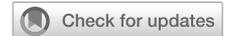


ONCOLOGY

Sexual Inactivity During the Last 4 Weeks in Long-Term Cervical Cancer Survivors: Prevalence and Associated Factors



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ABSTRACT

Background: Most studies of cervical cancer (CC) survivors describe sexual inactivity in relation to treatment modalities, but few consider that inactivity varies with age and partner status.

Aim: The aim of this study was to investigate the prevalence of sexual inactivity in long-term CC survivors according to age and partner status, and to examine cancer-related, health, demographic, and psychological factors related to sexual inactivity.

Methods: All 974 women treated for CC from 2000 through 2007 in 2 areas of Norway, who were alive and cancer-free by the end of 2013, received a mailed questionnaire. Among them, 523 delivered valid data on current sexual activity (response rate 57%). The prevalence rates of sexual inactivity in relation to age groups and partner status were compared to normative sample (NORMs).

Main Outcome Measure: Sexual inactivity during the 4 weeks before the survey was administered.

Results: Median age of the sample at survey was 53 years (range 32–77) and median time since diagnosis was 11 years (range 6–15). Of the survivors aged 35–69 years, 39% (95% CI 35–44%) were sexually inactive at survey compared to 36% (95% CI 32–38%) in the NORMs. Compared with sexually active survivors, inactive ones were significantly older, more frequently had single partner status, and had less frequently been childbearing. Inactive survivors more frequently had low education, did not hold paid work at survey, had poorer self-rated health, and were more often obese. They also had higher prevalence of depression, high neuroticism, and chronic fatigue. On most cancer-related quality of life measures, sexually inactive survivors had significantly lower mean scores than sexually active ones. They significantly more often had been treated with chemotherapy and/or radiation than with conization or major surgery. In multivariable regression analysis, only older age, no prior childbearing, and single partner status remained significantly associated with sexual inactivity.

Clinical implications: Sociodemographic variables may be more relevant than clinical and cancer-related variables concerning sexual inactivity in long-term CC survivors.

Strengths & Limitations: Our study had a considerable sample size and used instruments with established psychometric qualities. The moderate response rates of the study and of the NORMs imply risks for selection biases.

Conclusion: Close to 4 in 10 survivors were sexually inactive which is similar to the rate among NORMs. Demographic factors were most strongly associated with sexual inactivity. Some other significant factors are eventually amenable to treatment and should be checked by the health-care providers. **Dahl AA, Bentzen AG, Fosså SD, et al. Sexual Inactivity During the Last 4 Weeks in Long-Term Cervical Cancer Survivors: Prevalence and Associated Factors. J Sex Med 2020;17:1359–1369.**

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Key Words: Cervical Cancer; Sexuality; Long-Term Survivors; Sexual Inactivity

INTRODUCTION

Women with cervical cancer (CC) are exposed to a wide range of treatment modalities depending on tumor stage: conization, major surgery, radiation and chemotherapy, as well as combinations of them. The ensuing treatment-related damage to the vulvovaginal area varies considerably. Besides reproduction, sexual activity is a source of excitement, intimacy with a beloved partner, drive satisfaction, and release of emotional tension. Therefore, lack of sexual activity can be considered as a major sexual problem, and termination of such activity often implies negative consequences for partnered relationship and health-related quality of life (HRQoL) of patients who become inactive.¹ Many studies of CC survivors have documented high prevalence of sexual problems, mostly relating such problems to treatment modalities and somatic damage.^{2–4}

Studies of the general female population in Western countries have shown variable prevalence rates of sexual inactivity with much increased rates in women without partners and with increasing age.^{5–7} Poorer health status, obesity, physical inactivity, and smoking are also significantly associated with higher prevalence of sexual inactivity among women in the population.^{5,8} Studies reporting sexual inactivity among CC survivors usually provide a total prevalence rate without specifications related to age groups or partner status, and several of them lack normative control groups. To substantiate, here are 3 examples. One uncontrolled study reported that 18% of survivors were sexually inactive at a mean age of 52 years, 14 years after diagnosis, with 67% being married, 64% treated for stage I disease, and 90% after any type of surgery. Sexual inactivity was significantly related to low income, but not to age, education, or hysterectomy alone vs combinations with other treatment (ovary removal, radiation, or hormones).⁹ Another controlled study of 51 survivors found that 31% were sexually inactive at a mean age of 45 years, 8 years after diagnosis, with 61% being married. Among cancer-free controls with a mean age of 41 years, and 78% being married, the inactivity rate was 20% ($P = .26$, unadjusted for differences in mean age and marriage rate). In that sample, 81% had hysterectomy and 19% hysterectomy + oophorectomy.¹⁰ In our own group, we reported on 79 Norwegian survivors treated by pelvic radiotherapy, where 70% were sexually inactive at a mean age of 62 years, 8 years after diagnosis, and 59% had a partner. In the normative control sample, 53% were sexually inactive ($P = .12$).¹¹ None of these studies presented multivariable analyses of factors related to sexual inactivity among survivors.

On this background, our cross-sectional questionnaire study of a cohort of Norwegian long-term CC survivors has 2 aims: (i)

to explore the prevalence of sexual inactivity at the time of the survey according to age groups and partner status and to compare these findings to female normative sample; and (ii) in univariable and multivariable analyses to examine the associations of medical, CC-related, demographic, health, psychological factors, and CC-specific HRQoL in relation to sexual inactivity.

METHODS

Patient Sampling

The sampling procedure has been described previously.¹² Briefly, the Cancer Registry of Norway identified all women with CC diagnosed between January 1, 2000 and December 31, 2007 and treated at hospitals located in the Health Regions of South-Eastern and Northern Norway (3.4 million inhabitants). This study included 974 survivors considered tumor-free and not on any cancer treatment as of December 31, 2012. In 2015 they were mailed a questionnaire covering cancer-related, demographic, and health-related issues. The response rate was 57%, but we omitted 23 survivors who did not complete the principal sexual activity item, and, therefore, our study sample consisted of 523 survivors.

Treatment for CC in Norway 2000–2007

The treatment alternatives have also been described previously.¹² Women with minimal disease (International Federation of Gynecology and Obstetrics [FIGO] stage Ia) were treated with conization (conization group). Patients with disease of limited volume (FIGO stage Ib–IIa) usually had radical hysterectomy with pelvic lymph node dissection with or without bilateral salpingo-oophorectomy (major surgery group). Patients with locally advanced disease (FIGO stage IIb–IVa) were treated by external-beam pelvic radiation to the tumor and the regional lymph nodes, combined with intracavitary brachytherapy (chemoradiotherapy group).¹³ In addition, low-dose cisplatin-containing chemotherapy was given concomitantly to enhance the efficacy of the radiation.¹⁴ Another group either received neoadjuvant chemotherapy followed by major surgery, or had other combinations of major surgery and external beam pelvic radiation along with chemotherapy (major surgery + chemoradiotherapy group).

Main Outcome measure: Sexual Inactivity

The Current Sample

Item #19 of The European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire-CX24: “Have you been sexually active during the past 4 weeks?”

Table 1. Characteristics of sexually inactive and sexually active long-term cervical cancer survivors

Variables	Sexually inactive (N = 214)	Sexually active (N = 309)	P-value	Total sample (N = 523)
Age at diagnosis (years), median (range)	46 (26–68)	39 (24–68)	<.001	41 (24–68)
Time diagnosis to survey, median (range)	11 (6–15)	11 (7–15)	.13	11 (6–15)
Treatment modalities, N (%)				
Any radiotherapy	89 (42)	65 (21)	<.001	154 (29)
External radiotherapy	86 (40)	63 (20)	<.001	149 (29)
Brachytherapy	70 (33)	42 (14)	<.001	102 (21)
Relapse, N (%)	21 (10)	22 (7)	.12*	43 (8)
Another cancer, N (%)	24 (11)	16 (5)	.10*	40 (8)
Current HRT use, N (%)	42 (20)	74 (24)	.31*	117 (22)
Age at survey (years), median (range)	57 (36–76)	50 (32–77)	<.001	53 (32–77)
Level of education, N (%)				
≤12 years	73 (34)	155 (50)	.022*	228 (44)
>12 years	139 (66)	152 (50)		291 (56)
Partner status, N (%)				
Married, living together	116 (55)	246 (80)	<.001*	362 (70)
Single, widow, divorced	97 (45)	62 (20)		159 (30)
Childbearing, N (%)	105 (49)	194 (63)	.002*	299 (57)
Income status at survey, N (%)			<.001	
Paid work	112 (53)	225 (73)	<.001	337 (65)
Disability pension	37 (17)	40 (13)	.17	77 (15)
Retirement pension	47 (22)	25 (8)	<.001	72 (13)
Other statuses	17 (8)	18 (6)	.38	35 (7)
Work ability at survey, mean (SD)	6.0 (3.5)	7.5 (3.3)	<.001*	6.9 (3.4)
Charlson's comorbidity index, N (%)			.07*	
0 points	116 (54)	212 (69)		328 (63)
1 point	71 (33)	25 (24)		146 (28)
≥2 points	27 (13)	22 (7)		49 (9)
Current self-rated health, N (%)			<.001*	
Excellent to good	136 (64)	249 (81)		386 (74)
Moderate to poor	76 (36)	59 (19)		135 (26)
Obesity, N (%)	45 (22)	37 (12)	.005*	82 (16)
Daily smoking, N (%)	49 (24)	54 (18)	.22*	103 (20)
HADS-anxiety sum score ≥8, N (%)	86 (40)	112 (36)	.20*	198 (38)
PHQ-9 depression sum score ≥10, N (%)	58 (27)	41 (13)	<.001*	99 (19)
Chronic fatigue, N (%)	85 (31)	64 (21)	.002*	129 (25)
Neuroticism score ≥3 points, N (%)	97 (46)	108 (35)	.01*	205 (40)
Changed sexual function, N (%)	59 (28)	70 (23)	.21	129 (25)

HADS = Hospital Anxiety and Depression Scale; HRT = hormone replacement treatment; PHQ = Patient Health Questionnaire.

Significant *P* values are set in bold types.

*Adjusted for age at survey.

represented the principal sexual variable, and there were 4 response alternatives: 1 (“not at all”), 2 (“a little”), 3 (“quite a bit”), and 4 (“very much”). The responses were dichotomized so that survivors who reported “not at all” were defined as “sexually inactive,” while those who reported “a little” or more were classified as “sexually active.”¹⁵

The Normative Sample (NORMs)

The Sexual Activity Questionnaire (SAQ)⁷ includes the item: “Do you engage in sexual activity with anyone now?” with the response alternatives “yes” or “no.” Women who responded with

“no” were considered as sexually inactive. The NORMs was based on a target population of 2,800 Norwegian women aged 20–69 years who received a mailed questionnaire. Among them 1,165 (42%) returned a valid questionnaire. We have previously published the SAQ findings from this sample, and the age groups 35–44, 45–55, and 56–69 years and their total were relevant for comparisons with our survivors' sample.⁷ For this study, we divided the NORMs age groups into women with a partner vs those without one (Table 2).

It is important to note that neither the CX24 nor the SAQ item specifies the relevant sexual activity further. Anything

Table 2. Prevalence of sexual inactivity among CCSs and NORMs according to age groups

Groups	35–44 years N (%)	45–55 years N (%)	56–69 years N (%)	Total sample N (%)
All women				
CCSs	32/109 (29.4)*	64/189 (33.9)	87/168 (51.8)	183/466 (39.3)
NORMs	35/213 (16.4)	78/283 (27.6)	214/405 (52.8)	327/901 (36.3)
Women with partner				
CCSs	20/85 (23.5)*	34/125 (27.2)	48/117 (41.0)	102/327 (31.2)
NORMs	23/198 (11.6)	36/235 (15.5)	107/296 (36.1)	166/729 (22.8)
Women without partner				
CCSs	12/24 (50.0)	29/62 (46.8)*	39/51 (76.5)*	80/137 (58.4)*
NORMs	12/15 (80.0)	42/48 (87.5)	107/109 (98.2)	161/172 (93.6)
CCSs				
With partner	20/85 (23.5)*	34/125 (27.2)*	48/117 (41.0)*	102/327 (31.2)*
Without partner	12/24 (50.0)	29/62 (46.8)	39/51 (76.5)	80/137 (58.4)
NORMs				
With partner	23/198 (11.6)*	36/235 (15.5)*	107/296 (36.1)*	166/729 (22.8)*
Without partner	12/15 (80.0)	42/48 (87.5)	107/109 (98.2)	161/172 (93.4)

CCSs = cervical cancer survivors; NORMs = normative sample.

Significant *P* values are set in bold types.

*Vertical comparisons *P* < .05.

considered as sexual activity by the respondents could be performed alone as well as with one or more partners. We could not further specify types of sexual activity. Since the CX24 item specifies the time frame of 4 weeks, while the SAQ item seems to imply just at the time when the survivors completed the questionnaire, our definitions of sexual inactivity and activity concerned the last 4 weeks before the time of the survivors' response to the survey.

Scales

All the scales used in this study had tested psychometric properties concerning reliability and validity.

CC-specific HRQoL (European Organization for Research and Treatment of Cancer CX24)—the CX24 consists of 24 items that for all survivors could be reported as 2 scales (symptom experience and body image) and 4 single items (lymphedema, peripheral neuropathy, menopausal symptoms, and sexual worry). 5 items (#50–54) are only relevant for sexually active survivors with the sexual/vaginal function scale, and the sexual enjoyment item. For the analyses, all subscale scores and single item ratings were transformed to 0–100, where higher scores on the scales and on single items represented higher symptom intensity.¹⁵ For the subscales, Cronbach's coefficient alpha was 0.67 for symptom experiences, 0.86 for body image, and 0.78 for sexual/vaginal functioning. *The Fatigue Questionnaire* measured fatigue severity and included items concerning mental (4 items) and physical fatigue (7 items), and their sum (total fatigue) for the last 4 weeks. Each item was rated from 0 (“as before”) to 3 (“very much worse”). An additional item covered the duration of the fatigue experience with one response alternative being “6 months or more.”¹⁶ Concerning chronic fatigue, a dichotomized score for each response alternative (0 = 0, 1 = 0, 2 = 1, 3 = 1) was

used, and chronic fatigue was defined as a dichotomized sum score of ≥ 4 with a duration of ≥ 6 months. Alpha was 0.90 for total fatigue.

The Hospital Anxiety and Depression Scale comprised 7 items each on the anxiety and depression subscales rated for last week. The item scores ranged from 0 (“not present”) to 3 (“highly present”), providing a 0–21 severity score. Only the anxiety subscale was adopted, and alpha was 0.66. A probable case of anxiety disorder had a sum score ≥ 8 .¹⁷

The Patient Health Questionnaire-9 contained 9 items covering depression for the last 2 weeks, and each item was scored from 0 (“not at all”) to 3 (“nearly every day”), providing a 0–27 severity score. A probable case of major depressive episode had a sum score ≥ 10 . Alpha was 0.87.¹⁸

Current work ability was compared to the lifetime best on a continuous 10 points Numerical Rating Scale from 0 (“currently not able to do work”) to 10 (“work ability as previous life-time best”) from the Work Ability Index instrument.^{19,20} *Neuroticism* was self-rated on an abridged version of the Eysenck Personality Questionnaire with 6 items concerning long-term personality characteristics. Each item was rated as 1 (“present”) or 0 (“absent”). The sum score ranged from 0 to 6 and was dichotomized into high (sum score 3–6) and low neuroticism (sum score 0–2) groups according to the use in the third Health Study of North-Trøndelag County (The HUNT-3 study).²¹

Other Variables

Sociodemographic

Partner status was dichotomized as married or living together (with partner) vs single, divorced, or widow (without partner).

Having had children was rated as yes or no. Level of education was dichotomized into low (≤ 12 years) and high (> 12 years). Income status at the time when the survey was administered was classified as paid work, disability pension, retirement pension, or other statuses.

Comorbidity was based on self-report of diseases described in the Charlson's Comorbidity Index²² where myocardial infarction, congestive heart failure, stroke, diabetes, chronic obstructive lung diseases, ulcer disease, connective tissue diseases all get 1 point, and kidney disease 2 points. We defined 3 comorbidity groups: none (0), 1, and ≥ 2 points.

Self-rated health was dichotomized according to response alternatives into good ("excellent"/"very good"/"good") and poor ("fair"/"poor"). Lifestyle issues included smoking any number of cigarettes daily. Obesity was defined as a body mass index ≥ 30 . Experience of changed sexual function or not after treatment for CC was recorded as yes or no. Current use of hormone replacement treatment (HRT) was noted, but no other information concerning medication was collected.

Statistical Evaluation

Group comparisons of continuous variables were carried out with t-tests, and in case of skewed distributions Mann-Whitney *U* tests were used. Comparisons of categorical variables were performed with chi-square tests. Since the sexually inactive group showed significantly higher median age compared to the active group, age-related group comparisons were adjusted for age at the time the survey was administered. The internal consistencies of scales were examined with Cronbach's coefficient alpha. Associations between independent variables and sexual inactivity vs sexual activity (reference) as the dependent variable were examined with univariate and multivariable logistic regression analyses. The strength of associations was expressed as odds ratios with 95% CI as appropriate. Variables included in the multivariable analysis were tested for multicollinearity, which only was present for work-related variables. The *P*-value was set as $< .05$, and all tests were 2-sided. The statistical software applied was SPSS version 25 for PC (IBM Corporation, Armonk, New York, USA).

Ethical Considerations

The Regional Committee for Medical and Health Research Ethics of South-Eastern Norway has approved the study. All survivors gave written informed consent when returning their questionnaires. They were not economically compensated.

RESULTS

Description of the Total Sample

The median age at diagnosis was 41 (range 24–68) years, median age at survey was 53 (range 33–77) years, and median time from diagnosis to survey 11 (range 6–15) years. Further, characteristics of the total sample are displayed in Table 1. Of the total sample, 41% (95% CI 37–45%) of survivors reported

sexual inactivity and 59% (95% CI 55–63%) reported sexual inactivity during the last 4 weeks. In all 25% reported changed sexual function after their treatment for CC, implicating that 75% of survivors had unchanged sexual function. The prevalence of sexual inactivity was 26% in the conization group, 35% in the major surgery group, 62% in the chemoradiotherapy group, and 49% in the major surgery + chemoradiotherapy group. Only the latter 2 treatment groups differed significantly from the NORMs prevalence concerning sexual inactivity ($P < .001$ and $P = .012$, respectively). Among sexually inactive survivors, 42% had any form of radiotherapy, while that proportion was 21% among sexually active survivors ($P < .001$). HRT was used by 22% of the total sample at the time of the survey.

Comparisons with NORMs

The prevalence of sexual inactivity among the total sample of survivors aged 35–69 years was 39% (95% CI 35–44%), while among NORMs of the same age group 36% (95% CI 32–38%) were inactive ($P = .32$) (Table 2). For the 35–44 years group, the prevalence rates of sexual inactivity were significantly higher than NORMs for all survivors and for survivors with a partner.

Survivors without a partner had significantly lower prevalence of sexual inactivity in the 45–55 and 56–69 years age groups and the total group compared to NORMs. Both for survivors and for NORMs the prevalence of sexual inactivity increased with older age. All age groups of survivors without a partner had significantly higher prevalence of sexual inactivity than those with a partner. The same prevalence pattern was found among NORMs.

Comparisons of the Sexually Inactive and Active Survivor Groups

Median age at survey of the inactive group was 57 years vs 50 years in the active group ($P < .001$). Consequently, age-related between-group comparisons were adjusted for age at the time of the survey in Table 1. Figure 1 shows that the inactive group had significantly more chemoradiotherapy treatment and significantly less conization than the sexually active group.

Table 1 further shows that among the sexually inactive survivors significantly more were unmarried, divorced, or widows, and a lower proportion had given birth than among sexually active survivors. At the time of the survey, significantly fewer of the inactive group were in paid work, and they had significantly lower mean work ability compared to the sexually active group. No significant between-group differences were observed concerning comorbidity or the current use of HRT, while a higher proportion among those sexually inactive reported fair or poor self-rated health. Obesity was significantly more common in the inactive group, and survivors belonging to that group reported higher prevalence rates of depression, chronic fatigue, and high neuroticism. For CC-specific HRQoL (CX24), the sexually inactive survivors had significantly more problems with cramps

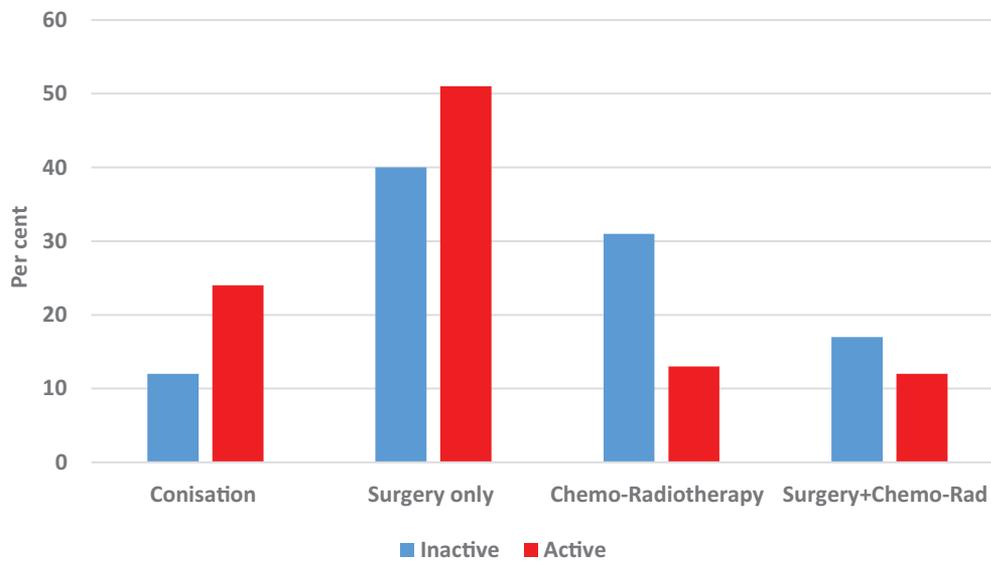


Figure 1. Percent of sexually inactive and active survivors according to treatment group. Significant between-group differences for conization ($P < .001$) and chemoradiotherapy ($P < .001$). Figure 1 is available in color online at www.jsm.jsexmed.org.

in the abdomen, swelling of the leg(s), and low back pain than the active group (Table 3). In addition, they felt less attractive and feminine, were more dissatisfied with their bodies, and more frequently worried that sex would be painful than the sexually active survivors. The mean scores on body image and lymphedema were significantly worse in the inactive than in the sexually active group (Table 3). Among the sexually active survivors, 73% found sex enjoyable.

Bivariate and Multivariable Regression Analyses

In the bivariate analyses, significant between-group differences were observed within the CC-related, demographic, health and lifestyle, psychological, and HRQoL domains (Table 4). In the multivariable analysis, only the demographic variables remained significantly associated with being a sexually inactive survivor: older age, having single civil status, and less frequently had children.

DISCUSSION

In our sample of long-term CC survivors diagnosed and treated for CC at a median of 11 years earlier, 41% (age range 33–77 years) reported that they had been sexually inactive during the last 4 weeks. For the 35–69 years age group, the prevalence among survivors was 39% and did not differ significantly from the 36% reported by NORMs. For both survivors and NORMs, the rate of sexual inactivity increased with age. The survivors with partners had a significantly higher rate of sexual inactivity compared to NORMs for the 35–44 year group, but with similar rates for NORMs and survivors in the older age groups. Survivors without a partner had a significantly lower rate of sexual inactivity than NORMs for the 45–55 and 56–69 year groups. These latter findings are counterintuitive,

and they concern the sampling bias of the NORMs covered in the Strengths and Limitations section.

Among the survivors, sexual inactivity was significantly associated with cancer-related, demographic, self-reported health, psychological factors, and CC-specific HRQoL in the bivariate analyses. However, only 3 demographic variables remained significantly associated with sexual inactivity in the multivariable analysis: older age, no partner status, and no childbearing. Factors like overall treatment modalities, self-rated health, fatigue, or mental distress showed weaker associations with sexual inactivity among survivors.

Only 25% of survivors reported change of sexual function after treatment with no significant differences between active and inactive survivors. This finding indicates that sexual function established before the CC and its treatment continues later in most of the survivors. A Danish sample treated with only radiotherapy reported that 63% of those who were sexually active before treatment remained active but with less frequency at 12 months after treatment.²³

Our findings of similar overall rates of sexual inactivity in survivors and normative control samples are in line with some previous studies,^{7,24,25} but these studies do not specify age groups like we do. We observed that the prevalence of sexual inactivity among survivors was significantly higher than for NORMs in the age group 35–44 and 45–55 years. For the 56–69 years group, the prevalence was similar, most probably due to the increasing rate of sexual inactivity reported by older women in general.^{5,6} Sexual inactivity before the age of 55 years is more common among survivors than NORMs and may represent a clinical problem for them.

Like previous studies we observed that the chemoradiotherapy group was significantly associated with sexual inactivity. This could be due to the associated prevalence of chronic fatigue as

Table 3. The EORTC cervical cancer module (CX24) items score as “quite a bit” or “very much” and mean (SD) in the sexually inactive and active groups

Variables	Sexually inactive (N = 214) N (%)	Sexually active (N = 309) N (%)	P-value	Total sample (N = 523) N (%)
Cramps in the abdomen	24 (11)	19 (6)	.019*	43 (8)
Difficult bowel control	26 (12)	19 (6)	.052*	45 (9)
Bloody stools	4 (2)	7 (2)	.32*	11 (2)
Frequent urination	84 (40)	92 (30)	.052*	176 (34)
Pain/burning when urinating	4 (2)	15 (5)	.69*	19 (4)
Leaking urine	37 (18)	41 (13)	.66*	78 (15)
Difficulty emptying bladder	31 (15)	30 (10)	.22*	61 (12)
Swelling of leg(s)	65 (31)	60 (20)	.006*	125 (24)
Lower back pain	81 (38)	80 (26)	.020*	161 (31)
Numbness/tingling hands or feet	55 (26)	71 (23)	.23*	126 (24)
Irritation/soreness vulva or vagina	19 (9)	27 (9)	.89*	46 (9)
Discharge from vagina	10 (5)	21 (7)	.06*	31 (6)
Abnormal vaginal bleeding	1 (0.5)	4 (1)	.28*	5 (1)
Hot flushes and/or sweats	47 (22)	71 (24)	.78*	118 (23)
Felt physically less attractive	51 (24)	43 (14)	<.001*	94 (18)
Felt less feminine	36 (17)	36 (12)	.008*	72 (14)
Dissatisfied with your body	64 (30)	58 (19)	.001*	122 (24)
Worried that sex would be painful	46 (22)	35 (11)	.001*	81 (16)
EORTC CX24 HRQoL, mean (SD)				
Symptom experience	17.1 (12.2)	15.1 (12.5)	.15*	16.1 (12.3)
Body image	27.7 (27.8)	20.5 (24.1)	<.001*	23.8 (26.0)
Lymphedema	34.1 (35.7)	25.6 (34.2)	.014*	29.2 (35.1)
Peripheral neuropathy	31.3 (33.7)	26.5 (31.6)	.24*	28.5 (32.6)
Menopausal symptoms	27.7 (35.8)	27.9 (31.6)	.74*	28.0 (33.4)
Sexual worry	23.2 (33.9)	13.9 (25.3)	.001*	17.9 (29.6)
For sexually active CCSs, N (%)				
Vagina dry during sexual activity	-	50 (16)	-	-
Vagina felt short	-	34 (11)	-	-
Vagina felt tight	-	16 (5)	-	-
Pain during sexual activity	-	33 (11)	-	-
Sexual activity enjoyable	-	225 (73)	-	-
Vaginal/sexual functioning, mean (SD)	-	18.6 (20.9)	-	-

EORTC = European Organization for Research and Treatment of Cancer; CCSs = cervical cancer survivors; HRQoL = health-related quality of life.

Significant *P* values are set in bold types.

*Adjusted for age at survey.

well as physical changes, which are frequent after this treatment modality.²⁶ In contrast to some other studies,⁴ we observed no significant association between major surgery (radical hysterectomy with pelvic lymph node dissection with or without bilateral salpingo-oophorectomy) and sexual inactivity. Other aspects like relapse of CC or the occurrence of another cancer showed no significant associations with sexual inactivity.

The occurrence of sexual inactivity in CC survivors was most strongly associated with demographic factors in the multivariable analysis. The association with older age is in line with findings from the general female population.^{5,6} Having single civil status (never married, divorced, or widow), as well as never having given birth, may indicate the lack of suitable sexual partners. In the general population, lack of partner is the most

frequent reason given by women for sexual inactivity.⁷ From studies of the general population, we know that women with a low level of education report more sexual inactivity,⁶ and this finding was confirmed in our bivariate analyses. However, that result did not remain significant in the multivariable analysis. Somatic issues are of clinical relevance since some of them can be identified and treated. Obesity, abdominal cramps, low back pain, and lymphedema are such concerns which were significantly more prevalent among sexually inactive survivors, as was moderate to poor self-rated health. Increasing number of comorbidities remained borderline significant in the sexually inactive group. Regular somatic workups by their general practitioners, therefore, could be of relevance for sexually inactive CC survivors.

Table 4. Logistic regression analyses of independent variables and being sexually inactive (N = 214) and sexually active (N = 309) (reference) at survey

Variables	Bivariate analyses			Multivariable analysis		
	OR	95% CI	<i>P</i>	OR	95% CI	<i>P</i>
Older age at survey	1.06	1.04–1.08	<.001	1.06	1.03–1.09	<.001
Low level of education	1.94	1.35–2.79	<.001	1.42	0.91–2.17	.12
Single civil status	3.31	2.25–4.89	<.001	3.42	2.17–5.38	<.001
Had children	0.57	0.40–0.81	.002	0.56	0.36–0.87	.009
Not paid work at survey	1.17	1.10–1.24	<.001	MC		
Work ability at survey	0.88	0.84–0.93	<.001	1.04	0.96–1.14	.34
Treatment modalities			<.001		0.16	
Conization (reference)	1.00	-	-	1.00	-	-
Major surgery	1.57	0.94–2.64	.09	0.98	0.54–1.79	.95
Chemoradiotherapy	4.76	2.63–8.62	<.001	1.92	0.92–4.01	.08
Surgery + chemoradiotherapy	2.81	1.49–5.30	.001	1.32	0.61–2.86	.48
Current self-rated health	2.36	1.58–3.52	<.001	1.66	0.89–3.08	.11
Obesity	1.97	1.22–3.17	.005	1.37	0.75–2.51	.31
High neuroticism	1.58	1.11–2.26	.012	MC	-	-
Chronic fatigue	1.71	1.14–2.55	.009	MC	-	-
PHQ-9 depression	2.44	1.56–3.82	<.001	1.63	0.89–2.98	.12
EORTC CX24 HRQoL						
Symptom experience	1.01	1.00–1.03	.08	-	-	-
Body image	1.01	1.00–1.02	.002	1.01	1.00–1.02	.31
Lymphedema	1.01	1.00–1.01	.007		1.00–1.01	.46
Abdominal cramps	1.24	0.96–1.61	.10	1.00	0.88–1.41	.36
Low back pain	1.22	1.07–1.31	.006	1.11		

HRQoL = health-related quality of life; OR = odds ratio; PHQ = Patient Health Questionnaire.

MC: Excluded from the multivariable analyses due to multicollinearity with not being in paid work.

Significant *P* values are set in bold types.

Among psychological variables, the prevalence of chronic fatigue and depression as well as problems with femininity and body image were more common among sexually inactive survivors. Both fatigue and depression are well-known risk factors for sexual inactivity,²⁷ but depression is more amenable to treatment than fatigue.

Interestingly, the CX24 symptom experience scale mean score covering bowel, urinary, and vulvar/vaginal symptoms did not show significant between-group differences. This finding indicates that local pelvic symptoms are not significantly associated with sexual inactivity in the total group of survivors.

Strengths and Limitations

An advantage of our study is the considerable sample size giving enough statistical power to the subgroup analyses of sexually inactive survivors in contrast to some previous studies. Our grouping according to age and partner status should be considered as progress compared to previous studies of sexual inactivity among survivors. We also included cancer-related, demographic, health, psychological factors, and HRQoL variables taking a broad approach to the sexual inactivity problem in survivors. Another strength is our use of well-established self-rating instruments with tested psychometric properties.

Our response rate of 57% at a mean of 11 years post diagnosis must also be considered as acceptable. However, the lack of data for an attrition analysis trying to characterize the non-respondents further must be considered a weakness. This issue raises the problem of the representativity of our sample, which also could be raised concerning the NORMs we used.⁷ Particularly, the very high rates of sexual inactivity among NORMs without a partner should raise concern about response bias. Perhaps women without partners are more concerned about their sexuality, and therefore they more likely report and complete studies. We have also presented the comparisons of sexual inactivity rates between survivors and NORMs despite some minor differences in the definitions of the SAQ and CX24. Another limitation is the lack of prospectively collected data including the pre-diagnostic prevalence of sexual inactivity in our sample of survivors. Since we only have cross-sectional data, we present significant associations between variables, rather than causal findings. Another weakness is the lack of data on specific sexual dysfunctions.

Finally, sexual inactivity is challenging to study mainly due to lack of proper instruments. For example, our questionnaires (the SAQ for NORMs and the CX24 for survivors) do not specify if masturbation shall be included or not when the respondents consider sexual activity. Our instruments also do not clearly

Table 5. Prevalence rates of sexual inactivity and other relevant variables in samples of cervical cancer survivors

Study	Sexually inactive cervical cancer survivors (%)				Other variables (%)			
	35–44 years	45–55 years	56–69 years	All women	Living with partner	All controls	Surgery only	Time since diagnosis*
Current study								
Norway								
All women	29.4	33.9	51.8	39.3		35.9	46.1	11.0
Living with partner	23.5	27.2	41.0	31.2	69.2	22.8		
Not living with partner	50.0	46.8	76.5	58.4	-	93.6		
Cull et al (1993) ²⁴								
Scotland								
All women	-	-	-	26.5	75.9	-	55.4	1.9
Bergmark et al (1999) ²⁵								
Sweden								
All women	-	-	-	30	64.5	30	89.5	6
Jensen et al (2003) ²³								
Denmark								
All women	-	-	-	10.8	85.0	14.9	100	2.0
Wenzel et al (2005) ¹⁰								
United States								
All women	-	-	-	31.0	60.8	20.0	63.0	8.0
Donovan et al (2007) ²⁹								
United States								
All women	-	-	-	10	66	4	64	3.0
Tangjitgamol et al (2007) ³⁰								
Thailand								
All women				7.6	-	-	91.8	1.7
Greenwald et al (2008) ⁹								
United States								
All women	-	-	-	18.9	67.0	-	89.9	13.9
Greimel et al (2009) ³¹								
Austria								
All women	-	-	-	43.0	39.0	-	52.1	9.0
Jensen et al (2004) ²⁸								
Denmark								
All women	-	-	-	47.0	64.0	26.0	0	1.0

*Mean time in years.

separate sexual activity with and without a partner, and this is a source of error in many studies of CC survivors. Another problem is the time frame concerning sexual inactivity. The SAQ states “at the moment of questionnaire completion,”⁷ while the CX24 specifies the last 4 weeks.¹⁵ Other studies of sexual inactivity among CC survivors (Table 5) hardly have any time specifications.^{9,10,23–31}

The next problem is the use of interview vs questionnaire for data collection. Both modalities have advantages and drawbacks. Sensitive sexual information could be easier to admit on a questionnaire than by an interview. On the other hand, unclear responses are perhaps more easily given in questionnaires than in interviews. Population studies of sexual functioning generally use interviews,^{5,6} as opposed to studies of CC survivors where questionnaires are more common.^{9,10,23–31} Another problem is that results on sexual inactivity in survivors rarely are reported by age groups and partner status (Table 5), thereby being less meaningful and hard to interpret. The problem of comparing the sexual inactivity rates of various studies also is complicated due to variation in treatment types and mean follow-up time (Table 5). Finally, the response bias problems of both CC survivors and population samples should be specified, and preferably adjusted for by statistical weighting procedures.

CONCLUSIONS

Close to 4 in 10 CC survivors were sexually inactive at the time the survey was administered, which is similar to the prevalence among normative females of the same age. Demographic factors were most strongly associated with sexual inactivity. Some other significantly associated factors are amenable to identification and possible treatment that calls for an active attitude of health-care providers.

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