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## Sexual Dysfunction and Reproductive Concerns in Young Men Diagnosed With Testicular Cancer: An Observational Study



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### ABSTRACT

**Introduction:** The survival rates for testicular cancer are excellent; still, there is a lack of knowledge regarding important survivorship issues, such as sexual dysfunction and reproductive concerns.

**Aim:** The aim of this study was to investigate the prevalence and predictors of sexual dysfunction and reproductive concerns and the potential association between these issues in young men ~2 years after a diagnosis of testicular cancer.

**Methods:** Data were collected from 111 men (response rate = 50%) diagnosed with testicular cancer at age 16–39. Patients were identified via the Swedish National Quality Registry for Testicular Cancer and approached with a survey, including standardized measures of sexual function, reproductive concerns, body image, and health-related quality of life. The survey was sent to participants approximately 2 years after their cancer diagnosis. Clinical variables were collected from the registry. Predictors were identified by multivariable linear regression analyses.

**Main Outcome Measures:** The main outcomes were sexual function, assessed with the Patient-Reported Outcomes Measurement Information System Sexual Function and Satisfaction measure version 2.0, and reproductive concerns, assessed with the Reproductive Concerns After Cancer scale.

**Results:** Sexual dysfunction was reported by 26% of men, and a high level of reproductive concerns was reported by 28%. Lower satisfaction with sex life was associated with older age ( $\beta = -0.41$ ), negative body image ( $\beta = -0.42$ ), not having a partner ( $\beta = 4.8$ ), and dissatisfaction with sex life before cancer ( $\beta = 8.31$ ). Negative body image was associated with reproductive concerns in the dimensions of fertility potential ( $\beta = 0.06$ ), partner disclosure ( $\beta = 0.08$ ), and child's health ( $\beta = 0.07$ ), whereas having had fertility preservation predicted higher levels of concerns with regard to personal health ( $\beta = 0.52$ ) and achieving pregnancy ( $\beta = 0.53$ ). Clinical variables did not predict either sexual function or reproductive concerns.

**Clinical Implications:** Our results show that the majority of young men diagnosed with testicular cancer do not report sexual dysfunction or reproductive concerns 2 years after diagnosis. A sizeable minority, however, does report dysfunction or reproductive concerns, which should be recognized in the follow-up care of this population.

**Strengths & Limitations:** A strength of the study is the use of high-quality registry data and validated instruments. The lack of Swedish norms for sexual function and reproductive concerns is a possible limitation.

**Conclusion:** A subgroup of young men treated for testicular cancer report sexual dysfunction or reproductive concerns approximately 2 years after diagnosis. Factors associated with these issues seem to mainly be psychological, rather than medical, nature. **Ljungman L, Eriksson LE, Flynn KE, et al. Sexual Dysfunction and**

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## Reproductive Concerns in Young Men Diagnosed With Testicular Cancer: An Observational Study. *J Sex Med* 2019;16:1049–1059.

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**Key Words:** Body Image; Reproductive Concerns; Sexual Dysfunction; Survivorship; Testicular Cancer; Young

### INTRODUCTION

Testicular cancer is the most common cancer among young men.<sup>1</sup> It is also one of the most curable cancers, with a 5-year survival rate of 97% in countries providing adequate oncology care.<sup>2</sup> Because the disease affects the reproductive organs, sexual dysfunction and concerns related to fertility are crucial aspects to take into consideration in survivorship care.

In a review of the literature, Carpentier and Fortenberry<sup>3</sup> found that survivors of testicular cancer reported higher levels of sexual dysfunction than healthy control subjects, including decreased sexual enjoyment, decreased desire, and erectile and ejaculatory dysfunction. These problems have been reported to persist up to 2 years after treatment; however, there are inconsistencies in the previous literature with regard to the prevalence of these issues, and reliable data are lacking.<sup>4</sup> Previous studies have identified general anxiety, lower levels of testosterone, older age, radiation therapy in combination with chemotherapy, or retroperitoneal lymph node dissection (RPLND) as predictors of sexual problems after testicular cancer.<sup>5,6</sup> Additionally, non-partnered compared with partnered survivors have reported more erectile and orgasmic dysfunction and lower levels of sexual satisfaction.<sup>3,5</sup> To increase knowledge about predictors of sexual problems in this population, researchers in the field have underscored the importance of analyzing different types of sexual problems separately (eg, erectile/ejaculatory function and satisfaction with sex life), because these may well be explained by different factors.<sup>4,7</sup> It has also been suggested that, aside from retrograde ejaculation, which is related to having had RPLND, psychological mechanisms may be the most important for explaining the development and persistence of sexual dysfunction after testicular cancer.<sup>8</sup>

Negative body image has been identified as a psychological mechanism potentially involved in sexual dysfunction after cancer.<sup>3,9</sup> Body image is a concept that includes affective (eg, feeling masculine/feminine), behavioral (eg, avoiding people because of appearance), and cognitive (eg, dissatisfaction with appearance or with scars) aspects of experiences related to one's own body.<sup>10,11</sup> In a previous publication, 17% of men treated for testicular cancer reported a negative change in masculinity, which also was related to higher levels of sexual problems.<sup>8</sup> The authors argued that this finding could be explained by the testes being associated with symbolism and fantasies of masculinity and physical strength. Overall, though, the impact of psychological factors, such as negative body image and masculinity on sexual

problems after testicular cancer in young men, has not been sufficiently described in the literature.<sup>9,12</sup>

Fertility is estimated to be reduced by approximately 30% after testicular cancer.<sup>13,14</sup> Even though cryopreservation is recommended for patients with cancer who are receiving highly toxic treatment, the proportion of patients who actually use sperm banking varies significantly among countries.<sup>15,16</sup> Fear of infertility, or knowing that one's fertility has been compromised, has been associated with negative effects on identity, masculinity, and psychological well-being in men diagnosed with cancer.<sup>17</sup> Fertility preservation has, in qualitative research, been suggested to function as a buffer against anxiety about possible future infertility.<sup>18,19</sup>

Reproductive concerns after cancer include not only concerns regarding fertility potential, but also concerns regarding parenthood-related factors, such as living long enough to raise children, genetic predisposition of cancer in one's offspring, discussing fertility problems with a partner, and acceptance of possible infertility.<sup>20,21</sup> In women with cancer, reproductive concerns have been associated with decreased quality of life and depressive symptoms,<sup>22,23</sup> and the prevalence of this type of concern has been reported to be as high as 60–65% in young women with breast cancer.<sup>24,25</sup> The prevalence of reproductive concerns has, to the best of our knowledge, not yet been examined in young men with testicular cancer.

Because adolescence and young adulthood are developmental periods, including specific tasks such as identity exploration, establishment of close intimate relationships, and family building,<sup>3</sup> receiving a diagnosis of testicular cancer during these periods may affect men's feelings regarding their masculinity, attractiveness, fertility, sexuality, and romantic relationships. However, there is a lack of firm knowledge regarding sexual problems and reproductive concerns in young men diagnosed with testicular cancer. Besides the small number of studies investigating these issues, the use of non-validated measures and the absence of reliable norms for comparison contribute further to the gap in knowledge.<sup>4,7,26</sup> Furthermore, the mechanisms involved in these issues, and the association between sexual problems and reproductive concerns, has not been described. The overall aim of this study was therefore to investigate the prevalence and predictors of sexual dysfunction and reproductive concerns in young men approximately 2 years after being diagnosed with testicular cancer. An additional aim was to identify the potential interdependence between these issues.

## Research Questions

1. What is the prevalence of sexual dysfunction and reproductive concerns in young men (16–39 years) diagnosed with testicular cancer ~2 years previously?
2. Is there an association between sexual function and reproductive concerns in this group?
3. What are the predictors of sexual dysfunction and reproductive concerns in this group?

## METHODS

### Study Design

The study was an observational prospective study using patient self-reported survey data to measure the outcome variables and registry data to measure the predictor variables.

### Setting, Participants, and Procedure

Men diagnosed with testicular cancer at the age of 16–39 in Sweden (from July 2014–June 2015) were identified using the Swedish nationwide high-quality registry for testicular cancer, “SWENOTECA,” which has a coverage of 98% of all new cases of testicular cancer in Sweden. Through linkage with the Swedish population registry, information on vital status and address details were collected. Men with no address information were excluded. At the time of survey data collection, participants were 1.5–2.5 years after diagnosis (mean 739, SD 106, range 550–914 days).

The survey was sent by mail to potential participants together with information about the study and a prepaid envelope for questionnaire return. Individuals who did not respond received 2 reminders, which were also sent by mail. By responding to the survey, participants gave their consent to participate in the study. Informed consent was thereby obtained from all individual participants included in the study.

No compensation was given for study participation. Ethical approval was obtained for the study procedures by the Regional Ethical Review Board in Stockholm, Sweden (Ref No: 20131746-31/4). In parallel to this study, a corresponding study with similar aims and procedures was conducted targeting young women diagnosed with breast cancer.<sup>24</sup>

### Treatment

Treatment for testicular cancer in Sweden is given according to the national SWENOTECA guidelines ([www.swenoteca.org](http://www.swenoteca.org)): All patients undergo unilateral orchiectomy. Patients with clinical stage I (confined only to the tumor-bearing testicle) are monitored by surveillance or receive 1 cycle of adjuvant chemotherapy. Disseminated disease (>stage I) is typically treated with chemotherapy; standard treatment is 3 cycles. Non-seminoma patients with residual disease after chemotherapy may receive additional surgery, most often RPLND. Radiotherapy is less commonly used and is reserved for specific clinical situations, either replacing chemotherapy or, in very advanced cases, given

as an additional treatment. Before the start of treatment, cryopreservation of sperm is offered free of charge to all men diagnosed with testicular cancer in Sweden.

## Measures

### Registry Data

Data collected from the testicular cancer registry included personal identification number, age at diagnosis, date of diagnosis, tumor type, clinical stage classification, and type(s) of treatment.

### Survey

#### Sociodemographic Variables

Study-specific questions were used to assess sociodemographic information, including birth country, education, employment, family situation (partner, children), sexual orientation, and wish for (additional) children. Additionally, information about any current cancer treatment and fertility preservation were collected.

#### Sexual Function

Sexual function was assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS) Sexual Function and Satisfaction measure version 2.0 (SexFS).<sup>27</sup> The SexFS has demonstrated content and construct validity and test-retest reliability in the United States.<sup>27,28</sup> For the purpose of the current study, the following 3 SexFS domains were selected: “Erectile function,” “Interest in sexual activity,” and “Satisfaction with sex life.” In each domain, scores are expressed on a T-score metric, with 50 corresponding to the mean of the population of U.S. adults who have been sexually active in the past 30 days.<sup>27</sup> A lower score indicates more problems in all domains. We considered 1 SD (10 points on the T-scale) under 50 as indicative of dysfunction in the respective domain, which is in accordance with the suggested interpretation of domain scores by the PROMIS Network (<http://www.nihpromis.org/>). Questions concerning satisfaction with sex life before cancer and reasons for not having had sexual activity with a partner during the past 30 days were also included.

The current study and the corresponding study targeting young women with breast cancer<sup>24</sup> were the first to use the SexFS in Sweden, and we, therefore, translated the English version of the instrument into Swedish. The translation of the SexFS into Swedish was conducted in accordance with the standardized procedure developed by FACITrans and PROMIS. The procedure included a forward/backward translation, followed by cognitive interviews with 22 adolescents and adults; the sample included participants with experience of cancer.<sup>29</sup> The final linguistically-validated version of a Swedish SexFS v2.0 has been approved by the PROMIS Translation Director.

#### Reproductive Concerns

Reproductive concerns were assessed using the Reproductive Concerns After Cancer scale (RCAC), which is a multidimensional

**Table 1.** Demographics and clinical variables for young men diagnosed with testicular cancer

|  | Total (N = 111) | Age ≤31 (n = 43) | Age ≥32 (n = 68) |
|--|-----------------|------------------|------------------|
| Age, mean(SD)                                    | 32.1 (5.5)      | 26.6 (3.0)       | 36.1 (3.0)       |
| Country of birth, n(%)                           |                 |                  |                  |
| Sweden   | 101 (91.0)      | 42 (97.7)        | 59 (86.8)        |
| Other  | 10 (9.0)        | 1 (2.3)          | 9 (13.2)         |
| Education  |                 |                  |                  |
| University degree                                | 53 (47.7)       | 24 (55.8)        | 29 (42.6)        |
| Vocational status                                |                 |                  |                  |
| Full-time employment                             | 85 (76.6)       | 28 (65.1)        | 57 (83.8)        |
| Currently on cancer treatment                    |                 |                  |                  |
| Chemotherapy                                     | 0 (0)           | 0 (0)            | 0 (0)            |
| Radiation therapy                                | 0 (0)           | 0 (0)            | 0 (0)            |
| Endocrine treatment                              | 4 (3.6)         | 1 (2.4)          | 3 (4.4)          |
| Other treatment                                  | 5 (4.5)         | 2 (4.8)          | 3 (4.4)          |
| Tumor type                                       |                 |                  |                  |
| Seminom  | 68 (61.3)       | 17 (39.5)        | 51 (75.0)        |
| Non-seminom                                      | 43 (38.7)       | 26 (60.5)        | 17 (25.0)        |
| Stage of disease                                 |                 |                  |                  |
| Stage I  | 82 (75.9)       | 30 (73.2)        | 52 (77.6)        |
| >Stage I   | 26 (24.1)       | 11 (26.8)        | 15 (22.4)        |
| Chemotherapy*                                    | 55 (50)         | 22 (51.2)        | 33 (48.5)        |
| Type of surgery                                  |                 |                  |                  |
| RPLND†   | 5 (4.5)         | 3 (7.0)          | 2 (2.9)          |
| Fertility preservation                           |                 |                  |                  |
| No   | 22 (20)         | 4 (9.3)          | 21 (32.3)        |
| Yes  | 83 (80)         | 39 (90.7)        | 44 (67.7)        |
| Have partner                                     |                 |                  |                  |
| Yes  | 90 (82)         | 32 (74.4)        | 58 (86.6)        |
| Have children                                    |                 |                  |                  |
| Yes  | 53 (48.2)       | 10 (23.8)        | 43 (63.2)        |
| Wish to have (additional) children in the future |                 |                  |                  |
| Yes  | 71 (64.5)       | 35 (83.3)        | 36 (52.9)        |
| Do not know/No                                   | 39 (35.5)       | 7 (16.7)         | 32 (47.1)        |
| Sexual orientation                               |                 |                  |                  |
| Heterosexual                                     | 104 (94.5)      | 42 (97.7)        | 62 (92.5)        |
| Homosexual                                       | 3 (2.7)         | 1 (2.3)          | 2 (3.0)          |
| Bisexual   | 1 (0.9)         | 0 (0)            | 1 (1.5)          |
| Other  | 1 (0.9)         | 0 (0)            | 1 (1.5)          |
| Do not want to declare                           | 1 (0.9)         | 0 (0)            | 1 (1.5)          |
| Satisfaction with sex life before cancer         |                 |                  |                  |
| High   | 85 (78.0)       | 35 (83.3)        | 50 (74.6)        |
| Low  | 24 (22.0)       | 7 (16.7)         | 17 (25.4)        |
| BIS, mean (SD)                                   |                 |                  |                  |
| Summary score                                    | 4.6 (6.2)       | 5.4 (5.9)        | 4.2 (6.4)        |
| Number above cutoff‡                             | 15 (14.0)       | 7 (17.1)         | 8 (12.1)         |
| QLQ-30, mean (SD)                                |                 |                  |                  |
| Summary score                                    | 86.4 (13.1)     | 87.2 (12.7)      | 86.1 (13.4)      |
| RCAC, mean (SD)                                  |                 |                  |                  |
| Fertility potential                              | 2.4 (1.2)       | 2.6 (1.2)        | 2.2 (1.2)        |
| Partner disclosure                               | 2.3 (1.2)       | 2.5 (1.2)        | 2.2 (1.2)        |
| Child's health                                   | 2.5 (1.3)       | 2.8 (1.3)        | 2.4 (1.2)        |
| Personal health                                  | 2.2 (0.9)       | 2.1 (1.0)        | 2.2 (1.0)        |
| Acceptance                                       | 2.5 (1.1)       | 2.9 (1.1)        | 2.3 (1.0)        |

(continued)

Table 1. Continued

|                             | Total (N = 111) | Age $\leq$ 31 (n = 43) | Age $\geq$ 32 (n = 68) |
|-----------------------------|-----------------|------------------------|------------------------|
| Achieving pregnancy         | 2.2 (0.9)       | 2.3 (1.0)              | 2.1 (0.9)              |
| Summary score               | 42.1 (14.0)     | 46.4 (13.2)            | 39.4 (14.0)            |
| SexFS, mean (SD)            |                 |                        |                        |
| Erectile function           | 51.6 (6.6)      | 51.1 (7.0)             | 52.0 (6.4)             |
| Satisfaction with sex life  | 49.8 (8.9)      | 50.9 (9.9)             | 49.1 (8.2)             |
| Interest in sexual activity | 51.5 (10.2)     | 52.8 (9.9)             | 50.6 (10.5)            |

BIS = Body Image Scale; QLQ-30 = EORTC QLQ-C30 version 3.0; RCAC = Reproductive Concerns After Cancer; RPLND = retroperitoneal lymph node dissection; SexFS = Sexual Function and Satisfaction measure version 2.0.

\*Adjuvant chemotherapy was received by 64% (n = 35).

†Among participants who had not completed fertility preservation 32% had a wish for children whereas among those who had completed fertility preservation 74% had a wish for children in the future.

‡Cut-off for BIS=10.

scale assessing a range of reproductive and parenthood concerns after cancer.<sup>20</sup> It includes 18 items scored on a 5-point response scale ranging from 1 = “Strongly disagree”–5 = “Strongly agree” and includes 6 dimensions, with 3 items per dimension: “Fertility potential,” “Partner disclosure,” “Child’s health,” “Personal health,” “Acceptance,” and “Achieving pregnancy.” Examples of questions from the dimensions are “I am afraid I won’t be able to have any (more) children” (Fertility potential), “I worry about telling my (potential) spouse/partner that I may be unable to have children” (Partner disclosure), “I am worried about passing on a genetic risk for cancer to my children” (Child’s health), “I am cautious about having (more) children because I might not be around to raise them” (Personal health), “I can accept it if I’m unable to have (more) children” (Acceptance), and “It is stressful to think about trying to achieve a pregnancy (again)” (Achieving pregnancy). The scale was initially developed and validated for use with female young adult cancer survivors between the ages of 18–35.<sup>20</sup> The scale was adapted for men based on expert opinion and cognitive interviews with 10 young adult male cancer survivors.<sup>30</sup> The RCAC has demonstrated satisfactory internal consistency and construct validity in women,<sup>25</sup> and preliminary results indicate that the scale and the 6 subscales also have acceptable internal consistency (0.74–0.92) in men.<sup>30</sup> 3 different reports of the RCAC are used in the current study: (i) A mean value of  $>4$  in 1 dimension to indicate a high level of reproductive concerns in that respective area<sup>20</sup>; (ii)  $\geq 1$  dimension with a mean value  $>4$  to indicate a high level of reproductive concerns overall; (iii) Total scores as continuous measures of level of reproductive concerns (within dimensions and as a summary of all items).

Because the current study and the corresponding study on young women with breast cancer<sup>24</sup> were the first to use the RCAC in Sweden, we translated the English version of the instrument into Swedish. The translation process was conducted by a dual panel as suggested by Swaine-Werdier et al.<sup>31</sup> The scale was independently translated into Swedish by 2 bilingual researchers, evaluated by 2 lay panels and 1 patient panel, and tested in cognitive interviews with 3 young persons with cancer. The evaluation indicated that the RCAC scale was understandable, acceptable, relevant, and covered the concepts/domains intended.

### Body Image

Body image was measured using the Body Image Scale (BIS), which assesses body image discomfort associated with cancer.<sup>10</sup> The BIS consists of 10 items, and responses are given on a 4-point scale, from “Not at all” (0)–“Very much”,<sup>3</sup> with higher scores indicating a more negative body image. A clinically relevant high level of negative body image is defined as a summary score  $>10$ .<sup>10,32</sup> The BIS has shown high test-retest reliability and good internal consistency (Cronbach’s  $\alpha = 0.93$ ) in a sample of patients with cancer.<sup>10</sup>

### Health-Related Quality of Life (QoL)

Health-related QoL was measured using the EORTC QLQ-C30 version 3.0 (QLQ-30-v3.0), which is a 30-item questionnaire developed to assess the QoL of persons with cancer.<sup>33,34</sup> The QLQ-30 has demonstrated good psychometric properties in cancer populations.<sup>33,35</sup> In the current study the summary score (higher values reflect better QoL) for the QLQ-30 was used according to the EORTC QLQ-C30 Scoring Manual (3rd edition) (2001) and Giesinger et al.<sup>34</sup>

### Statistical Analyses

Fisher’s exact test was used to analyze differences between responders and non-responders. Sexual dysfunction and reproductive concerns were calculated using descriptive statistics. The relationships between the domains of the SexFS and the dimensions of the RCAC were analyzed using Pearson’s correlation coefficient. Predictors of sexual dysfunction and reproductive concerns were analyzed using multivariable linear regression, with effects expressed as unstandardized regression coefficients,  $\beta$ , and overall model fit expressed by the  $R^2$ . For sexual dysfunction, the 3 domains “Erectile dysfunction,” “Interest in sexual activity,” and “Satisfaction with sex life” were used as model outcomes. For reproductive concerns, the 6 dimensions were used as model outcomes. The same variables were included as predictors in all models: age (continuous), have children (yes/no), currently partnered (yes/no), time since diagnosis (continuous), fertility preservation (yes/no), wish for (additional) children (yes/uncertain/no), satisfaction with sex life before cancer

**Table 2.** Patient-Reported Outcomes Measurement Information System Sexual Function and Satisfaction measure version 2.0 for young men diagnosed with testicular cancer

|  | n (%)      |
|--|------------|
| Have had sexual activity past 30 days (n = 110)              | 106 (96.4) |
| Have had sexual activity with partner past 30 days (n = 106) | 74 (69.8)  |
| Sexual dysfunction domains* <sup>†</sup>                     |            |
| Erectile function (n = 106)                                  | 8 (8)      |
| Satisfaction with sex life (n = 106)                         | 19 (18)    |
| Sexual interest (n = 109)                                    | 18 (17)    |
| ≥1 domain over cutoff for dysfunction                        | 29 (26)    |
| ≥2 domains over cutoff for dysfunction                       | 11 (11)    |

\*Transformed to T-score with mean = 50 and SD = 10 corresponding to the population of U.S. adults who have been sexually active in the past 30 days. <sup>†</sup>Dysfunction defined as 1 SD below 50.

(low/high), BIS total score (continuous), QLQ-30-summary score (continuous variable), stage of disease (stage I/>stage I), tumor type (seminom/non-seminom), cancer treatment (chemotherapy/no chemotherapy). The variable “Satisfaction with sex-life before cancer” was transformed to a dichotomous variable to facilitate interpretation when used as a predictor in the regression models according to the following principle: response 1–3 determined “low satisfaction” and 4–5 “high satisfaction.” The models were evaluated using significance level *P* < .05 and R<sup>2</sup>. All statistical analyses were performed using SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, NY, USA).

Missing value analyses were performed by visualizing the pattern of missing data, by calculating descriptive statistics (mean, SD, frequency), and by hypothesis testing per variable grouped by missing and observed values. The analyses indicated no significant or systematic patterns.

## RESULTS

### Participants

Of the 224 individuals matching the inclusion criteria, 111 returned the questionnaire representing a response rate of 50%. There were no significant differences between responders and non-responders with regard to age, time since diagnosis, treatment (chemotherapy vs no chemotherapy), clinical stage of the disease (stage I vs >stage I), or tumor type (seminom vs non-seminom).

Mean age at diagnosis was 30.1 years (SD 5.6; range 16–39), and mean age at study participation was 32.1 years (SD 5.5; range 18–42). Sweden was the birth-country for 91% of the participants, and mean number of days since diagnosis was 739 (SD 106, range 550–914). 92% of the participants were not on any current cancer treatment. Sexual orientation was declared as mainly heterosexual by 95% and mainly homosexual by 3% of the participants. Furthermore, 82% had a partnered relationship,

**Table 3.** Reasons for not having had sexual activity with a partner during the past 30 days (n = 32)

| Reasons*   | n (%)   |
|--|---------|
| Lack of partner                                    | 10 (31) |
| Being too tired                                    | 10 (31) |
| Feeling unattractive                               | 7 (22)  |
| Lack of interest in sexual activity                | 7 (22)  |
| Not enough time/too busy                           | 7 (22)  |
| Erectile problems or other problems with the penis | 4 (13)  |
| Partner unavailable                                | 2 (6)   |
| Does not enjoy sexual activities                   | 1 (3)   |
| Do not want to risk a pregnancy                    | 1 (3)   |
| Health issues                                      | 1 (3)   |
| Medication affecting sexual desire                 | 1 (3)   |
| Other  | 6 (18)  |

\*Question posed to participants who reported not having had sexual activity with a partner during the past 30 days. Reasons specified as other included have children, mental health issues, partner uninterested in sex, pregnant partner.

48% had children, and 65% wished for (additional) children in the future. 4 of 5 had conducted fertility preservation, and 50% had received chemotherapy previously. Total summary score for BIS was 4.6 (SD 6.2; Table 1).

### Prevalence Of Sexual Dysfunction and Reproductive Concerns

≥1 domain of sexual dysfunction was reported by one-fourth of the participants (26%), and 1 in 10 (11%) reported ≥2 domains of sexual dysfunction (Table 2). Erectile dysfunction was reported by 8% of the participants. Dysfunction related to satisfaction with sex life was reported by 18%, and dysfunction related to sexual interest was reported by 17%. Most participants had been sexually active in the past month. The most common reasons why participants (n = 32) had not had sex with a partner (besides lack of partner) during the past 30 days were being too tired, feeling unattractive, lack of interest in sexual activity, and not having enough time/being too busy (Table 3).

**Table 4.** Reproductive Concerns After Cancer scale for young men diagnosed with testicular cancer

|                               | Mean (SD)* | Cut off > 4, n(%) |
|-------------------------------|------------|-------------------|
| Fertility potential (n = 110) | 2.4 (1.2)  | 12 (11)           |
| Partner disclosure (n = 109)  | 2.3 (1.2)  | 10 (9)            |
| Child’s health (n = 110)      | 2.5 (1.3)  | 12 (11)           |
| Personal health (n = 110)     | 2.2 (0.9)  | 1 (1)             |
| Acceptance (n = 110)          | 2.5 (1.1)  | 12 (11)           |
| Achieving pregnancy (n = 110) | 2.2 (0.90) | 2 (2)             |
| ≥1 dimension above cutoff*    |            | 31 (28)           |
| ≥2 dimensions above cutoff*   |            | 11 (10)           |

\*Dimensions calculated using all available data.



**Table 5.** Multivariable linear models for the RCAC dimensions for young men diagnosed with testicular cancer

| Predictor variable*<br>β (95% CI) | Fertility potential                  | Partner disclosure                      | Child's health                       | Personal health                         | Acceptance                              | Achieving pregnancy                  |
|-----------------------------------|--------------------------------------|---|--------------------------------------|---|---|--------------------------------------|
| Age                               | 0.02 (-1.13, 5.35)                   | 0.03 (-0.03, 0.08)                      | -0.04 (-0.10, 0.02)                  | 0.03 (-0.01, 0.07)                      | <b>-0.05<sup>†</sup></b> (-0.10, -0.00) | 0.02 (-0.02, 0.06)                   |
| Partner                           | -0.65 (-1.35, 0.05)                  | <b>-0.76<sup>†</sup></b> (-1.48, -0.04) | 0.49 (-0.29, 1.28)                   | -0.11 (-0.72, 0.50)                     | -0.37 (-1.01, 0.28)                     | -0.42 (-0.10, 0.15)                  |
| QLQ-30                            | -0.10 (-0.03, 0.12)                  | 0.01 (-0.02, 0.03)                      | -0.02 (-0.05, 0.00)                  | <b>-0.02<sup>†</sup></b> (-0.04, -0.01) | -0.01 (-0.03, 0.02)                     | -0.02 (-0.34, 0.00)                  |
| BIS                               | <b>0.06<sup>†</sup></b> (0.01, 0.11) | <b>0.08<sup>†</sup></b> (0.02, 0.13)    | <b>0.07<sup>†</sup></b> (0.01, 0.13) | 0.02 (-0.03, 0.06)                      | 0.00 (-0.04, 0.05)                      | 0.01 (-0.03, 0.05)                   |
| Fertility preservation            | 0.15 (0.38, 0.69)                    | 0.32 (-0.25, 0.88)                      | 0.07 (-0.53, 0.67)                   | <b>0.52<sup>†</sup></b> (0.05, 0.98)    | -0.21 (-0.71, 0.30)                     | <b>0.53<sup>†</sup></b> (0.09, 0.97) |
| Wish for children in the future   | 0.41 (-0.11, 0.94)                   | 0.16 (-0.39, 0.70)                      | 0.33 (-0.26, 0.91)                   | 0.12 (-0.34, 0.58)                      | <b>0.58<sup>†</sup></b> (0.09, 1.07)    | 0.17 (-0.26, 0.60)                   |
| R <sup>2</sup>                    | .37                                  | .35                                     | .29                                  | .23                                     | .33                                     | .27                                  |

BIS = Body Image Scale; QLQ-30 = EORTC QLQ-C30 version 3.0; RCAC = Reproductive Concerns After Cancer.

Statistically significant β and CI marked in bold.

Non-significant predictors included in models: Chemotherapy, Fertility preservation, Have children, Satisfaction with sex life before cancer, Stage of disease, Time since diagnosis, and Tumor type. Statistically significant predictor variables reported in table.

\*The following coding was used for the dichotomous predictor variables: Partner: yes = 1, no = 0; Fertility preservation: yes = 1, no = 0; Wish for children in the future: yes = 1, no = 0. For the continuous predictor variables: Higher values on QOL implies higher health-related QoL, higher levels of BIS implies more negative body image.

<sup>†</sup>P < .05.

<sup>‡</sup>P < .01.

Approximately 1 of 4 participants (28%) reported a high level of reproductive concerns in  $\geq 1$  dimension (ie, a mean score  $> 4$  in 1 of the 6 dimensions), and 1 in 10 (10%) reported a high level of concerns in  $\geq 2$  dimensions (ie, a mean score  $> 4$  in 2 of the 6 dimensions; Table 4). With regard to type of concerns, 11% reported a high level in the dimensions “Fertility potential,” “Child’s health,” and “Acceptance.” A total of 9% of the participants reported a high level in the dimension “Partner disclosure.” For the remaining 2 dimensions, very few participants scored above the cutoff.

Combining the above results, 48 participants (43%) were found to report either sexual dysfunction or high levels of reproductive concerns in  $\geq 1$  dimension. Among these, 1 in 4 (n = 12) reported both types of problems. Correlations between the domains of sexual function and dimensions of reproductive concerns were small to medium, ranging from 0.002 to -0.38. The highest correlation was observed between the SexFS domain “Erectile function” and the RCAC dimension “Partner disclosure.”

## Predictors of Sexual Dysfunction and Reproductive Concerns

Results from the multivariable linear regression models are shown in Tables 5 and 6. The models of sexual dysfunction explained 24–51% of the variance in the outcomes, whereas the models of reproductive concerns explained 23–37% of the variance in the outcomes.

Model results showed that higher age predicted lower levels of sexual interest and lower levels of satisfaction with sex life. Having a partner, however, predicted a higher satisfaction with sex life. Both higher sexual interest and satisfaction with sex life were related to higher satisfaction with sex life before cancer. For erectile function, a higher health-related quality of life was associated with higher function. Last, having a negative body image was associated with dissatisfaction with sex life.

For reproductive concerns, having a negative body image was related to more concerns in the dimensions “Fertility potential,” “Partner disclosure,” and “Child’s health.” Having had fertility preservation predicted higher levels of reproductive concerns in the dimensions “Personal health” and “Achieving pregnancy.” A wish for (more) children in the future was associated with lower levels of acceptance of possible infertility, whereas higher age predicted higher levels of acceptance.

## DISCUSSION

The results from this study show that the majority of young men diagnosed with testicular cancer do not report sexual problems or reproductive concerns approximately 2 years after diagnosis. Still, about 1 in 4 report sexual dysfunction in  $\geq 1$  domain, and 1 in 4 report reproductive concerns in  $\geq 1$  dimension.

**Table 6.** Multivariable linear models for the SexFS domains for young men diagnosed with testicular cancer

| Predictor variable*<br>$\beta$ (95% CI)  | Sexual interest                         | Erectile function                    | Satisfaction with sex life              |
|--|---|--------------------------------------|---|
| Age                                      | <b>-0.54<sup>†</sup></b> [-1.02, -0.05] | 0.07 (-0.24, 0.38)                   | <b>-0.41<sup>†</sup></b> [-0.76, -0.07] |
| Partner                                  | 0.18 [-6.51, 6.87]                      | -0.59 [-4.80, 3.63]                  | <b>4.8<sup>†</sup></b> (0.12, 9.49)     |
| QLQ-30                                   | 0.10 [-0.12, 0.32]                      | <b>0.16<sup>†</sup></b> (0.03, 0.30) | 0.06 [-0.10, 0.21]                      |
| BIS                                      | -0.27 [-0.76, 0.22]                     | -0.30 [-0.61, 0.02]                  | <b>-0.42<sup>†</sup></b> [-0.77, -0.07] |
| Satisfaction with sex life before cancer | <b>5.66<sup>†</sup></b> (0.71, 10.60)   | -0.96 [-4.18, 2.27]                  | <b>8.31<sup>†</sup></b> (4.73, 11.89)   |
| R <sup>2</sup>                           | .24                                     | .33                                  | .51                                     |

BIS = Body Image Scale; QLQ-30 = EORTC QLQ-C30 version 3.0; SexFS = Sexual Function and Satisfaction measure version 2.0.

Statistically significant  $\beta$  and CI marked in bold. Non-significant predictors included in models: Chemotherapy, Fertility preservation, Have children, Stage of disease, Time since diagnosis, Tumor type, and Wish for children in the future.

\*The following coding was used for the dichotomous predictor variables: Partner: yes = 1, no = 0; Satisfaction with sex life before cancer: high = 1, low = 0. For the continuous predictor variables: Higher values on QOL implies higher health-related QoL, higher levels of BIS implies more negative body image.

<sup>†</sup> $P < .05$ .

<sup>‡</sup> $P < .001$ .

The prevalence of sexual dysfunction (26%) should be compared with the prevalence of (any) sexual problems in the general male population (all ages), which is about 15% in the United States.<sup>36</sup> Our results, thus, indicate an increased occurrence of sexual dysfunction after a diagnosis of testicular cancer in young men. Among study participants, about 1 in 5 reported dissatisfaction with sex life or low sexual interest, which can be compared to 13–14% of young men in the general U.S. population, who report a low interest in sexual activities.<sup>37</sup> In contrast, the prevalence of erectile dysfunction corresponds to prevalence rates in the general population of young men (8–11%)<sup>38</sup> and, thus, indicates that erectile function is preserved in young men diagnosed with testicular cancer. This result differs from a previous finding for older survivors of testicular cancer where erectile function has been reported to be compromised; however, lack of reliable norms for the measures used in that study hampers conclusions.<sup>8</sup> Besides comparing prevalence rates, the mean scores in the domains can be compared with results from the general population. In each PROMIS domain, the score 50 represents the mean value for the whole U.S. population (all ages). To improve comparisons, however, we used norm values for a younger male population. Such values have been reported for the SexFS, with figures indicating an overall higher sexual function in young men (under the age of 44) as compared with the whole general population.<sup>27</sup> Using these comparison values, the mean scores reported in the present study (49.8–51.6) are lower than the mean scores in these domains for the age-matched norms (52.1–57.0).<sup>27</sup> Thus, in sum, our results indicate that sexual problems are more common among young men who have been diagnosed with testicular cancer than among young men in the general population. Interestingly, this seems to mainly concern the more psychological aspects of sexual function, that is, sexual interest and satisfaction with sex life, whereas erectile function appears to be less affected.

28% of the participants reported a high level of reproductive concerns in  $\geq 1$  dimension of the RCAC. Although there is a lack

of studies examining these concerns in men diagnosed with cancer, the present figures are much lower compared with prevalence rates reported by women after cancer, ranging from 60–65%.<sup>24,25</sup> These results could be related to the specific context of being diagnosed with testicular cancer and the relatively favorable prognosis this implies for both survival and fertility potential. The results could, however, also be explained by gender differences in terms of worry tendency, because women overall have been found to report higher levels of worry as compared with men.<sup>39</sup> It should also be acknowledged that “reproductive concerns” is a multidimensional concept that includes concerns related to both reproduction and parenthood following cancer. The most common areas of reproductive concerns among men in this study were “Fertility potential,” “Child’s health,” and “Acceptance,” reported by 11%, respectively. Future studies are needed to confirm the prevalence of these concerns after testicular cancer, as well as after other cancer diagnoses among men. Our results show that 1 of 4 young men reported high levels of reproductive concerns in  $\geq 1$  areas at 2 years after a diagnosis of testicular cancer, which should be acknowledged during follow-up care.

Sexual function and reproductive concerns were found to be associated, to a limited degree, with the largest correlation seen between the domain “Erectile function” and the RCAC dimension “Partner disclosure” ( $r = 0.38$ ). In a previous study by our group on women with breast cancer,<sup>24</sup> correlations  $< 0.21$  were seen between sexual function and reproductive concerns. The current results, thus, suggest these issues to be somewhat more associated in young men after testicular cancer, although the group who reported both a sexual dysfunction and a high level of reproductive concerns was rather small (11%). Still, our finding that 43% of young men diagnosed with testicular cancer reported either a sexual dysfunction or a high level of reproductive concerns should be acknowledged in survivorship care.

Model results showed that predictors varied between the different types of sexual problems. Older age predicted lower

sexual interest and satisfaction with sex life, which confirms previous findings for men with testicular cancer.<sup>8</sup> Having a partner, on the other hand, was related to a higher satisfaction with sex life, which is consistent with findings identifying a positive impact of partnership on sexual function after testicular cancer.<sup>3,5</sup> Our result that a negative body image was significantly associated with low sexual interest is in line with previous findings among young women with cancer<sup>24</sup> and highlights that body image is an important mechanism related to sexual function among young men after a cancer diagnosis. Another important result is that level of satisfaction with sex life before cancer turned out to be significantly related to both level of sexual interest and satisfaction with sex life. Even though this variable was collected as a retrospective assessment of the pre-cancer level of satisfaction, this finding suggests potential continuity in sexual dysfunction and that mechanisms involved in sexual problems after cancer may not solely be cancer-specific. Last, it is important to acknowledge that none of the clinical variables included in the models (ie, previous chemotherapy, clinical stage of disease, tumor-type) predicted any of the outcomes with regard to sexual function. This result supports the suggestion that psychological mechanisms may be more important in relation to sexual problems after testicular cancer than factors related to diagnosis and treatment.<sup>8</sup> To further improve our understanding of this, future studies could expand models of sexual dysfunction after a cancer diagnosis in young men to also include other potential psychological mechanisms involved in these issues, such as intolerance of uncertainty, emotional avoidance, feelings of loss and grief related to the cancer experience, and levels of depression and anxiety.

Several variables were related to reproductive concerns. Higher age predicted lower levels of reproductive concerns in the area of acceptance, which corresponds with previous results on age and these types of concerns in young women after a cancer diagnosis.<sup>21</sup> Having a partner was related to lower levels of reproductive concerns in the area of partner disclosure, which is not a surprising finding because participants who have a partner may have had opportunities to “practice” these types of conversations. Interestingly, our results showed that having had fertility preservation predicted higher levels of concerns in the dimensions “Personal health” and “Achieving pregnancy.” This finding contradicts results from qualitative studies indicating that male cancer patients regard sperm banking as a proof that care providers believed that they would survive,<sup>40</sup> as a “safety net,” and a buffer against anxiety over possible future infertility.<sup>18,19</sup> However, recent results in young women with cancer have shown similar results with higher levels of reproductive concerns among those who had used fertility preservation.<sup>41</sup> The authors suggested that these findings could be explained by the increased information about the adverse treatment effects on reproductive potential that this group of women may have received. Although such an explanation could apply also to male patients, previous results have suggested that men perceive sperm banking to be performed in haste and not always after discussion and patient involvement in decision-making.<sup>18,42</sup>

Another possible explanation could be that there are other factors, not included in the model, that correlate both with having had fertility preservation and with higher levels of reproductive concerns. 1 such potential factor could be “intolerance of uncertainty,” which is a psychological mechanism known to predict higher levels of worry.<sup>43</sup> This could be a factor explaining both a higher level of reproductive concerns and the choice to preserve sperm. Men who choose to bank sperm may also be more in touch with vulnerable feelings concerning attempts to achieve a pregnancy and future health risks. Last, the association between negative body image and high levels of reproductive concerns underscores that aspects of reproduction are closely related to how men perceive their body, including their masculinity. Previous qualitative research has identified that fertility and sexual virility often are inherently linked in young men,<sup>17</sup> and negative body image (including a perceived loss of masculinity) may be a joint factor explaining both these processes. Our results give some support to such a notion; however, body image, masculinity, and other psychological mechanisms potentially involved in sexual and reproductive sequelae after cancer should be evaluated further in future studies.

### Methodologic Considerations

A strength of this study is the use of the Swedish National Quality Registry for Testicular Cancer. Using this registry allowed collection of high-quality data, with excellent coverage for a year-cohort of all young men diagnosed with testicular cancer in Sweden. However, because testicular cancer is rather uncommon, the sample size ( $n = 111$ ) might still have been too small to precisely characterize some relationships in the regression models. It should be noted that we did not adjust for multiple comparisons in the models, and, thus, the significant associations should be interpreted with some caution. The response rate of 50% should also be considered with regard to the risk of selection bias. Importantly, analyses of non-responders revealed no correlation with background variables, which lowers this risk and increases the external validity of the results. Furthermore, a strength of the study is the use of validated instruments and reliable comparison data that enhance the study quality and enables comparisons. It should be acknowledged that the American norms used to analyze data from the SexFS might not correspond exactly to the Swedish population and that using an age-matched Swedish control group would have strengthened the study design. The clinical validity of the cutoff score that we used to define sexual dysfunction (1 SD below the mean score as recommended by the PROMIS Network [<http://www.nihpromis.org/>]) is reasonable but yet to be confirmed. The conclusions with regard to the prevalence of sexual dysfunction and reproductive concerns should, therefore, be drawn with some caution. Additionally, the single item assessing satisfaction with sex life before cancer is subject to recall bias and is not fully comparable to the SexFS domain “Satisfaction with sex life.” The single item “Satisfaction with sex life previous to cancer” was, thus, useful mainly as a predictor in the regression models to

facilitate interpretation of the model results. Last, it should be mentioned that self-reported sexual function, reproductive concerns, body image, and QoL were collected simultaneously in the survey, and that future longitudinal studies should be conducted to validate the relationships between these concepts.

## CONCLUSION

Although the current study shows that most young men with testicular cancer do not experience sexual dysfunction or high levels of reproductive concerns at 2 years after diagnosis, the subgroup who does experience such problems should be acknowledged. Furthermore, our results indicate that clinical factors do not predict these outcomes; rather, psychological factors were the main mechanisms involved in sexual problems and reproductive concerns after testicular cancer in young men. Negative body image was identified as 1 such factor; however, to fully map and understand the psychological factors involved in these issues, more research will be needed. Last, to improve care provided to this population in the future, men suffering from sexual dysfunction or reproductive concerns in the aftermath of testicular cancer should be offered treatment accordingly.

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