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Sexual function and experience among long-term survivors of childhood cancer

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ABSTRACT

Aim: The objective was to compare sexual function, sexual experience and quality of partner relationship by gender in a cohort of long-term survivors of childhood cancer with a sample from the general population.

Methods: A 30-item self-reported postal questionnaire was completed by a cohort of 224 (64%) long-term survivors of childhood cancer and 283 (51%) randomly selected persons from the general population.

Results: Male survivors more often reported periods of low sexual interest ($p = 0.019$), more frequently reported low sexual satisfaction ($p = 0.015$), less frequently reported feeling sexually attractive ($p = 0.020$) and reported a lower total number of sexual partners ($p = 0.031$) than males in the comparison group did. Males diagnosed with a central nervous system (CNS) tumour more frequently reported sexual arousal problems ($p = 0.003$), low sexual satisfaction ($p = 0.021$) and total number of sexual partners ($p = 0.012$) than did males with other diagnoses. There were no statistically significant differences regarding sexual function between the female survivors and the females in the comparison group.

Conclusion: The results indicate that cancer disease and treatment have more impact on sexual function of male survivors than on the sexual function of female survivors. Amongst the survivors, males diagnosed with CNS tumours were shown to be the most vulnerable group. Assessment of sexual function is recommended to be included in regular follow-ups after childhood cancer.

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1. Introduction

According to current statistics in Sweden, one in every 700 adults between the ages of 25 and 35 has lived through the experience of childhood cancer.¹ Survivors of childhood cancer have a high rate of chronic health conditions with a higher risk for persistent disability in multiple functional domains amongst those diagnosed with central nervous system (CNS) tumours.^{2,3} Diagnosis and treatment prior and during

the onset of puberty may affect the appearance of secondary sexual characteristics, linear growth, fertility and psychosexual development.⁴

Sexual health, defined by the World Health Organization (WHO) as a state of physical, emotional, mental and social wellbeing related to sexuality, has been recognised as an integral part of overall health and quality of life.⁵ The possible influence of childhood cancer on the sexual health of young adult survivors in terms of infertility and negative reproduc-

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tive effects has been documented.^{6–8} Negative impact on psychosexual development and sexual experience after childhood cancer have been reported in a few studies.^{9–12} Two of these reports have shown that survivors were older than a comparison group when they started to date and first experienced sexual intimacy and sexual intercourse.^{11,12} It has also been reported that physical reminders of cancer treatment, such as stretch marks and scars lead to concerns regarding appearance^{13,14} which can be sources of embarrassment and of a perception of being ‘different’.^{15,16} This may have negative implications for self-esteem, views on the physical self¹⁴ and the chance to have an intimate or romantic relationship.¹⁷ To the best of our knowledge only one report has published results on sexual function among young adult survivors of childhood cancer.¹⁸ Their results showed significant associations between sexual function and health status and that almost half of the survivors reported at least ‘a little of a problem’ in one or more of the areas measured.

There is no consensus of what aspects of sexual function that should be measured, though, interest, desire, arousal, performance and overall satisfaction are attributes often included.¹⁹ Accordingly, sexual function can be defined as the capacity and wish to perform a sexual activity including perceived sexual pleasure. In two recent general population studies in Europe women were found to more frequently have low levels of sexual desire as compared to men.^{20,21} The young adults (age 18–30) of both genders rarely reported sexual desire as ‘very low or absent’ and they reported high sexual activity rates.²⁰ In a Danish study men and women reported similar prevalence estimates of sexual dysfunction in total across all ages, but different kinds of dysfunctions varied in frequency depending on age.²² The most common sexual dysfunctions reported among men were erectile dysfunction and premature ejaculation and among women lubrication insufficiency and dyspareunia.

The paucity of studies on the impact childhood cancer and treatment may have on several areas of sexual health was the rationale for this study. Survivors diagnosed with CNS tumours have a higher risk of treatment related morbidity why it is important to consider this group separately. The objective was to compare sexual function, sexual experience and quality of partner relationship by gender in a cohort of long-term survivors of childhood cancer with a sample from the general population. An additional objective was to compare the findings for survivors diagnosed with CNS tumours with the findings for those with other diagnoses.

2. Materials and methods

2.1. Participants

2.1.1. Long-term survivors

Survivors of childhood cancer ($N = 369$) were recruited from a regional cohort identified from the Swedish Childhood Cancer Registry. They were all former patients diagnosed with cancer at ages 0–18 during the period 1985–1999, at least 5 years beyond diagnosis and at least 18 years of age at the time of the study. Twenty patients were excluded: they had undergone bone marrow transplantation and were currently included in another study ($n = 14$), they were experiencing a

relapse or a second cancer in progress ($n = 2$) or they had a cognitive dysfunction ($n = 4$). A total of 349 individuals were enrolled in the study and 224 (64%) completed a self-reported questionnaire. At the time of the study their mean age was 24 years and the median time after diagnosis was 16 years. The mean age at the time of diagnosis was 9 years. The distribution of cancer diagnoses among the survivors was: 25% CNS tumours, 22% leukaemia, 19% lymphoma and 34% other tumours.

2.1.2. Comparison group

A random sample of 600 persons living in the Stockholm region was drawn from the Swedish population register. The sample was stratified for age and gender so as to resemble the participating survivors. Forty-two persons were excluded because they did not speak Swedish ($n = 7$), no longer lived in the Stockholm region ($n = 34$) or had a cognitive dysfunction ($n = 1$). A total of 558 were enrolled in the study and 283 (51%) completed a self-reported questionnaire at a mean age of 25 years.

2.2. Data collection

A 30 items self-reported questionnaire was used to assess sexual function and sexual experience, as well as emotional quality in a partner relationship. Twenty-two items measure sexual functions/dysfunctions and sexual experience (19 items) and reflections regarding own sexuality (three single items) (Fig. 1) which have been validated in the epidemiological study ‘Sex in Sweden’ thus providing population-based normative data.^{23–25} The items have also been found to be reliable when used in a group of men treated for testicular cancer.²⁶ Verbal response choices vary from four to six, defining to what extent a dysfunction had occurred during the last 12 months. Subsequently each dysfunction *per se* was reported in the same format if it was perceived as a problem. Only participants who had been sexually active with a partner during the past 12 months answered the items regarding sexual arousal and performance. The remaining eight items in the questionnaire exploring emotional quality of the relationship²⁷ were answered by participants with a current partner relationship.

2.3. Procedure

The study was considered unproblematic from an ethical point of view by the Regional Ethical Review Board in Uppsala.

Potential participants in both sample groups were sent an invitation letter informing them about the study and that participation was voluntary and confidential. The dispatched questionnaire was preceded by a telephone interview collecting other data for this project, which are presented elsewhere.^{13,28} All the interviewees received a questionnaire by post in which the present items were included, followed by a reminder if the questionnaire was not returned within 2 weeks.

2.4. Analysis

Data were prepared by dichotomising the verbal responses to facilitate the analysis and the interpretation of the data. The

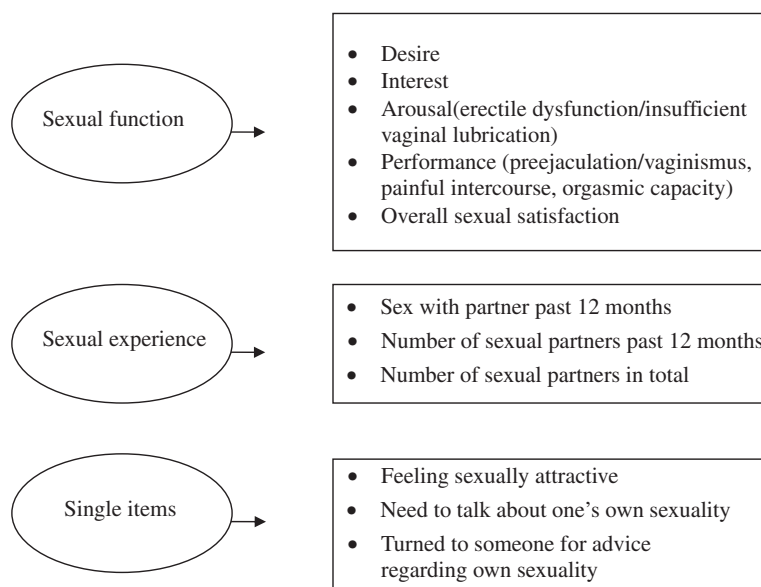


Fig. 1 – Items of sexual function, sexual experience and three single items regarding own sexuality.

item measuring sexual desire had four response alternatives and was dichotomised into *never/rarely* and *sometimes/often*. Items with six response choices were cut off in the middle, for example experience of sexual interest during the past 12 months was divided into *frequent periods of low sexual interest* (all the time/nearly all the time/quite often) and *rare periods of low sexual interest* (seldom/almost never/never). The item measuring sexual satisfaction had five response alternatives and was dichotomised into *low sexual satisfaction* (very dissatisfying/dissatisfying/neither satisfying nor dissatisfying) and *high sexual satisfaction* (satisfying/very satisfying), the items regarding perceived problems were dichotomised in the same way. The SPSS version 17.0 for Windows was used for the analyses. Chi-square tests and Fisher's exact tests were used to compare proportions of categorical variables between groups. The Student's t-test was used for comparison of means between groups. A statistical significance level of $p < 0.05$ was applied in all analyses.

3. Results

No differences were found regarding age and clinical characteristics between the participants and the non-participant survivors. From the eligible sample a higher proportion of women (77%) than men (68%) chose to participate ($p = 0.04$). The situation in the comparison group was similar (62% women, 52% men, $p = 0.03$). No statistically significant differences were found between the survivors and the comparison group with respect to age and gender. Socio-demographic characteristics are presented in Table 1.

3.1. Findings by gender

3.1.1. Sexual function

Male survivors more frequently reported sexual dysfunctions and less frequently reported feeling sexually attractive than males in the comparison group did (Table 2). It was twice as

common amongst male survivors as amongst males in the comparison group to report frequent periods of low sexual interest. It was also twice as common for male survivors (14%) to report this as a problem than for males in the comparison group to do so (6%) [$\chi^2 = 4.13$, $p = 0.042$]. There were no statistically significant differences regarding sexual function between the women in the two groups.

Table 1 – Socio-demographic characteristics of long-term survivors ($n = 224$) and comparison group ($n = 283$).

	Survivors		Comparison group		p-Value
	n	%	n	%	
Gender					
Women	116	52	141	50	0.571
Men	108	48	142	50	
Age					
18–22	93	41	101	35	0.126
23–29	103	46	130	46	
30–37	28	13	52	19	
Education level					
Junior compulsory	38	17	37	13	0.001
Senior high school	137	61	133	47	
Postgraduate/university	49	22	113	40	
Occupation					
Student	92	41	59	21	0.000
Working	107	48	189	67	
Unemployed	11	5	12	4	
Sick leave	9	4	15	5	
Parental leave	5	2	8	3	
Married/cohabitant/relationship					
Single	127	57	192	68	0.007
	97	43	91	32	

Tested for differences by χ^2 statistics.

Table 2 – Sexual function and partner relationship by gender in long-term survivors and comparison group (CG).

	Women				p-Value	Men				p-Value
	Survivors		CG			Survivors		CG		
	n	%	n	%		n	%	n	%	
Answered by total number of participants	116		141			108		142		
Feeling sexually attractive	70	63	99	71	0.20	65	61	106	75	0.02
Need to talk about one's own sexuality	42	37	53	38	0.99	32	30	30	21	0.12
Turned to someone for advice regarding own sexuality	79	68	92	65	0.41	47	44	59	42	0.80
Never/rarely sexual desire	16	14	23	16	0.64	5	5	3	2	0.26
Frequent periods of low sexual interest	32	28	51	37	0.19	22	20	14	10	0.02
Low sexual satisfaction	29	25	35	25	0.70	36	35	29	21	0.02
Sex with partner past 12 months	94	81	129	92	0.02	91	84	126	89	0.23
Sexual arousal problems	14	15	23	18	0.55	7	8	4	3	0.15
Painful intercourse	9	10	15	12	0.60	2	2	5	4	0.43
Vaginismus	2	2	4	3	0.64					
Premature ejaculation						8	9	9	7	0.71
Orgasmic difficulty during intercourse	34	37	52	41	0.55	9	10	4	3	0.04
Participants with a partner relationship	67	59	104	72	0.02	60	53	88	63	0.11
Showing affection towards partner	60	90	90	87	0.67	51	85	78	89	0.52
Satisfied with affection from partner	58	87	92	88	0.71	55	92	82	93	0.73
Deals well with problems with partner	59	88	88	85	0.62	53	88	78	89	0.95
Can talk freely with partner about sex	53	79	85	82	0.67	49	82	74	84	0.55
Differences tested by χ^2 .										

Differences tested by χ^2 .

3.1.2. Sexual experience and emotional quality of partner relationship

A smaller proportion of female survivors than of females in the comparison group reported having had sex with a partner during the past 12 months (Table 2). The male survivors reported a lower number of sexual partners in total (8.6, sd = 11.3) than the males in the comparison group did (12.6, sd = 16.5) [$t = 2.14$, $p = 0.03$]. Number of sexual partners during the past 12 months did not differ between the two groups [female survivors 1.5, sd = 1.7, female in the comparison group 1.4, sd = 1.5, $t = -704$, $p = 0.48$ and male survivors 1.6, sd = 2.4, males in the comparison group 1.8, sd = 2.3, $t = 546$, $p = 0.59$]. Female survivors reported having a partner relationship (married, cohabitant or having a close relationship) to a lower degree than did females in the comparison group. In both genders, there was no mean difference in duration of a current relationship [female survivors 44.2, sd = 39.5 months, females in the comparison group 55.1, sd = 46.8 months, $t = 1.57$, $p = 0.119$ and male survivors 36.2, sd = 32.7 months, males in the comparison group 47.9, sd = 39.4 months, $t = 1.85$, $p = 0.065$].

There were no differences reported within genders regarding emotional quality of a partner relationship (Table 2). Seventy percentage of the female survivors and half of the male survivors had turned to someone for advice regarding their own sexuality. The men most commonly had turned to their partner and to a physician. The women had most commonly turned to a friend and to their partner.

3.2. Findings related to diagnosis by gender

There were no differences in any aspects between female survivors of CNS tumours and female survivors with other diagnoses. Comparing the men from the two groups showed that

those diagnosed with a CNS tumour more frequently reported sexual arousal problems and low sexual satisfaction (Table 3). Furthermore, those diagnosed with a CNS tumour were less likely to have had sex with a partner during the past 12 months and reported a lower number of sexual partners in total (3.2, sd = 5.1) than did males with other diagnoses (9.9, sd = 12.1) [$t = 2.55$, $p = 0.01$].

4. Discussion

Overall, this representative cohort of young adult survivors of childhood cancer reported sexuality and partner relationship similar to what was reported by a comparison group from the general population. However, the results show that the men in the survivor group were less likely to feel sexually attractive and more often had less experience of sexual partners in total than the men in the comparison group. Moreover, the male survivors who had been sexually active with a partner during the past 12 months reported dysfunctions in some sexual aspects to a higher extent than the comparison group. Among the survivors, men diagnosed with CNS tumours showed more vulnerability regarding sexual function and experience.

Male survivors more often reported frequent periods of low sexual interest as well as perceiving this as a problem than males in the comparison group did. This was the only detected difference between the male groups in regard to perceiving a sexual dysfunction as a problem. In the general population, psychological and medical conditions have been associated with low sexual interest as these may restrain the deployment of genital sexual response in men.²⁹ Recent research shows that adult male survivors of childhood cancer are at risk of hypogonadism and androgen deficiency.³⁰ This is known to influence to what extent a man wishes to have sex and it could

Table 3 – Sexual function and partner relationship between male survivors of CNS tumours and males of other diagnoses.

	CNS tumours		Other diagnoses		p-Value
	n	%	n	%	
<i>Answered by total number of participants</i>	22		86		
Feeling sexually attractive	11	50	54	63	0.16
Need to talk about one's own sexuality	10	45	22	26	0.06
Turned to someone for advice regarding own sexuality	8	36	39	45	0.47
Never/rarely sexual desire	2	9	3	3	0.27
Frequent periods of low sexual interest	3	14	19	22	0.38
Low sexual satisfaction	12	55	25	29	0.02
<i>Sex with partner past 12 months</i>	15	68	76	87	0.03
Sexual arousal problems	4	26	3	4	0.01
Painful intercourse	1	6	1	1	0.52
Premature ejaculation	3	20	5	6	0.09
Orgasmic difficulty during intercourse	2	13	7	8	0.46
<i>Participants with a partner relationship</i>	11	50	49	57	0.77
Showing affection towards partner	11	100	40	82	0.12
Satisfied with affection from partner	10	91	45	92	0.92
Deals well with problems with partner	10	91	43	88	0.77
Can talk freely with partner about sex	8	73	38	78	0.48
Differences tested by χ^2 .					

be argued that replacement therapy is under-used in male survivors of childhood cancer as there is a lack of accurate assays and population-based normative ranges for testosterone concentrations.³¹ Research on gender differences in sexual arousal and response indicate that men have a stronger correlation between subjective arousal and genital congestion (erection/swelling and lubrication) than women do.^{32,33} Thus, this could mean that men who report sexual dysfunctions such as arousal problems and orgasmic disorders may perceive these problems as more troublesome than women do.

Furthermore, male survivors more frequently reported periods of low overall sexual satisfaction which in the general male population has been shown to be closely linked to sexual function and having a partner.³⁴ However, in the general population those factors only partially explained the variance in overall sexual satisfaction indicating the broad range of interpretation of the term sexual satisfaction. In the present study the percentage of male survivors having a partner relationship did not differ from the comparison groups which is why it may not be a conclusive factor for how male survivors rated sexual satisfaction. The female survivors in the present study reported overall sexual satisfaction in parity with females in the comparison group. Both female groups reported frequent periods of low sexual interest and orgasmic difficulties which is in accordance with a large Swedish study showing that women commonly report such sexual concerns independent of age.²⁴ The high prevalence of mild dysfunctions that was shown among women, were rarely experienced as manifestly distressing which is why the authors suggested that mild dysfunction need not be regarded as a clinical condition.²⁴

The male survivors were less likely than males in the comparison group to perceive themselves as sexually attractive, which previously has been reported among long-term survivors of childhood cancer.¹² Cancer disease and treatment in childhood have the potential to alter physical development which may lead to short stature and undeveloped secondary

sexual characteristics.⁴ In a study of survivors of childhood cancer with testicular damage, embarrassment about genitals and dissatisfaction with the body were reported.¹⁰ Furthermore, physical impairments and dysfunction, as well as altered body appearance have previously been reported in this cohort of survivors.¹³ Dissatisfaction with the body may influence how sexually attractive a person perceives him-/herself to be which could impact on self-esteem and the initiative for sexual relationships. This may be reflected in the present findings of less total sexual experience among male survivors than in the comparison group. Moreover, male survivors in the CNS tumour group reported less frequent sex with a partner during the past 12 months. It has been suggested that low rates of sexual activity among CNS tumour survivors are due to lower frequencies of intimate relationships³⁵ which could be explained by impaired memory, physical shortcomings and emotional distress.³⁶ Survivors of CNS tumours who have experienced radiation to the hypothalamic-pituitary axis commonly suffer from neuroendocrine disturbances.³⁷ The adverse impact on sexual function can be due not only to gonadotrophin insufficiency, but also to impaired growth, altered body image and reduced quality of life.

The female survivors were less likely to have had sex with a partner in the past 12 months as well as having a current relationship when contrasted to the comparison group. The strong association between low sexual activity and lacking a partner is discussed in the population study by Beutel et al.²⁰ However, it is not possible in the present study to explain the causality of this finding. The figures show that female survivors frequently reported sexual dysfunctions but not more frequently than females in the comparison group whilst male survivors in fact, on average reported more dysfunctions than did males in the comparison group. Zebrack et al.¹⁸ have suggested that female survivors are more affected in their sexual function than males survivors are. That study included no comparators, however, and as research has shown that men and women report sexuality differently^{20–22}

we believe that sexuality in childhood cancer survivors should be studied only within gender and not between genders. Thus, in contrast to Zebrack et al.¹⁸ we suggest that cancer disease and treatment have more impact on sexual life of male survivors than on the sexual life of female survivors.

A major strength of this study is the unique and representative cohort of survivors presented here. The similarities of the participating and the non-participating survivors regarding age and clinical data decrease the risk of non-response bias. Another strength, is the randomly selected comparison group equivalent in age and gender although the high non-response rate in the comparison group is a potential threat to validity and may limit the significance of these findings. Nevertheless, when comparing the sexual function of the comparison group with the population-based normative data of the Swedish survey from 1996²³ our comparison group can be considered representative. Another limitation is the use of a non standardised instrument which would facilitate direct comparisons with other reports. However, the selection of valid generic instruments is strongly limited.³⁸ The questions used presently²³ are considered relevant concerning the content as compared with other validated instruments.³⁸ The present study reports on the understudied topic of sexual function of survivors of childhood cancer and adds knowledge in this field. However, further research, preferably longitudinal, is recommended to increase the knowledge of how sexual dysfunctions may be related to different aspects of health, such as physical, emotional and social wellbeing as well as the young adult survivors' own perceptions of their sexual lives.

Overall, despite being diagnosed with a severe illness in childhood and having received treatment associated with high risk for chronic health problems, sexual difficulties were not frequently reported by the young adult survivors. Knowing this, clinicians and nurses can be supportive when talking to teenagers with cancer and their parents about future quality of life. Nevertheless, the present results indicate that sexuality in adulthood may be a greater concern amongst men than amongst women surviving childhood cancer. Assessment of sexual function is recommended to be included in regular follow-ups after childhood cancer so that potential problems can be detected and addressed.

Conflict of interest statement

None declared.

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