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Psychosexual functioning of female childhood cancer survivors: a report from the St. Jude Lifetime Cohort Study

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Abstract

INTRODUCTION: There is a growing population of childhood cancer survivors at risk for adverse outcomes, including sexual dysfunction.

AIM: To estimate the prevalence of and risk factors for sexual dysfunction among adult female survivors of childhood cancer and evaluate associations between dysfunction and psychological symptoms/quality-of-life (QOL).

METHODS: Female survivors (N=936, mean 7.8±5.6 years at diagnosis; 31±7.8 years at evaluation) and non-cancer controls (N=122) participating in the St. Jude Lifetime Cohort Study completed clinical evaluations, Sexual Functioning Questionnaires (SFQ), and Medical Outcomes

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Survey Short Forms 36 (SF-36). Linear models compared SFQ scores between sexually active survivors (N=712) and controls; survivors with scores <10th percentile of controls were classified with sexual dysfunction. Logistic regression evaluated associations between survivor characteristics and sexual dysfunction, and between sexual dysfunction and QOL.

OUTCOMES: Sexual dysfunction was defined by scores <10th percentile of non-cancer controls on the SFQ overall, as well as the domains of arousal, interest, orgasm and physical problems, while QOL was measured by scores on the SF-36 with both physical and mental summary scales.

RESULTS: Sexual dysfunction was prevalent among 19.9% (95%CI 17.1,23.1) of survivors. Those diagnosed with germ cell tumors (OR=8.82, 95%CI 3.17,24.50), renal tumors (OR=4.49, 95%CI 1.89,10.67) or leukemia (OR=3.09, 95%CI 1.50,6.38) were at greater risk compared to controls. Age at follow-up (45–54 vs. 18–24 years; OR=5.72, 95% CI 1.87,17.49), pelvic surgery (OR=2.03, 95%CI 1.18,3.50), and depression (OR=1.96, 95% CI 1.10,3.51) were associated with sexual dysfunction. Hypogonadism receiving hormone replacement (vs. non-menopausal/non-hypogonadal; OR=3.31, 95%CI 1.53,7.15) represented an additional risk factor in the physical problems (e.g. vaginal pain and dryness) subscale. Survivors with, compared to those without sexual dysfunction, were more likely to score <40 on the physical (21.1% vs. 12.7%, p=0.01) and mental health (36.5% vs. 18.2%, p<0.01) summary scales of the SF-36. Only 2.9% of survivors with sexual dysfunction reported receiving intervention.

CLINICAL IMPLICATIONS: Health care providers should be aware of the increased risk of sexual dysfunction in this growing population, inquire about symptomology, and refer for appropriate intervention.

STRENGTHS & LIMITATIONS: Strengths of this study include the use of a validated tool for evaluating sexual function in a large population of clinically assessed female childhood cancer survivors. Limitations include potential for selection bias, and lack of clinically confirmed dysfunction.

CONCLUSION: Sexual dysfunction is prevalent among female childhood cancer survivors and few survivors receive intervention; further research is needed to determine if those with sexual dysfunction would benefit from targeted interventions.

Keywords

childhood cancer; survivorship; sexual dysfunction; sexual function; psychosexual function

Introduction:

Ten-year survival rates of individuals with childhood cancer diagnoses now exceed 80%,[1] resulting in an increasing population of adult survivors. Many survivors experience adverse health and psychosocial outcomes related to their cancer diagnosis and treatment,[2,3] with over 95% experiencing at least one treatment-related chronic health condition by age 45 years[4,5]. Survivors have an increased prevalence of suboptimal outcomes across physical and psychosocial health domains. Previous studies suggest childhood cancer survivors are at risk for impaired sexual functioning[6–10], postulated to result from disruption of normal psychosexual development during cancer treatment, and/or to long-term effects of cancer therapy[6,8,11–15].

Although research indicates that female survivors have lower scores on measures of sexual function compared to females without a history of childhood cancer[6,10], the burden of dysfunction in this population is not well understood and little is known about the availability of receipt of care for these impairments. Understanding disease- and treatment-related risk factors that may predispose female survivors to poor sexual function may improve targeted screening and/or development of tailored interventions for this population.

In this study of adult, female survivors of childhood cancer, we sought to: (i) estimate the prevalence of sexual dysfunction, and (ii) evaluate socio-demographic, medical, hormonal, health-related quality of life and psychological factors associated with sexual dysfunction.

Methods:

St. Jude Lifetime Cohort Study

Participants were women enrolled in the St. Jude Lifetime Cohort Study (SJLIFE), who were previously treated for a childhood malignancy at St. Jude Children's Research Hospital (SJCRH), or members of a comparison group of community controls. The study was approved by the SJCRH Institutional Review Board (IRB ID SJLIFE) and informed consent was obtained from all participants prior to initiation of any study activities, including questionnaires. Details about the SJLIFE study design, recruitment and participant characteristics have been previously described[16–18]. For this analysis, survivors were females at least 10 years from diagnosis, ≥18 years of age at time of survey completion, responded to health surveys that assessed quality of life and validated measures of psychosexual health, had an intelligence quotient (IQ) ≥70, and had completed a clinical assessment on the St. Jude campus (Figure 1). Community controls, recruited among friends and non-first-degree relatives of patients, were females without a history of childhood cancer, ≥18 years of age at time of survey, and completed a campus visit and surveys assessing quality of life and psychosexual health.

Disease and Treatment Variables

Disease and treatment data, including diagnosis, cumulative dose of individual chemotherapeutic agents, surgical procedures, radiation site and dosage, were obtained from medical records by trained abstractors as previously described[16]. Pelvic surgery was defined as invasive surgical procedures involving pelvic structures undertaken at the time of and up to five years after cancer diagnosis.

Survey Measures

Survivor and control participants completed questionnaires assessing health history, social and demographic factors, and psychosocial functioning, including a women's health questionnaire that specifically assessed reproductive and sexual health.

Sexual Health

Sexual health and functioning were assessed by the Sexual Functioning Questionnaire (SFQ), a gender-specific multi-item questionnaire, previously validated in sexually active cancer survivor cohorts and used in childhood cancer survivors[8,19]. The SFQ addresses

activity, arousal, desire, interest, orgasm, masturbation, problems (including vaginal dryness, tightness, bleeding and pain, as well as increased skin sensitivity), relationships and satisfaction, and provides an overall score and individual sub-scale scores ranging from 0–5, except for the problems sub-scale, ranging from 0–6, with lower scores indicating poorer function. The SFQ does not include a cut-off score, and because estimates of sexual dysfunction prevalence are widely variable across studies,[20–24] for this analysis sexual dysfunction was conservatively defined as a score falling below the 10th percentile score (overall and sub-scales) of the non-cancer controls. The masturbation sub-scale was excluded from this analysis due to a 10th percentile score of zero in controls.

Quality of Life and Psychosocial Outcomes

The Medical Outcomes Study SF-36 was used to assess health-related quality of life (QOL) and includes summary measures of physical and mental health. The SF-36 includes eight sub-scales: physical function, role physical, bodily pain, general health, vitality, social function, role emotional and mental health. This instrument has been used previously to characterize QOL in childhood cancer survivors[25–27]. Results are reported as sex-standardized t-scores with a population mean of 50 and a standard deviation of 10. Those whose t-score was <40, after adjusting for age at assessment, were classified with poor QOL[28]. Psychological symptoms were measured by the Brief Symptom Inventory (BSI-18), an 18-item questionnaire with sub-scales assessing anxiety, depression and somatization[29]. Scores ≥63 after adjustment for age in each sub-scale were considered to represent psychological distress.

Body image was assessed using the Body Image Scale (BIS). Scores on the BIS range from 0–12, with higher scores representing more distress or dissatisfaction[30,31]. Relationship satisfaction was assessed with the Relationship Assessment Scale, composed of a 7-item Likert scale, items scored 1 through 5 on a continuous scale, where higher scores represent higher satisfaction[32].

Hypogonadism and Hormonal Status

Presence or absence of hypogonadism was determined by history and laboratory studies, and included both premature ovarian insufficiency (POI), as well as hypogonadotropic hypogonadism (FSH/LH deficiency); normally timed menopause was considered separately. In women with amenorrhea prior to the age of 40, not on hormone replacement therapy or hormonal contraception, POI was defined by laboratory findings including follicle stimulating hormone (FSH) >30 IU/L and estradiol <17 pg/mL; hypogonadotropic hypogonadism was defined by an estradiol <17 pg/mL and FSH <11.2 IU/L[33]. In women receiving hormone therapy, the diagnosis was based on historical medical information. Women with amenorrhea that occurred after the age of 40, regardless of hormonal values, were assumed to be menopausal. Patients with hysterectomies were grouped with either non-hypogonadal/non-menopausal women, or with menopausal women depending on age, history and hormonal values. Patients with bilateral oophorectomies were defined as having POI if the surgery took place prior to the age of 40 and were otherwise classified as normally-timed menopause.

Statistical analyses

Descriptive statistics were calculated for demographic variables. Comparisons between groups utilized chi-square statistics or t-tests as appropriate. Linear models, adjusting for age at assessment, were used to compare mean sexual functioning scores between survivors and controls. Associations between survivor characteristics and sexual dysfunctions, overall and for arousal, interest, orgasm and problems subscales, which most closely resembled diagnoses in the *Diagnostic and Statistical Reference Manual, 5th Edition*[34], and for associations between sexual dysfunction and QOL were evaluated in separate multivariable logistic regression models. Results are reported as odds ratios (OR) with 95% Confidence Intervals (CI). Initial analyses included all 936 female survivors and are presented in the supplement. However, because the SFQ is validated only among individuals who are sexually active, data presented in the manuscript pertain to the 712 sexually active survivors. When available, missing data was completed with relevant data from the patient medical chart, otherwise left blank if patient report unavailable. Analyses were performed with SAS Version 9.4 (SAS Institute, Cary, NC). Significance was defined using a two-sided p-value of ≤ 0.05.

Results:

Data for this analysis were derived from 1376 survivors who completed a clinical assessment at SJCRH, of whom 936 (68%) completed the SFQ, and 122 community controls who completed both assessments (Figure 1). Participants (N=936) did not differ from eligible non-participants (N=1109) by age at diagnosis, primary diagnosis, pelvic tumors or treatment with chemotherapy or radiation. There were significant differences in race/ethnicity with participants less likely than non-participant survivors to be black and more likely to be Hispanic or other race/ethnicity (Supplemental Table 1). Of 936 participants, 224 did not report having any sexual activity, alone, or with a partner, in the four weeks prior to filling out the SFQ.

Compared with sexually active controls, sexually active survivors were younger at age of assessment, less likely to be married or living as married, less likely to have an annual household income ≥$20,000, have a college degree or higher, be non-Hispanic white, or live independently, and were more likely to have had more than one sexual partner in the last year (Table 1). Survivors were diagnosed with cancer at a mean age of 8.05 years (SD 5.58), and were most commonly diagnosed with leukemia, lymphoma, renal tumors, soft tissue tumors and central nervous system (CNS) tumors (Table 1). Among survivors, almost 85% received chemotherapy, 51.8% received radiation and 14.9% had undergone invasive pelvic surgery at or within five-years of cancer diagnosis (pelvic surgery may not be related to cancer-directed therapy). Of the 12.5% of survivors with a history of hypogonadotropic hypogonadism or premature ovarian insufficiency, 39.3% were receiving hormone replacement (Table 2).

Non-sexually active survivors

The 224 participant survivors with no reported sexual activity in the prior month were younger at diagnosis, less likely to have been married, have an annual household income ≥

$20,000, live independently, have had a child, or to have ever had sexual intercourse (with 67.3% having no sexual partners over the last year) compared to survivors reporting sexual activity in the previous month (Supplemental Table 2). Non-sexually active survivors were more likely to have received radiation therapy, including cranial irradiation, and have hypogonadism without receiving hormone replacement, but did not differ significantly with respect to diagnosis, perceptions of sexual dysfunction, or presence of psychological symptoms (Supplemental Table 2). When analyses were performed with and without the 224 survivors who did not report sexual activity, results were essentially equivalent (Supplemental Table 3). Because the SFQ is validated only for persons who report sexual activity, the final analysis included only the 712 sexually active female survivors and 122 sexually active female controls.

Sexual functioning of sexually active survivors

Survivors were more likely than controls to report overall sexual dysfunction (19.9%, 95% CI 17.1–23.1; vs. 10.7%, 95% CI 5.8–17.5). Survivors with primary diagnoses of germ cell tumors (OR 8.82, 95% CI 3.17–24.50), renal tumors (OR 4.49, 95% CI 1.89–10.67), and leukemia (OR 3.09, 95% CI 1.50–6.38), had the highest odds of reporting dysfunction as compared to controls after adjusting for age at assessment, race and education status (Supplemental Figure 1). Compared to controls, survivors' mean scores on the SFQ were lower overall, and for the arousal desire, interest, orgasm, problems, relationship and satisfaction sub-scales (Table 3, Figure 2).

There were no statistically significant differences between survivors with and without sexual dysfunction regarding marital status, household income, or race/ethnicity, though survivors with dysfunction were less likely to have ever had sexual intercourse or any sexual partners over the last year (Table 1). Moreover, when comparing survivors with and without sexual dysfunction, there were no statistically significant differences in exposures to any chemotherapy, including alkylating agents, or radiation therapy (Table 2). However, a greater proportion of those with dysfunction received an oophorectomy (unilateral or bilateral) than those without.

In a multivariable logistic regression model, survivors aged 35–44 years and ≥45 had increased odds of reporting sexual dysfunction compared to women 18–24 years at time of assessment, in the overall SFQ score as well as the interest and arousal sub-scores (Table 4). Higher educational attainment was associated with a lower odds of overall dysfunction, as well as, orgasm and arousal dysfunction. Survivors with depression had higher odds of sexual dysfunction both overall and in difficulties in the orgasm sub-scale. Survivors with hypogonadism had lower scores on the problems sub-scale than those with normal menstruation or menopause (Table 4). Common sexual problems reported during 75% or more of sexual encounters included lack of interest/desire (18.4% of survivors), inability to achieve orgasm (16.5%), and physical discomfort (e.g. vaginal dryness (15.7%) and vaginal tightness (18.0%) (Table 5)).

Psychological factors of sexually active survivors

Among survivors with sexual dysfunction, 41% reported a perception that they were at greater risk for this impairment compared to other women their age without a history of childhood cancer (Table 6). Despite this perceived risk, only 2.9% of survivors with poor function reported receiving an intervention (medical, psychological or alternative/complementary therapy) addressing sexual function. Sexual dysfunction was also associated with increased symptoms of depression, anxiety and somatization as well as greater distress with body image and lower relationship satisfaction (Table 6).

Quality of Life of sexually active survivors

Compared to survivors without sexual dysfunction, a greater proportion of survivors with dysfunction reported poor health-related quality of life on measures of both composite scores for mental (32.9% vs. 16.1%) and physical health (21.9% vs. 13.8%), and sub-scales for physical functioning (24.8% vs. 12.9%), bodily pain (29.6% vs. 18.5%), general health (34.8% vs. 19.8%), vitality (34.0% vs. 16.6%), social functioning (26.8% vs. 13.7%), role emotional (29.3% vs. 15.2%) and mental health domains (33.3% vs. 15.7%) (Figure 3).

Discussion:

In a large and well-characterized cohort of adult female survivors of childhood cancer with comprehensive treatment, detailed medical history, and clinical and laboratory evaluations, we found the prevalence of self-reported sexual dysfunction to be nearly two-fold higher than that reported by community controls (19.9% vs. 10.7%). Among sexually active survivors, sexual dysfunction was observed overall, and in nearly every sub-scale of the SFQ, including activity, orgasm, problems, relationship, interest, and desire. A substantial proportion of survivors (19.0%) reported dysfunction on the physical problems subscale during sexual activity compared to controls (6.6%) (Table 3). The problems most commonly reported were lack of desire, vaginal tightness, inability to orgasm and vaginal dryness (Table 5). Risk of overall dysfunction was associated with older age at assessment, marital status, depression, and cancer therapy exposures, including pelvic surgeries proximal to cancer diagnosis, as well as laboratory validated hypogonadism, a downstream effect of radiation and alkylating agent exposure[33]. Additionally, sexual dysfunction was associated with psychological distress, underscoring the potential for concurrent emotional and sexual dysfunction in this population.

Unlike our study, a previous analysis from the Childhood Cancer Survivor Study (CCSS) did not consistently find an association between marriage and sexual dysfunction.[8] The reason for the discordance in these results from two large populations of childhood cancer survivors is not clear. However, in the SJLIFE analysis there is a higher proportion of women who reported being married, or living as married, than in the CCSS analysis (67.6% vs. 39.5%, respectively). Other populations have shown an association between being in a relationship or marriage and higher prevalence of sexual dysfunction, including in adult women diagnosed with gynecologic cancer.[35] Similarly, among a general population of women transitioning to menopause, those who were married had lower sexual function scores.[36]

Spousal or partner expectations and/or relationship dynamics affects an individual's sexual function and contributes to these differences.

In assessing differences between diagnostic groups, germ cell tumors, renal tumors and leukemia all demonstrated an increased risk of sexual dysfunction (Supplemental Figure 1). Females with germ cell tumors typically require pelvic surgery and oophorectomy. However, the increased risk of sexual dysfunction among survivors of leukemia and renal tumors was unexpected. While this may be attributable to both psychologic and physiologic factors, in our univariate analysis of treatment characteristics, a greater proportion of survivors with sexual dysfunction received therapy with vincristine than those without dysfunction (Table 2). Treatment for both acute lymphoblastic leukemia (ALL), and Wilms tumor, includes vincristine, a vinca-alkaloid known to increase risk for peripheral and sensory neuropathy.[37] Additional research in larger cohorts is needed to elucidate factors underpinning the higher risk for sexual dysfunction, observed in specific diagnostic groups.

While 40% of our study population perceived that they were at higher risk of sexual dysfunction compared to their peers, less than 3% reported receiving interventions, including psychological, medical or an alternative therapy despite existing treatment guidelines[38,39]. Our study did not specifically assess if female cancer survivors had discussions surrounding sexual functioning with a health care provider, but results suggest that lack of intervention in this population may relate to a deficiency in identifying sexual dysfunction among survivors. While previous reports have shown that childhood cancer survivors have demonstrated problems with sexual development and functioning during their adolescent and young adult years,[11,13,40,41] our data supports that this burden of dysfunction persists well into adulthood, as our cohort includes patients over 18, at least 10 years from diagnosis and the mean age of the women in our cohort was in their 30s.

The literature also highlights deficiencies and gaps between adolescent and young adult cancer patients and their oncologists in communicating about sexual health[42]. While patients desire these conversations, many oncologists feel they lack appropriate training to tackle these discussions or do not feel comfortable engaging in these topics[43]. Furthermore, conversations regarding sexual health may focus on fertility issues rather than being inclusive of all aspects of sexual health, including sexual function[42,43]. While pediatric clinicians share responsibility for discussing sexual health and function with their patients at diagnosis, during therapy and into survivorship (when developmentally appropriate), the persistence of sexual dysfunction into adulthood demonstrates the need for awareness of this high risk population by adult providers, and sexual medicine professionals who may be called upon in ameliorating the burden of symptoms in this population. Childhood cancer survivors experience the bulk of their sexual life outside the ages cared for by their pediatric and oncology practitioners, so early identification of deficiencies in sexual function prompting referral to sexual medicine providers will increase the likelihood of appropriate intervention.

Providing intervention is important, as our study shows an association between survivors with sexual dysfunction experience poorer QOL in both physical and mental health domains, symptoms of emotional distress, concerns with body image, and relationship dissatisfaction.

Prior studies have also shown an association between sexual dysfunction and psychosocial/health-related QOL measures in both survivor and non-cancer populations[6,41,44]. In a cohort of 599 survivors assessing the association between sexual functioning and health-related QOL, female survivors showed a significant association between sexual dysfunction and poorer scores on multiple sub-scales of the SF-36, including bodily pain, general health, vitality, social functioning, role-emotional status, role physical, and overall mental health and physical functioning[41]. It is unclear whether poor function or psychosocial symptoms manifest first, but there likely is a complex reciprocal association as emotional symptoms may contribute to, or be the result of, sexual dysfunction[44]. As other reports in the literature do not consistently show an association between sexual function and mental health or quality of life measures,[40,45] further investigation of this relationship among female survivors of childhood cancer is warranted.

Furthermore, while there are established interventions for sexual dysfunctions, including pelvic floor therapy, and mindfulness techniques, with emerging pharmacologic therapies, such as flibanserin, which may be offered for certain dysfunctions, including decreased sexual desire,[46] it remains unclear whether female childhood cancer survivors will respond similarly to these interventions as their peers without cancer. Providers who care for childhood cancer survivors should inquire about sexual problems and be positioned to facilitate referral to appropriate sexual-health providers, and these providers, including psychologists, sexual therapists, gynecologists and/or pelvic floor therapists should be aware of this growing population of at-risk women[38,47].

Strengths of this research include large sample size, and inclusion of detailed information from prospective medical assessments, as well as patient reported data. However, larger studies are necessary to investigate treatment and psychosocial factors that may be associated with dysfunctions among specific diagnostic categories, as the heterogeneity of diagnosis, treatment exposures, and dysfunction may have limited the power to detect an effect. We were also limited by patient self-report of dysfunction and were unable to document the actual presence or absence of a disorder. Future studies may benefit by correlating SFQ scores to diagnosis of sexual dysfunction via structured interviews by professionals experienced in diagnosing and treating these disorders and testing interventions for sexual dysfunction established in the non-cancer population among cancer survivors. As an important caveat to consider in interpreting the results of this study, the sexually active survivors differed from controls in age at assessment, marital status and annual household income. While these differences have been reported in other studies comparing childhood cancer survivors to a non-cancer population,[8,15] they may represent a source of bias. In addition, this analysis likely underreported sexual problems. Discussing one’s sexual experiences is a sensitive topic. Adolescent and young adult cancer survivors have reported discomfort in initiating conversations surrounding sexual health (42,48) and those with sexual dysfunction may be less likely to complete a survey reporting on this topic.

Conclusions:

Sexual dysfunction is prevalent among female survivors of childhood cancer. Risk factors for sexual dysfunction in this population include pelvic surgery occurring proximal to cancer diagnosis, as well as hormonal deficiencies. Although survivors with sexual dysfunction perceive that they are at risk for sexual dysfunction, few reported receiving intervention. Screening for, and interventions to further identify and treat sexual dysfunction among survivors are needed. Addressing this important problem has potential to improve mental health and enhance overall quality of life. Providers who care for childhood cancer survivors should inquire regularly about sexual functioning and refer to sexual health specialists when indicated. Continued research is necessary to identify risk factors among survivors that characterize high-risk subgroups, as well as, targeted screening and intervention strategies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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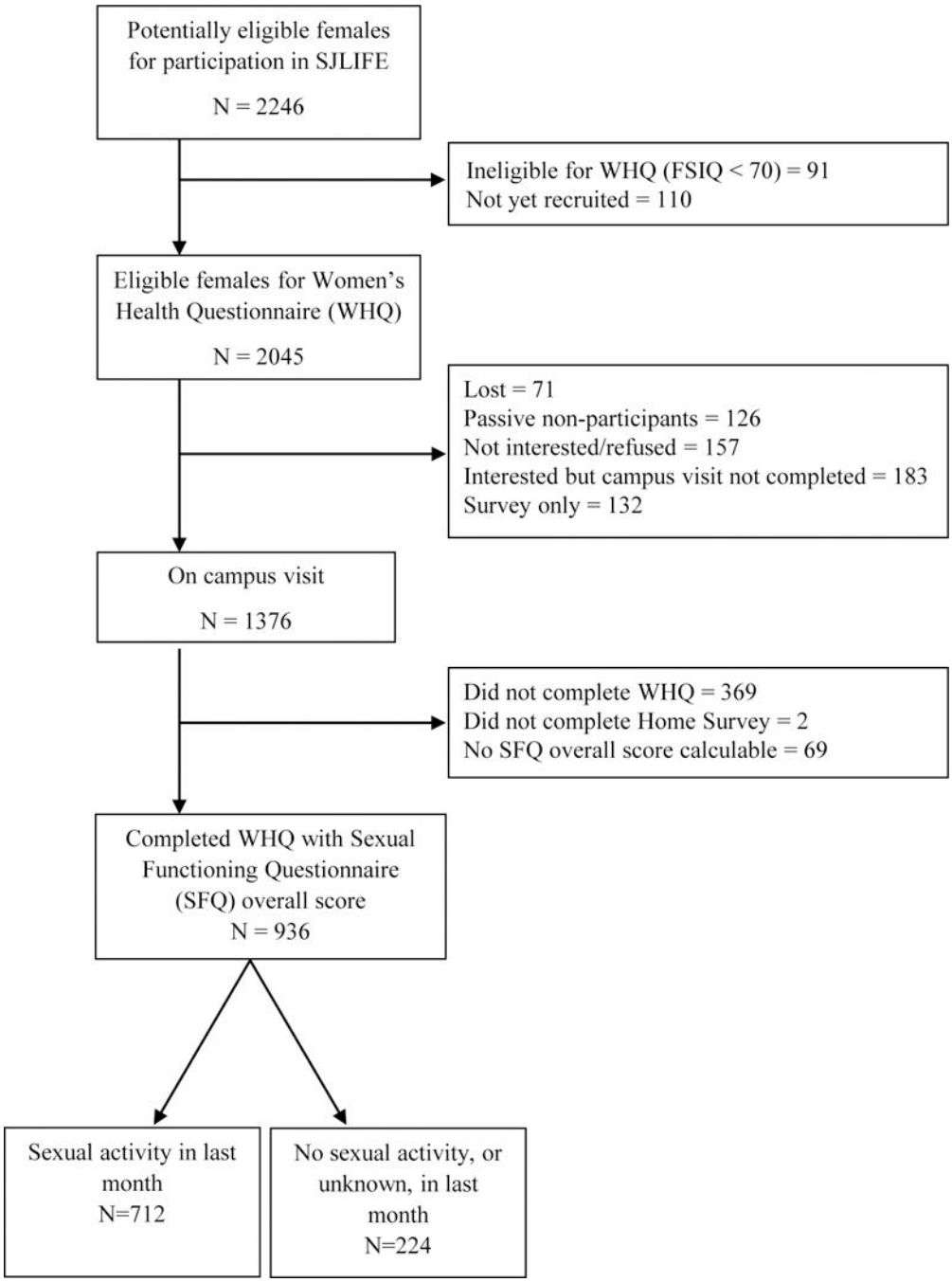

Figure 1:
Consort diagram of enrollment as of June 30, 2015.

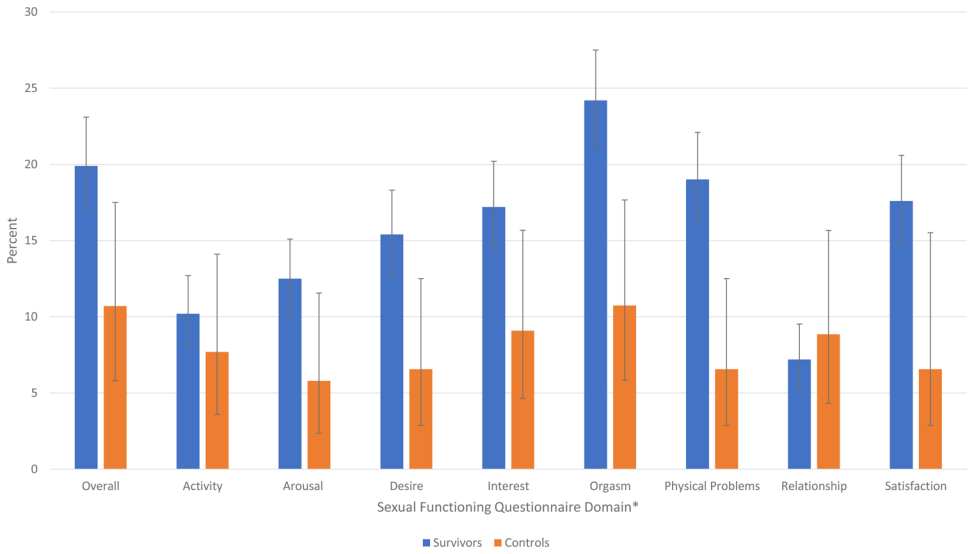

Figure 2:

Percent of survivors and controls reporting sexual dysfunction across Sexual Functioning Questionnaire (SFQ) domains with 95% confidence intervals. *All p-values are <0.02, except for activity and relationship (Table 3).

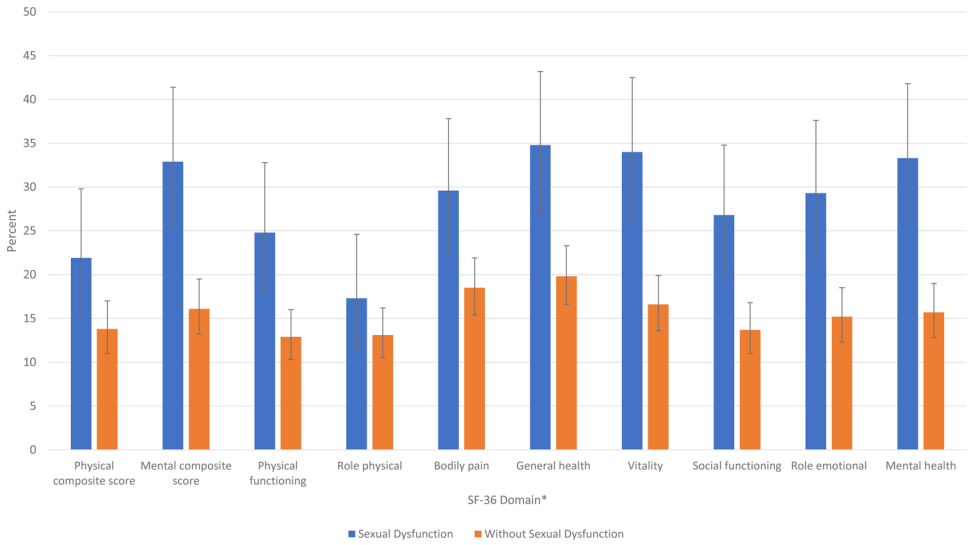

Figure 3:

Percent of sexually active survivors with poor health-related quality of life (score ≤40) on domains of the SF-36 stratified by sexual dysfunction status, with 95% confidence intervals. *All p-values are <0.02, except for role physical (supplemental Table 4).

Table 1.

Sexually active participant sociodemographic characteristics

	Survivors							Controls		
	Total (n=712)		Survivors with sexual dysfunction (n=142)		Survivors without sexual dysfunction (n=570)			Total (n=122)		
Characteristic	Mean (SD)	95% CI	No.	Mean (95% CI)	No.	Mean (95% CI)	p	No.	Mean (95% CI)	p
Age at assessment, years	31.21 (7.71)	(30.64,31.78)	142	33.15 (31.72,34.58)	570	30.72(30.12,31.33)	**0.002**	122	35.79 (34.21,37.37)	**<0.001**
Age at diagnosis, years	8.05 (5.58)	(7.64,8.46)	142	8.47 (7.57,9.37)	570	7.95 (7.49,8.41)	0.31	--	--	
	No.	**%**	**No.**	**%**	**No.**	**%**	**P**	**No.**	**%**	**P**
Marital Status							0.37			**<0.001**
Single, never married	162	22.8	30	21.1	132	23.2		8	6.7	
Married or living as married	481	67.6	102	71.8	379	66.5		102	85.7	
Widowed/ divorced/ separated	69	9.7	10	7.0	59	10.4		9	7.6	
Household income							0.67			**<0.001**
<$20,000	118	17.1	25	18.0	93	16.8		3	2.5	
≥$20,000	511	73.8	99	71.2	412	74.5		113	93.4	
Do not know	63	9.1	15	10.8	48	8.7		5	4.1	
Education							**0.005**			**0.02**
Less than college	164	24.0	44	33.3	120	21.8		17	14.5	
College degree or higher	519	76.0	88	66.7	431	78.2		100	85.5	
Ethnicity/race							0.9			**0.003**
White	566	79.5	116	81.7	450	79.0		104	85.3	
Black	98	13.8	17	12.0	81	14.2		5	4.1	
Hispanic	37	5.2	7	4.9	30	1.6		7	5.7	
Other	11	1.5	2	1.4	9	5.3		6	4.9	
Independent Living							0.86			**0.009**
Not living independently	134	18.8	26	18.3	108	19.0		11	9.1	
Living independently	578	81.2	116	81.7	462	81.1		110	90.9	
Age at first intercourse							**<0.001**			0.14
Never had intercourse	16	2.3	10	7.1	6	1.1		0	0	
<16 years of age	130	18.3	25	17.7	105	18.5		28	23.0	

	Survivors							Controls		
	Total (n=712)		Survivors with sexual dysfunction (n=142)		Survivors without sexual dysfunction (n=570)			Total (n=122)		
Characteristic	Mean (SD)	95% CI	No.	Mean (95% CI)	No.	Mean (95% CI)	p	No.	Mean (95% CI)	p
≥16 years of age	563	79.4	106	75.2	457	80.5		94	77.0	
Number of sexual partners in last year							**<0.001**			**0.009**
None	29	4.1	17	12.1	12	2.1		6	5.0	
1 sexual partner	566	80.4	105	75.0	461	81.7		108	90.0	
> 1 sexual partner	109	15.5	18	12.9	91	16.1		6	5.0	
Biologic Children							0.20			0.10
None	320	44.9	57	40.1	263	46.1		45	36.9	
At least one	392	55.1	85	59.9	307	53.9		77	63.1	
Primary diagnosis							**0.01**			
Leukemia	260	36.5	54	38.0	206	36.1				
Lymphoma	127	17.8	26	18.3	101	17.7				
CNS tumor	51	7.2	6	4.2	45	7.9				
Soft tissue tumor	57	8.0	9	6.3	48	8.4				
Renal Tumor (Wilms)	68	9.6	19	13.4	49	8.6				
Osteosarcoma	24	3.4	4	2.8	20	3.5				
Ewing sarcoma family of tumors	15	2.1	2	1.4	13	2.3				
Retinoblastoma	25	3.5	4	2.8	21	3.7				
Germ cell tumor	31	4.4	13	9.2	18	3.2				
Neuroblastoma	39	5.5	1	0.7	38	6.7				
Other	15	2.1	4	2.8	11	1.9				

Abbreviations: CI, confidence interval; CNS, central nervous system.

Table 2.

Treatment characteristics of sexually active survivors, with and without sexual dysfunction

Characteristic	Survivors, total (n=712) No.	%	Survivors with sexual dysfunction (n= 142) No.	%	Survivors without sexual dysfunction (n= 570) No.	%	p
Any chemotherapy							0.45
No	110	15.5	19	13.4	91	16.0	
Yes	602	84.6	123	86.6	479	84.0	
Any vincristine							**0.03**
No	234	32.9	36	25.4	198	34.7	
Yes	478	67.1	106	74.7	372	65.3	
Alkylators							0.99
None	326	46.1	64	45.7	262	46.2	
0–8000 CED	181	25.6	36	25.7	145	25.6	
8001–12000 CED	121	17.1	25	17.9	96	16.9	
≥12000 CED	79	11.2	15	10.7	64	11.3	
Any radiation							0.11
None	343	48.2	60	42.3	283	49.7	
Yes	369	51.8	82	57.8	287	50.4	
Any cranial radiation							0.29
None	550	77.3	105	73.9	445	78.1	
Yes	162	22.8	37	26.1	125	21.9	
Any pelvic radiation							0.10
None	585	82.2	110	77.5	475	83.3	
Yes	127	17.8	32	22.5	95	16.7	
Any abdominal radiation							0.73
None	564	79.2	111	78.2	453	79.5	
Yes	148	20.8	31	21.8	117	20.5	
Any chest radiation							0.74
None	549	77.1	111	78.2	438	76.8	
Yes	163	22.9	31	21.8	132	23.2	
Pelvic tumor							0.08
No	677	95.1	131	92.3	546	95.8	
Yes	35	4.9	11	7.8	24	4.2	
Pelvic surgery							**0.009**
No	606	85.1	111	78.17	495	86.8	
Yes	106	14.9	31	21.83	75	13.2	
Oophorectomy (uni- or bilateral)							**0.03**
No	625	89.3	116	84.1	509	90.6	
Yes	75	10.7	22	15.9	53	9.4	
Hysterectomy							0.28
No	645	91.0	125	88.7	520	91.6	

Characteristic		Survivors, total (n=712) No.	%	Survivors with sexual dysfunction (n= 142) No.	%	Survivors without sexual dysfunction (n= 570) No.	%	p
	Yes	64	9.0	16	11.4	48	8.5	
Mastectomy								0.09
	No	699	98.2	136	96.5	558	98.6	
	Yes	13	1.8	5	3.6	8	1.4	
Any limb amputation								0.80
	No	686	97.4	136	97.1	550	97.5	
	Yes	18	2.6	4	2.9	14	2.5	
Overall gonadal status								0.09
Non-menopausal/non-hypogonadal		596	83.7	109	76.8	487	85.4	
Hypogonadism with no hormone replacement		54	7.6	15	10.6	39	6.8	
Hypogonadism with hormone replacement		35	4.9	11	7.8	24	4.2	
Menopausal		27	3.8	7	4.9	20	3.5	

Abbreviations: CNS, central nervous system; CED, cyclophosphamide equivalent dose; HSCT, hematopoietic stem cell transplant.

Table 3.

Sexual functioning questionnaire (SFQ) scores of sexually active survivors and controls, adjusted by age at assessment

	Survivors			Controls				Percent of survivors with sexual dysfunction			Percent of controls with sexual dysfunction			
SFQ Scores	**n**	**Mean**	**95% CI**	**n**	**Mean**	**95% CI**	**p**	**n**	**%**	**95% CI**	**n**	**%**	**95% CI**	**p**
Overall	712	3.19	(3.13,3.23)	122	3.47	(3.35,3.60)	**<0.01**	142	19.9	(17.1,23.1)	13	10.7	(5.80,17.50)	**0.015**
Activity	704	2.65	(2.55,2.74)	117	2.87	(2.63,3.10)	0.10	72	10.2	(8.10,12.7)	9	7.69	(3.58,14.10)	0.39
Arousal	706	2.4	(2.30,2.50)	121	2.7	(2.45,2.94)	**0.03**	88	12.5	(10.1,15.1)	7	5.79	(2.36,11.56)	**0.03**
Desire	708	3.43	(3.32,3.53)	122	3.82	(3.56,4.08)	**0.01**	109	15.4	(12.8,18.3)	8	6.56	(2.87,12.5)	**<0.01**
Interest	710	2.08	(1.99,2.17)	121	2.33	(2.11,2.55)	**0.04**	122	17.2	(14.5,20.2)	11	9.09	(4.63,15.68)	**0.02**
Orgasm	712	3.42	(3.35,3.50)	121	3.86	(3.66,4.04)	**<0.01**	172	24.2	(21.1,27.5)	13	10.74	(5.85,17.67)	**<0.01**
Physical Problems	710	4.28	(4.23,4.34)	122	4.52	(4.39,4.65)	**<0.01**	135	19.0	(16.2,22.1)	8	6.6	(2.87,12.51)	**<0.01**
Relationship	625	4.07	(4.00,4.13)	113	4.27	(4.11,4.43)	**0.03**	45	7.2	(5.30,9.52)	10	8.85	(4.33,15.67)	0.54
Satisfaction	712	3.7	(3.62,3.78)	122	4.21	(4.01,4.41)	**<0.01**	125	17.6	(14.8,20.6)	8	6.56	(2.87,15.51)	**<0.01**

Abbreviations: SFQ, Sexual functioning questionnaire; CI, confidence interval.

Table 4.

Multivariable analysis of characteristics of sexually active survivors with sexual dysfunction

	Arousal			Interest			Orgasm			Physical Problems			Overall		
Characteristic	**OR**	**95% CI**	**p**	**OR**	**95% CI**	**p**	**OR**	**95% CI**	**p**	**OR**	**95% CI**	**p**	**OR**	**95% CI**	**p**
Age at diagnosis	1.01	(0.96,1.06)	0.65	1.01	(0.97,1.05)	0.79	1.00	(0.96,1.04)	0.98	1.00	(0.96,1.04)	0.81	0.99	(0.95,1.03)	0.45
Age at follow-up, yrs v. 18–24 yrs															
25–34	1.93	(0.86,4.34)	0.11	1.52	(0.75,3.07)	0.24	1.23	(0.71,2.14)	0.46	0.85	(0.47,1.53)	0.58	1.29	(0.67,2.48)	0.44
35–44	1.47	(0.56,3.87)	0.44	1.68	(0.75,3.74)	0.21	1.58	(0.83,3.01)	0.17	0.87	(0.43,1.77)	0.70	1.68	(0.80,3.55)	0.17
45–54	**8.35**	**(2.22,31.37)**	**0.002**	**4.15**	**(1.29,13.37)**	**0.02**	1.91	(0.66,5.57)	0.23	0.74	(0.24,2.30)	0.60	**5.72**	**(1.87,17.49)**	**0.002**
Marriage status v. single, never married															
Married, living as married	0.72	(0.34,1.51)	0.38	1.35	(0.68,2.68)	0.40	1.34	(0.77,2.35)	0.30	1.27	(0.69,2.33)	0.44	**2.26**	**(1.09,4.66)**	**0.03**
Widowed/divorced	0.43	(0.14,1.37)	0.15	0.63	(0.22,1.80)	0.39	0.64	(0.29,1.42)	0.27	0.69	(0.30,1.64)	0.40	1.15	(0.45,2.96)	0.77
Education status v. less than college degree															
College degree or higher	**0.35**	**(0.20,0.60)**	**<0.001**	0.62	(0.38,1.00)	0.05	**0.59**	**(0.39,0.89)**	**0.01**	0.81	(0.51,1.29)	0.38	**0.56**	**(0.35,0.89)**	**0.01**
Number of sexual partners in last year v. no sexual partners															
1 sexual partner	**0.08**	**(0.03,0.20)**	**<0.001**	1.64	(0.45,5.99)	0.46	0.73	(0.29,1.83)	0.50	1.24	(0.39,3.95)	0.71	**0.08**	**(0.03,0.21)**	**<0.001**
>1 sexual partner	**0.06**	**(0.02,0.17)**	**<0.001**	0.92	(0.22,3.81)	0.90	0.94	(0.35,2.50)	0.90	1.79	(0.54,5.93)	0.34	**0.09**	**(0.03,0.24)**	**<0.001**
Cranial Irradiation v. none															
Yes	1.72	(0.82,3.64)	0.15	1.45	(0.78,2.67)	0.24	1.52	(0.88,2.62)	0.13	0.90	(0.51,1.59)	0.71	1.32	(0.73,2.39)	0.36
Abdominal/Pelvic Irradiation v. none															
Yes	0.77	(0.39,1.52)	0.46	0.77	(0.44,1.34)	0.35	0.62	(0.38,1.00)	0.05	1.30	(0.79,2.15)	0.31	0.89	(0.52,1.51)	0.66
Pelvic Surgery v. none															
Yes	**2.24**	**(1.16,4.33)**	**0.02**	1.30	(0.72,2.36)	0.38	1.62	(0.98,2.67)	0.06	**1.97**	**(1.17,3.31)**	**0.01**	**2.03**	**(1.18,3.50)**	**0.01**
Gonadal Status v. non-menopausal/hypogonadal															
Hypogonadal without hormone replacement	0.69	(0.26,1.82)	0.45	0.97	(0.44,2.13)	0.94	0.87	(0.43,1.77)	0.70	1.93	(0.97,3.84)	0.06	0.97	(0.46,2.07)	0.94
Hypogonadal with hormone replacement	2.44	(0.92,6.42)	0.07	1.79	(0.75,4.25)	0.19	1.95	(0.91,4.21)	0.09	**3.31**	**(1.53,7.15)**	**0.002**	1.74	(0.76,4.00)	0.19
Menopausal	0.41	(0.10,1.73)	0.22	0.64	(0.19,2.18)	0.47	0.71	(0.22,2.30)	0.57	1.22	(0.35,4.17)	0.76	0.47	(0.14,1.54)	0.21
Presence of Depression (BSI-18) v. none															
Yes	1.02	(0.47,2.19)	0.96	1.34	(0.70,2.54)	0.37	**2.00**	**(1.17,3.42)**	**0.01**	1.12	(0.61,2.08)	0.71	**1.96**	**(1.10,3.51)**	**0.02**

Table 5.

Percent of sexual problems experienced by sexually active survivors and controls

	Survivors							Controls							
		Not at all		25%–50% of the time		≥ 75% of the time			Not at all		25%–50% of the time		≥ 75% of the time		
	Total	No.	%	No.	%	No.	%	Total	No.	%	No.	%	No.	%	p
Anxiety about performance	702	505	71.9	156	22.2	41	5.8	122	100	82.0	21	17.2	1	0.8	**0.02**
Lack of sexual desire/interest	705	282	40.0	293	41.6	130	18.4	122	39	32.0	67	54.9	16	13.1	**0.02**
Vaginal tightness	693	367	53.0	201	29.0	125	18.0	120	83	69.2	30	25.0	7	5.8	**<0.01**
Vaginal bleeding or irritation from penetration or intercourse	699	557	79.7	119	17.0	23	3.3	120	98	81.7	19	15.8	3	2.5	0.84
Sharp pain inside or outside your vagina	702	558	79.5	110	15.7	34	4.8	121	110	90.9	7	5.8	4	3.3	**<0.01**
Vaginal dryness during sexual activity	707	270	38.2	326	46.1	111	15.7	122	56	45.9	57	46.7	9	7.4	**0.04**
Pain during penetration or intercourse	708	384	54.2	258	36.4	66	9.3	122	83	68.0	30	24.6	9	7.4	**0.02**
Unable to orgasm	697	316	45.3	266	38.2	115	16.5	122	74	60.7	42	34.4	6	4.9	**<0.01**
Increased skin sensitivity to intimate touching	694	514	74.1	132	19.0	48	6.9	121	86	71.1	27	22.3	8	6.6	0.70
Other problem with sexuality	627	594	94.7	21	3.4	12	1.9	109	103	94.5	4	3.7	2	1.8	0.98

Table 6.

Psychological and pubertal variables of sexually active survivors with and without sexual dysfunction

Characteristic	Survivors, total (n= 712) No.	%	Survivors with sexual dysfunction (n= 142) No.	%	Survivors without sexual dysfunction (n= 570) No.	%	p
Puberty Status							0.21
Early	130	18.4	29	20.9	101	17.8	
Normal	471	66.6	84	60.4	387	68.1	
Late	106	15.0	26	18.7	80	14.1	
Depression							**<0.01**
No	623	88.6	100	70.9	468	83.3	
Yes	80	11.4	41	29.1	94	16.7	
Anxiety							**0.02**
No	622	88.6	117	83.0	505	90.0	
Yes	80	11.4	24	17.0	56	10.0	
Somaticizing							**<0.01**
No	568	80.8	113	80.1	510	90.8	
Yes	135	19.2	28	19.9	52	9.3	
History of intervention for sexual dysfunction							0.15
No	688	98.4	132	97.1	556	98.8	
Yes	11	1.6	4	2.9	7	1.2	
Perception of sexual dysfunction (compared to peers)							**<0.01**
Less	117	16.8	20	14.3	97	17.5	
same	400	57.5	63	45.0	337	60.6	
more	179	25.7	57	40.7	122	21.9	
Perceptions of infertility (compared to peers)							0.83
less	103	14.7	22	15.6	81	14.5	
same	229	32.7	48	34.0	181	32.3	
more	369	52.6	71	50.4	298	53.2	
Overall body image	709	6.6	142	8.7	567	6.1	**<0.01**
Relationship Satisfaction	606	30.0	111	26.8	495	30.8	**<0.01**