, problems related to sex and intimacy can be identified and actions to deal with them planned. Although this is typically the physician's responsibility, educational interventions indicate that nurses also may have an important role in this area [38]. Such a discussion corresponds to the initial step of the PLISSIT model's four steps (Permission, Limited Information, Specific Suggestions, and Intensive Therapy). According to this framework, the first step of permission-giving, acknowledging that thinking and worrying about sex-related issues are common, is considered to be a key element in all the steps. With regard to specific suggestions, women with symptoms of vaginal and/or vulvar atrophy should be recommended to regularly use lubricants and vaginal moisturizers for sexual activity and touch [30,39]. Additionally, women with hormone-positive breast cancer may be considered for low-dose vaginal estrogen, after

thoroughly reviewing risks and benefits [30,37]. Furthermore, a recent study on women younger than 50 years treated for cervical cancer with more intensive treatment (radiotherapy), found that regularly use of hormone replacement therapy (HRT) and/or low-dose vaginal estrogen was associated with significantly less vaginal dryness, vaginal shortening and pain during intercourse [40]. Therefore, most young women with cervical, and also ovarian cancer, who have received treatment that has trigged an early menopause, should be prescribed HRT and/or low-dose estrogen until age of natural menopause, which is also recommended in guidelines [41,42].

Psychosexual interventions may include counseling of the individual woman, couple therapy or be delivered in a group format [37]. Based on the results showing that non-partnered women were less satisfied with their sex life, interventions should include components to also meet the needs of women without a partner. Furthermore, as body image disturbance and emotional distress were found to be associated with sexual dysfunction in the present and previous studies, these aspects need to be integrated in psychosexual interventions.

Methodological considerations

This population-based study has several methodological strengths and also a few limitations to be considered. First, with a large sample identified through national quality registries, we were able to approach the total cohort of patients with selected diagnoses and retrieve clinical data for responders as well as non-responders. The total response-rate among women with cancer was high (72%); however, the lower participation rate of women with ovarian cancer limits the possibility to draw conclusions about their situation, and emphasizes the need for further studies in this group of women. Furthermore, we do not know if those accepting participation were more sexually active and had less sex problems than those not participating, potentially overestimating sexual activity and function. Second, we included a large comparison group drawn from the general population, approached for this specific study and assessed with the same measures as the study sample, enabling us to draw conclusions regarding prevalence of sexual dysfunction. However, the relatively low response rate (51%) of the comparison group constitutes a possible source of bias. Third, by categorizing all eligible patients' treatment intensity with a valid measure (ITR-YA) [28], we could take clinical characteristics into consideration across diagnoses. Additionally, we used standardized instruments, psychometrically evaluated in people with cancer, for measurement of primary and secondary outcomes. The cut-off for sexual dysfunction was based on the sexually active American general population, which may differ from the Swedish, even though many aspects are similar between the countries including the age for sexual debut [43].

Conclusion

A majority of women diagnosed with cancer before the age of 40 experience sexual dysfunction and they do so to a significantly higher extent than young women of the general population. We have identified groups more likely to report sexual dysfunction; women diagnosed with breast or gynecological cancer, those receiving intensive treatment, and women rating emotional distress and body image disturbance. Our results underscore the need to routinely assess sexual health in clinical care and follow-up. In addition to offering counseling and aids we recommend development of specific interventions directed to women.

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Disclosure statement

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Data availability statement

The data that support the findings of this study are available from the corresponding author [LW], upon reasonable request.

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