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Sexuality and body image in long-term survivors of testicular cancer

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ABSTRACT

Objective: This study explores sexual function and the influence of different treatment modalities on sexual function and body image among long-term survivors of testicular cancer (TCSs).

Methods: A long-term follow-up assessment of all testicular cancer patients treated at Aarhus University Hospital, Denmark, from 1990 to 2000 was conducted. A total of 401 survivors (mean age: 46.6 years; response rate: 66%) completed questionnaires concerning sexuality and changes in body image. Based on the treatment received, patients were categorised into one of four groups: surveillance, radiotherapy, chemotherapy, or chemotherapy supplemented with retroperitoneal lymph node dissection (RPLND).

Results: Sexual dysfunctions were reported: 24% reduced sexual interest, 43% reduced sexual activity, 14% reduced sexual enjoyment, 18% erectile dysfunction, 7% ejaculatory problems and 3% increased sexual discomfort. Seventeen percent of the long-term TCSs reported changes in body image, and this was significantly associated with all six parameters of sexual dysfunction. When comparing treatments, only the RPLND procedure was associated with sexual dysfunction in the form of ejaculatory dysfunction.

Conclusion: Apart from RPLND, which was associated with ejaculatory dysfunction, treatment strategies for testicular cancer appeared not to influence sexual dysfunction. The level of erectile dysfunction seen in this sample of TCSs seemed to be higher than the level observed in the general male population and high levels of erectile dysfunction were associated with negative changes in body image. The results suggest that changes in body image are of importance when explaining the variation in sexual dysfunctions, but further prospective studies are needed to clarify this issue.

1. Introduction

Testicular cancer (TC) is the most common form of cancer in men between 20 and 35 years of age.[1,2] Major improvements in treatment have been achieved with the introduction of cisplatin-based chemotherapy, which has yielded cure rates of 70–85% in patients with metastatic disease.[3] The effectiveness of treatment has resulted in a progressively larger number of young men who have become long-term survivors and who have to cope with possible long-term effects of the disease and cancer treatment on sexuality and body image. The results of studies comparing testicular cancer survivors

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(TCSs) to a norm population have suggested that TCSs generally have higher levels of sexual dysfunction, primarily erectile and ejaculatory dysfunction.[4,5] Studies examining the influence of various treatment regimens on sexual function in TCSs have shown mixed results. For instance, while some studies have not found evidence that levels of erectile and ejaculatory dysfunctions and libido are influenced by treatment regimens,[6–8] others have shown reduced sexual interest and sexual activity in patients who had received chemotherapy with or without radiotherapy compared to men who have received surgery only.[9–11] When investigating the consequences of retroperitoneal lymph node dissection (RPLND), there seems to be fairly consistent evidence that this procedure is associated with increased risk of ejaculatory dysfunction.[10,12,13] Definitive conclusions based on the available studies are difficult to obtain since the field has been characterised by patient populations receiving a variety of different treatment regimens, variations in lengths of follow-ups and the use of different instruments for assessing sexual dysfunction. Moreover, validated norm material concerning sexual function is often lacking.

There is often no obvious explanation of the sexual morbidity reported in studies of sexual function among TCSs, suggesting that sexual dysfunction could have both biological and psychological causes. Only a small number of studies have considered psychological function and the possible interactions between psychological distress and sexual dysfunction.[13,14] Patients diagnosed with TC are treated with orchiectomy, and removal of a testicle might be seen as a disembodying procedure in a time of heightened fixation on the 'perfect body' and a striving for physical fitness.[15] The results of one study have shown negative changes in body image approximately 4 years following treatment for TC,[16] and it appears relevant to investigate whether changes in body image following treatment for TC are associated with sexual dysfunction.

On this background, the purpose of this study was to examine sexual morbidity in TCSs who had received surveillance, radiotherapy, chemotherapy or chemotherapy followed by RPLND. Furthermore, the purpose was to examine whether sexual morbidity was associated with perceived changes in body image. In many of the studies investigating the sexual dysfunction in TCSs, the group of surveillance patients has constituted a minority (approximately 10–20%). In the present study, the vast majority of patients with stage I disease were consistently assigned to surveillance during the entire study period. This treatment strategy increased the number of surveillance-only-patients, and the proportion of surveillance patients in the present study was generally higher than in other studies of sexual dysfunction (approximately 50%). Hence, the statistical power when comparing surveillance with other treatment modalities is increased compared to previous studies.

2. Methods

2.1. Study design

A long-term follow-up assessment was conducted on all TC patients treated at the Department of Oncology, Aarhus University Hospital, Denmark from 1st January 1990 to 31st December 1999. All patients with a diagnosis of germ cell tumour, including bilateral TC, were included into a Germinative Tumour Database (GTD). A total of 695 patients were included in the GTD. The medical record for each patient was reviewed, and information concerning age at diagnosis, histopathology, disease stage at diagnosis, treatment received and current status was entered into the GTD.

2.2. Patients

In the early spring of 2007, all patients included in the GTD who were alive, had a known and non-protected address, and who had completed cancer treatment more than 3 years earlier, were invited to participate in the questionnaire survey. Of the 695 patients registered in the GTD, 18 were considered ineligible due to emigration and overseas residence (10 patients), protected or unknown address (five patients) or recent cancer treatment (three patients). Finally, 66 patients (10.8%) had died, leaving 611 patients eligible for participation. Respondents were classified into four groups according to the treatment received: surveillance, consisting of patients who had undergone orchiectomy followed by a surveillance programme without recurrence; radiotherapy, consisting of patients who had undergone orchiectomy followed by subdiaphragmatic radiotherapy; chemotherapy, consisting of patients who had undergone orchiectomy and had received chemotherapy at some stage of their treatment irrespective of other treatment modalities, including radiotherapy; and chemotherapy plus retroperitoneal lymph node dissection (RPLND), consisting of patients who had undergone orchiectomy and had received chemotherapy at some stage of their treatment followed by RPLND. The vast majority of patients who had received chemotherapy were treated with the BEP regimen consisting of bleomycin, etoposide and cisplatin.

2.3. Assessments

2.3.1. Sociodemographic variables

Sociodemographic variables included: marital and employment status before diagnosis and at the time of completing the questionnaire, along with their current age, educational level, height and weight. Marital status was categorised as 'married/cohabiting' or 'single' and employment status was categorised as 'working' or 'unemployed/retired'. The patients were also asked about parenthood at the time of diagnosis and follow-up. Educational level was classified as below or above post-secondary non-tertiary educational level. Based on the reported height and weight, the body mass index (BMI) was calculated. Patients with a BMI above 30 were classified as obese. Smoking status and weekly alcohol consumption were also assessed. Alcohol consumption was classified as below or above 21 units of alcohol per week (the recommended safe limits for alcohol drinking for men according to the Danish National Board of Health).

2.3.2. Sexuality

A validated questionnaire regarding sexual functioning in TC patients and survivors is not available. The European Organisation for Research and Treatment of Cancer (EORTC)

QLQ-PR25 is a questionnaire designed for use among patients with prostate cancer and validation approaches such as multitrait scaling analysis, known-group comparisons and scale responsiveness have supported the psychometric robustness of the scale.[17,18] Six questions from the QLQ-PR25 questionnaire addressing sexual functioning were used in this study. Each item was scored on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much). To define 'caseness', sexuality scores were dichotomised. Patients scoring 'not at all' and 'a little' on items dealing with sexual drive were categorised as having reduced sexual interest, activity and enjoyment, while patients scoring 'quite a bit' and 'very much' were categorised as having satisfactory levels. Patients scoring 'quite a bit' and 'very much' on items dealing with erection and ejaculation problems and sexual discomfort were categorised as having erectile and ejaculatory dysfunction, and problems with sexual intimacy. The questions concerning sexual enjoyment, erection dysfunctions, ejaculatory dysfunctions and sexual discomfort should only be completed by patients who had been sexually active (with or without intercourse) during the past 4 weeks.

2.3.3. *Body image*

TCSs were asked whether they had felt less masculine as a consequence of the testicular cancer and its treatment. The item was scored on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much).TCSs scoring 'quite a bit' and 'very much' were categorised as having experienced negative changes in body image as a result of their illness or treatment, while patients scoring 'not at all' and 'a little' were categorised as having an unchanged body image.

3. Statistics

Differences in age, histopathology, disease stage at diagnosis and type of treatment between respondents and non-respondents were explored with chi-square tests (categorical data) and Student's *t*-tests for independent variables (continuous data). Differences in age between treatment groups were explored with one-way analyses of variance (ANOVAs) using the Bonferroni procedure to adjust for multiple comparisons. Differences in marital status, parenthood, employment status, educational level, smoking status, obesity status and alcohol consumption between treatment groups were explored with chi-square tests. Inter-treatment differences concerning sexual dysfunctions and changes in body image were examined by multivariate logistic regression analyses. Covariates, which differed between treatment groups, were seen as possible confounders and were included in the multivariate logistic regression analyses.

4. Results

Eligibility criteria for participation were met by 611 patients. Of these, 401 returned questionnaires corresponding to a response rate of 66%. Respondents were younger than non-respondents ($t = -4.63$, $p < .0001$), but did not differ with respect to any of the disease-related factors including histopathology ($chi^2 = 4.86$, $p = 0.09$), disease stage at diagnosis ($chi^2 = 4.45$, $p = 0.22$), and type of treatment ($chi^2 = 1.04$, $p = 0.60$). Patients were classified into four groups according to the treatment received: surveillance ($n = 204$, 50.9%); radiotherapy ($n = 47$, 11.7%); chemotherapy ($n = 99$, 24.7%); and chemotherapy plus RPLND ($n = 51$, 12.7%). Characteristics of the patient cohort are listed in Table 1. Significant differences were found regarding age ($F = 5.40$, $p = 0.001$), marital status ($chi^2 = 12.12$, $p = 0.059$) and obesity status ($chi^2 = 12.76$, $p = 0.047$) between treatment groups. Patients in the chemotherapy groups (+/−RPLND) were younger than patients in the surveillance group ($p < 0.020$). Significantly more patients in the chemotherapy plus RPLND group were singles (31.4%) compared to patients in the surveillance (18.1%) and radiotherapy groups (10.6%). Likewise, significantly more patients in the chemotherapy group were singles (27.3%) compared to patients in the radiotherapy group (10.6%). More patients in the radiotherapy group were classified as 'obese' (23.4%) compared to patients in the surveillance group (9.8%) and patients in the chemotherapy group (7.1%).

4.1. *Body image*

Among TCSs, 69 (17.2%) reported a change in perceived body image. No differences in body image were found between treatment groups ($chi^2 = 10.63$, $p = 0.100$).

4.2. *Sexuality*

Sexual dysfunction was reported: 24.4% of the TCSs experienced reduced sexual interest and 42.6% reported reduced sexual activity. Reduced sexual interest was significantly associated with changes in body image, older age and obesity. Reduced sexual activity was significantly associated with changes in body image and older age (see Table 2).

Of the 329 (82.0%) TCSs who had been sexually active during the last 4 weeks, 14.3% reported reduced sexual enjoyment, 17.6% reported erectile dysfunction, 7.3% reported ejaculation dysfunction and 3.0% reported sexual discomfort. Reduced sexual enjoyment was significantly associated with changes in body image. Erectile dysfunction was associated with changes in body image and older age, whereas ejaculation dysfunction was significantly associated with changes in body image, increasing age and having undergone chemotherapy + RPLND. Feelings of sexual discomfort were associated with changes in body image and being single (see Table 3)

5. Discussion

Although several studies have examined the influence of treatment on sexuality of TCSs,[9,11,12,14] due to the mixed results, the question remains as to whether and to what degree TCSs are at risk for sexual morbidity, and which factors are associated with sexual dysfunction. Problems with sexual function were prevalent among the TCSs included in this study. Twenty-five percent of the survivors reported reduced sexual interest and 43% reduced sexual activity. These findings are in accordance with previous results,[12] but have to be considered relative to the prevalence of sexual inactivity

Table 1 – Sociodemographic characteristics of the questionnaire respondents (*N* = 401).

Treatment groups	At time of treatment				At follow-up			
	Surveillance N = 204	Radiotherapy N = 47	Chemotherapy N = 99	Chem retroperitoneal lymph node dissection (RPLND) N = 51	Surveillance N = 204	Radiotherapy N = 47	Chemotherapy N = 99	ChemRPLND N = 51
Mean age (SD)	36.08 (10.26)	36.91 (11.66)	32.27 (10.00)	31.07 (11.66)	48.85 (10.58)	48.83 (8.98)	44.75 (10.70)	43.98 (11.51)
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Marital status								
Married or cohabiting	154 (75.49)	40 (85.11)	57 (57.58)	30 (58.82)	163 (79.90)	41 (87.23)	72 (72.73)	35 (68.63)
Single	45 (22.06)	6 (12.77)	40 (40.40)	20 (39.22)	37 (18.14)	5 (10.64)	27 (27.27)	16 (31.37)
Unknown	5 (2.45)	1 (2.13)	2 (2.02)	1 (1.96)	4 (1.96)	1 (2.13)	0 (0.00)	0 (0.00)
Children status								
Children	113 (55.39)	33 (70.21)	44 (44.44)	21 (41.18)	146 (71.57)	40 (85.11)	64 (64.65)	34 (66.67)
No children	87 (42.65)	14 (29.79)	53 (53.54)	30 (58.82)	55 (26.96)	7 (14.89)	33 (33.33)	17 (33.33)
Unknown	4 (1.96)	0 (0.00)	2 (2.02)	0 (0.00)	3 (1.47)	0 (0.00)	2 (2.02)	0 (0.00)
Employment status								
Working	167 (81.86)	40 (85.11)	78 (78.79)	36 (70.59)	165 (80.88)	39 (82.98)	79 (79.80)	45 (88.24)
Unemployed or retired	31 (15.20)	5 (10.64)	19 (19.19)	14 (27.45)	35 (17.16)	7 (14.89)	19 (19.19)	6 (11.76)
Unknown	6 (2.94)	2 (4.26)	2 (2.02)	1 (1.96)	4 (1.96)	1 (2.13)	1 (1.01)	0 (0.00)
Education								
< Post-secondary level					131 (64.22)	33 (70.21)	71 (71.72)	31 (60.78)
⩾ Post-secondary level					68 (33.33)	13 (27.66)	28 (28.28)	19 (37.25)
Unknown					5 (2.45)	1 (2.13)	0 (0.00)	1 (1.96)
Health behaviours								
Smokers					57 (27.94)	16 (34.04)	39 (39.39)	10 (19.61)
⩾ 21 units of alcohol/wk					16 (7.84)	7 (14.89)	9 (9.09)	3 (5.88)
Body mass index (BMI) ⩾ 30					20 (9.80)	11 (23.40)	7 (7.07)	7 (13.73)

Table 2 – Results of multivariate logistic regression analyses with reduced sexual interest and reduced sexual activity as dependent variables and body image, treatment groups, age, marital status and obesity as independent variables (*N* = 401).

	Reduced sexual interest N = 98 (24.4%)			Reduced sexual activity N = 171 (42.6%)		
	Adjusted OR	95% Confidence interval	*p*-value	Adjusted OR	95% CI	*p*-value
Body image						
No changes (ref)	1.00			1.00		
Reduced masc.	3.87	2.15–6.96	<0.001	3.26	1.83–5.80	<0.001
Treatment						
Surveillance (ref)	1.00			1.00		
Radiotherapy	0.99	0.46–2.15	0.977	0.66	0.32–1.36	0.261
Chemotherapy	0.77	0.41–1.46	0.420	1.25	0.74–2.12	0.398
Chem + retroperitoneal lymph node dissection (RPLND)	0.55	0.23–1.31	0.175	1.28	0.65–2.52	0.475
Age	1.05	1.02–1.07	<0.001	1.04	1.02–1.06	0.001
Marital status						
Single (ref)	1.00			1.00		
Cohabiting	0.97	0.52–1.79	0.917	0.61	0.36–1.03	0.063
Obesity						
Body mass index (BMI) < 30 (ref)	1.00			1.00		
BMI ⩾ 30	2.45	1.21–4.98	0.013	1.52	0.77–2.98	0.225

OR = Odds Ratio

and lack of sexual interest in the general population, which are not well investigated.[1]

Treatment of TC may influence ejaculation and erection, as these functions are directly related to innervation. The results of a questionnaire study conducted among a representative sample of sexually active Danish men ($n = 2120$) have revealed that ejaculation difficulties, in the form of premature ejaculation, were perceived as a problem in 7% of the men and the prevalence exhibited only minor variation by age.[21] The prevalence of perceived ejaculatory dysfunction in the present study was found to be 7%, but comparisons with other studies are difficult due to variations in the way that ejaculatory dysfunction has been measured. An American study revealed that erectile dysfunction was prevalent in about 10% of the general male population.[19] Likewise, another study reported moderate and complete erectile dysfunction in respectively 6% and 2% of Norwegian men between the ages of 40 and 50.[20] In the Danish study mentioned above, the overall prevalence of erectile dysfunction was found to be 5%. However, the prevalence varied considerably by age. Thus, only 1% of men younger than 50 years reported erectile dysfunction, but the prevalence increased to 5% in 50–59 year-olds and to 16% in men aged 60 years or older.[21] The prevalence of erectile dysfunction in the present study was found to be 18%, and appears to be higher than in the general population. The explanation of this finding is unknown, but may be rooted in the psychological changes following the diagnosis and treatment of testicular cancer.

About 17% of TCSs reported a negative change in body image, i.e. perceived reduced masculinity, following TC and its treatment. The results yielded statistically significant associations between changes in body image and all six parameters of sexual dysfunction: reduced sexual interest, reduced sexual activity, reduced sexual enjoyment, erectile dysfunction, ejaculation dysfunction and increased sexual discomfort. A negative change in body image was the factor most strongly related to sexual dysfunction. For instance, the risk of experiencing sexual discomfort increased with a factor 15 and the risk of experiencing erectile dysfunction with a factor 9 in TCSs who reported a change in body image as a consequence of the disease and its treatment. As the testes are associated with symbolism, (hemi)- castration is often anticipated to have psychological consequences in the form of fantasies about reduced masculinity and physical strength.[22,23] Despite the cross-sectional design of the present study limiting the interpretation of causality, it may be beneficial to explore possible fantasies and myths among men exposed to orchiectomy and to provide counselling to avoid long-term negative changes in body image.

Generally, the type of treatment was not associated with sexual function. Only ejaculation dysfunction was found to be influenced by type of treatment with TCSs exposed to the RPLND procedure reporting significantly higher levels of ejaculation dysfunction. RPLND is known to be associated with so-called 'dry ejaculation',[24] and a previous review has concluded that ejaculatory dysfunction is the most common problem associated with having received treatment for TC.[13]

It is well-known from the literature that a cancer disease is a challenge to many committed romantic relationships and may result in increased divorce rates.[25] However, men who are singles at the time of diagnosis may also constitute a particular vulnerable group. First, it has been shown that unpartnered TCSs express high levels of worry concerning how the disease and its treatment might influence future relationships.[26] Second, the results of a study of 219 TCSs revealed that survivors who developed a relationship after completion of treatment reported less marital satisfaction than their partners.[27] In concordance with these findings, our results revealed that TCSs, who had been sexually active over the last 4 weeks, but described themselves as 'unpartnered' at the

Table 3 – Results of multivariate logistic regression analyses with reduced sexual enjoyment, erectile dysfunction, ejaculation dysfunction and increased sexual discomfort as dependent variables and body image, treatment groups, age, marital status and obesity as independent variables. The analyses include TCSs who had been sexually active during the past 4 weeks (N = 329).

	Reduced sexual enjoyment N = 47 (14.3%)			Erectile dysfunction N = 58 (17.6%)			Ejaculation dysfunction N = 24 (7.3%)			Increased sexual discomfort N = 10 (3.0%)		
	Adjusted OR	95% Confidence interval	*p*-value	Adjusted OR	95% CI	*p*-value	Adjusted OR	95% CI	*p*-value	Adjusted OR	95% CI	*p*-value
Body image												
No changes (ref)	1.00			1.00			1.00			1.00		
Reduced masc.	4.98	2.42–10.27	<0.001	9.43	4.39–20.27	<0.001	3.82	1.46–10.02	0.006	15.53	3.54–68.19	<0.001
Treatment												
Surveillance (ref)	1.00			1.00			1.00			1.00		
Radiotherapy	0.98	0.35–2.73	0.975	1.42	0.52–3.86	0.488	1.39	0.32–5.97	0.662	1.43	0.21–9.60	0.713
Chemotherapy	0.70	0.28–1.76	0.442	1.19	0.52–2.72	0.688	1.08	0.27–4.30	0.908	1.14	0.19–6.96	0.885
Chem + retroperitoneal lymph node dissection (RPLND)	0.76	0.26–2.26	0.662	0.45	0.12–1.60	0.215	6.76	2.16–21.17	0.001	Omitted[a]		
Age	1.01	0.98–1.04	0.56	1.08	1.04–1.12	<0.001	1.05	1.00–1.10	0.030	1.01	0.95–1.08	0.783
Marital status												
Single (ref)	1.00			1.00			1.00			1.00		
Cohabiting	0.68	0.30–1.56	0.37	0.85	0.36–1.98	0.700	0.61	0.21–1.77	0.365	0.18	0.05–0.76	0.019
Obesity												
Body mass index (BMI) < 30 (ref)	1.00			1.00			1.00			1.00		
BMI ⩾ 30	2.25	0.92–5.53	0.077	1.49	0.56–3.91	0.423	1.32	0.36–4.75	0.657	0.36	0.03–4.26	0.418

OR = Odds Ratio

[a] Omitted since no TCSs in the chemotherapy plus RPLND group reported increased sexual discomfort.

time of questionnaire completion, reported significantly greater sexual discomfort. Despite that we are ignorant of the nature of the relationship between the TCS and the level of sexual activity, we suggest that future studies are conducted in order to clarify the role of the testicular cancer history with particular reference to the first phases in the formation of an intimate relationship.

The strengths of the present study include the long follow-up period, the relatively large sample size, and the high response rate. Due to the availability of the Danish Central Person Register (CPR), we were only unable to reach very few patients. In contrast to many previous studies, we adjusted for possible age differences between treatment groups when investigating differences in sexuality. Our study does, however, have some limitations. First, the lack of norm data and the lack of data concerning premorbid level of sexual dysfunction make it difficult to identify the level of sexual dysfunction which can be attributed to the TC and its treatment. Provided the presence of valid norm data concerning sexual functioning in the general male population, it would be possible to examine to what extent orchiectomy alone influences sexual life, both in the short-term and in the long-term. Further prospective studies are needed to clarify this issue. Second, the cross-sectional design of the study makes it difficult to draw clear conclusions regarding causality.

6. Conclusion

In summary, sexual dysfunctions were present to a relatively high degree: 18% of the TCSs reported erectile dysfunction, 7% reported ejaculatory problems and 24% reported reduced sexual interest. Furthermore, 17% of the long-term TCSs reported changes in body image. Ejaculatory dysfunction was related to RPLND, but apart from this, no significant associations were found between treatment modalities and sexual dysfunction. The level of erectile dysfunction in this sample appeared higher compared to the level observed in the general population. We found that changes in body image were independently associated with all parameters of sexual dysfunctions, and the results of this study seem to warrant further studies examining whether counselling about changes in body image after orchiectomy can reduce the risk of long-term sexual dysfunction in TCSs.

Conflict of interest statement

None declared.

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