ORIGINAL RESEARCH—ONCOLOGY

Sexual Function in Childhood Cancer Survivors: A Report from Project REACH

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ABSTRACT

Introduction. Of the approximately 12,000 children and adolescents that will be diagnosed with cancer in 2013, it is expected that over 80% of them will become long-term adult survivors of childhood cancer. Although it has been well established that cancer treatment often has profound negative impact on sexual functioning, sexual functioning in adult survivors of childhood cancer is not well understood.

Aim. The aim of the current study was to examine the report of sexual function in adult survivors of childhood cancer in relationship to both physical and emotional functioning.

Methods. Two hundred ninety-one participants enrolled in Project REACH, a longitudinal study of childhood cancer survivors, completed questionnaires as part of an annual health survey.

Main Outcome Measure. Primary outcome measures included the sexual functioning subscale of the Swedish Health-Related Quality of Life Survey, the SF-12, and the BSI-18.

Results. Results indicate that 29% of young adult survivors reported two or more discrete symptoms of sexual dysfunction. Females were twice as likely to report sexual problems. Sexual problems were not related to specific types of childhood cancer treatments such as type of chemotherapy or radiation. Young adults with sexual dysfunction did report poorer functioning across the range of SF-12 subscales including physical functioning, general health, fatigue, and mental health.

Conclusions. Significant sexual dysfunction is common in adult survivors of childhood cancer. A greater understanding of the particular relationship between sexual dysfunction and both physical and emotional well-being in this relatively young population is needed. Even when long-term cancer survivors are young adults and report generally good health, results underscore the need for clinicians to specifically assess sexual functioning. **Bober SL, Zhou ES, Chen B, Manley PE, Kenney LB, and Recklitis CJ. Sexual function in childhood cancer survivors: A report from Project REACH. J Sex Med 2013;10:2084–2093.**

Key Words. Cancer Survivorship; Young Adult; Psycho-Sexual; Pediatric Cancer

Introduction

Adult Survivors of Childhood Cancer

More than 80% of children diagnosed with cancer will be successfully treated and join the estimated 329,000 adult survivors of childhood cancer in the United States [1]. Unfortunately, the intensive treatments that effectively cure these pediatric cancers also leave survivors at increased risk for significant late effects, including decrements to neuro-cognitive and psychosocial functioning, as well as a host of complex medical issues (e.g., endocrine and cardiopulmonary dysfunction). These treatment-related effects have been documented up to 30 years postdiagnosis [2], and such late effects can lead to notable compromises in quality of life for these survivors [3,4].

Despite the attention paid to medical late effects of childhood cancer treatment, the topic of sexual functioning in young adult survivors of childhood cancer has garnered considerably less attention [5,6,7]. This is surprising as many of the organ systems involved in sexual function, including hormonal, vascular, genitourinary, and neurological, can be disrupted by childhood cancer treatment [8,9]. For example, it is well known that childhood cancer survivors are at risk for impaired fertility [10,11], underscoring the effects of treatment on their normal physiological development [10–13]. In addition, it is also known that childhood cancer survivors face potential disruptions in social and psychosexual development [14,15], which may leave them less sociable and more isolated than their peers [16], less likely to marry [17], and more likely to depend on their family to meet their psychosocial needs [18]. Given this tendency to be more closely engaged with family and less engaged with peers, it is not surprising that this population shows greater restriction in sexual behavior (decreased masturbation and likelihood of talking with friends about sex) [19,20], delays in reaching psychosexual milestones (e.g., dating, masturbation, and intercourse [21]), and decreased sexual interest and satisfaction with sex [22].

Aims

Given their increased risk for sexual dysfunction, the goal of this study is to better describe sexual health problems in childhood cancer survivors and to investigate the relationship of these problems to general health and well-being. To date, there has been limited research that specifically examined sexual dysfunction in young adult survivors of childhood cancer [21–23]. In order to expand and contribute to the current literature, we sought to: (i) describe self-reported sexual function in a sample of young adult survivors of childhood cancer, with a particular focus on identifying the prevalence of significant sexual dysfunction; (ii) determine if observed cases of sexual dysfunction were associated with specific treatments associated with disruption in physiological functions important for normal sexual function; and (iii) evaluate the relationships between sexual function and psychological and physical quality of life for these survivors.

Methods

Study Participants and Procedures
Participants were adult survivors of childhood cancers enrolled in Project REACH (Research

Evaluating After Cancer Health), a cohort study designed to evaluate psychosocial and medical outcomes in cancer survivors [24–27]. Survivors enrolled on this study agree to complete a yearly self-report survey of health outcomes, as well as periodic supplementary mailed surveys. To be eligible for Project REACH, participants are required to be: (i) survivors of a malignancy other than nonmelanoma skin cancer; (ii) ≥2 years from their cancer diagnosis; (iii) ≥1 year from completion of cancer therapy (excluding chemopreventive agents); (iv) English speaking; and (v) not have a sensory or cognitive impairment that would interfere with their ability to independently complete self-report health measures. Consenting participants completed the measures during a clinic visit and medical information was abstracted to provide data on treatment history and health status. All procedures were approved by the cancer center's Institutional Review Board.

Participants in the study were recruited from one of two long-term follow-up clinics specializing in the care of childhood cancer survivors. Self-report measures of sexual health were included as part of Project REACH survey administered to survivors age 18 and older. A total of 291 participants self-reported on their sexual health.

Main Outcome Measures

Demographics and Treatment-Specific Variables
Participant demographic variables and treatment-specific variables were collected both in the study questionnaire and by chart review. To address the potential impact of cancer treatment on sexual function, participant's exposure to treatments known to or suspected to effect pubertal development, fertility, and/or sexual function was documented by medical record review. Participants were considered to have had a relevant chemotherapeutic exposure if they had received the alkylating agents carboplatin, lomustine, chlorambucil, cisplatin, cyclophosphamide, dacarbazine, ifosfamide, melphalan, nitrogen mustard, or procarbazine. Participants were considered to have had a relevant radiation therapy exposure if they had received radiation involving the abdomen, head, pelvis, nasopharynx, spinal, or testes. In addition, we also documented relevant surgical procedures that could affect sexual function including pelvic, genitourinary, abdominal, or cranial surgeries. Because of retrospective data collection limitations, the

participant's information related to doses of radiation or chemotherapeutic agents was not collected.

Sexual Functioning

Five items comprising a validated general sexual functioning subscale within the Swedish Health-Related Quality of Life Survey (Swed-QUAL [28]) were utilized to evaluate sexual functioning. The Swed-QUAL scale is a measure that was adapted from the Medical Outcomes Study scale [29]. Participants were asked to rate their sexual functioning on a four-point scale (Completely agree/Partly agree/Partly disagree/Completely disagree). Scale items can be seen in Table 2. In order to capture survivors with significant sexual dysfunction, participants were classified as "Cases" if they endorsed at least two Swed-QUAL items, by indicating they "completely" or "partly" agreed with the item.

Health-Related Quality of Life

The Short-Form 12 (SF-12 [30]) is a 12-item measure, validated across both general and multiple patient populations, including cancer survivors [31], that was used to evaluate the participant's current health-related quality of life. The SF-12 asks respondents to rate their emotional and physical health functioning, and their responses are used to generate scores on eight subscales: Energy/Fatigue, Bodily Pain, Physical Functioning, Role-Physical, General Health, Social Functioning, Role-Emotional, and Mental Health. These scales are scored as a standardized t-score with a mean of 50, and a standard deviation of 10. On each SF-12 scale a cutoff score of 1 standard deviation below the mean (scores ≤ 40) was used as an indicator of significant problems in health-related quality of life.

Psychological Distress

The Brief Symptom Inventory-18 (BSI-18 [32]) is an 18-item symptom checklist designed as a measure of psychological distress. It provides subscale scores for depression, anxiety, and somatization, as well as a total psychological distress summary score. The BSI-18 is scored with a mean of 50, and a standard deviation of 10. The BSI-18 scales have been previously utilized in adult survivors of childhood cancer populations [33]. In the present study, a cutoff score of 57 was used to indicate significant levels of psychological distress [25,34].

Statistical Analyses

Descriptive statistics were used to describe participants on demographic, treatment, and sexual health variables. Participants were classified as having significant impairment in sexual function if they endorsed two or more items on the Swed-QUAL measure. We compared sexual dysfunction cases vs. noncases across study variables including demographics, disease and treatment variables, and the SF-12 and BSI-18 scales. t-Tests were used to compare cases and noncases on continuous variables, and chi-square tests were used to compare them on categorical variables. The effect sizes for the comparison between cases and noncases on psychosocial outcomes were calculated utilizing Cohen's d. We examined the relationship between cases and noncases of sexual dysfunction with cases of significant psychological distress (BSI-18; scores ≥ 57) and significantly impaired health-related quality of life (SF-12; scores ≤ 40) for the whole sample, and separately by gender using chi-square tests. Additionally, we evaluated whether gender was a significant predictor of whether a participant was a case vs. a noncase of sexual dysfunction, after controlling for significant covariates, using logistic regression analyses.

Results

Demographics, Classification Criteria, and Case Characteristics

Participants were an average of 27 years of age (range: 18–57) at the time of the study, and 52% were female. They were diagnosed with a variety of forms of cancer, with the primary diagnoses being brain tumors (32%), lymphoma (23%), leukemia (22%), and sarcoma (12%). Further demographic and medical information is described in Table 1.

As described in Table 2, the most commonly endorsed items of sexual problems within the overall sample included a lack of interest in sex (30%), difficulties enjoying sex (24%), and difficulties being aroused (23%). Difficulties with erections were reported by 19% of men, and 29% of women reported problems achieving orgasm. After applying classification criteria (i.e., those experiencing ≥ 2 items on the Swed-QUAL sexual functioning measure), 29% of the participants were identified as sexual dysfunction cases.

Comparison between sexual dysfunction cases and noncases revealed that sexual dysfunction cases were significantly older (M = 30.8 years) than noncases (M = 25.4 years, P < 0.01). Females were significantly more likely to be sexual dysfunction cases than males (37% vs. 20%, P < 0.01). After controlling for age, gender was still a significant

Table 1 Demographic and medical information for sample (N = 291)

	Case N = 84		Noncase N = 207		Total N = 291		P value
	N	%	N	%	N	%	
Gender							0.001**
Female	56	37.3	94	62.7	150	51.5	
Male	28	19.9	113	80.1	141	48.5	
Age at survey (years)							<0.01**
18–21	14	14.4	83	85.6	97	33.3	
22–27	26	27.7	68	72.3	94	32.3	
≥28	44	44.0	56	56.0	100	34.4	
Age at diagnosis (years)							0.946
≤5	24	27.6	63	72.4	87	29.9	
6–12	22	28.9	54	71.1	76	26.1	
>13	38	29.7	90	70.3	128	44.0	
Diagnosis							0.913
Brain tumor	24	26.1	68	73.9	92	31.6	
Hodgkin's lymphoma	22	32.8	45	67.2	67	23.0	
Leukemia	19	29.7	45	70.3	64	22.0	
Sarcoma	10	29.4	24	70.6	34	11.7	
Other	9	26.5	25	73.5	34	11.7	
Treatment							
Chemotherapy							0.23
Yes	20	23.8	64	76.2	84	28.9	
No	64	30.9	143	69.1	207	71.1	
Cranial radiation							0.96
Yes	14	28.6	35	71.4	49	16.8	
No	70	28.9	172	71.1	242	83.2	
Abdominal radiation							0.33
Yes	6	40.0	9	60.0	15	5.2	
No	78	28.3	198	71.7	276	94.8	
Pelvic radiation							0.22
Yes	5	45.5	6	54.5	11	3.8	
No	79	28.2	201	71.8	280	96.2	
Cranial surgery							0.61
Yes	12	32.4	25	67.6	37	12.7	
No	72	28.3	182	71.7	254	87.3	
Pelvic surgery							0.99
Yes	2	28.6	5	71.4	7	2.4	
No	82	28.9	202	71.1	284	97.6	
Transplant							0.85
Yes	4	26.7	11	73.3	15	5.2	
No	80	29.0	196	71.0	276	94.8	

**P < 0.01
Noncase refers to survivors who endorsed <2 items on the Swed-QUAL sexual functioning subscale

predictor of whether an individual was a case of sexual dysfunction ($P < 0.01$). Contrary to expectations, sexual functioning was neither significantly related to the type of cancer diagnosis, nor with exposure to treatments possibly associated with sexual dysfunction ($P > 0.20$). In addition, sexual functioning was not related to age at diagnosis ($P > 0.90$).

As seen in Table 3, survivors experiencing sexual dysfunction also reported higher levels of anxiety ($P < 0.01$) and depression ($P < 0.01$) on the BSI-18, and poorer functioning across all subscales of the SF-12 including physical functioning, role-physical, general health, energy/fatigue, social functioning, role-emotional, and mental health ($P < 0.01$), with the exception of bodily pain ($P = 0.16$). Furthermore, survivors experiencing sexual dysfunction were more likely to report clinically elevated levels of depression and anxiety (scores ≥ 57 on the BSI-18), as well as significantly low levels of levels health-related quality of life (scores ≤ 40 on the SF-12) on the physical functioning, role-physical, energy, social functioning, role-emotional, and mental health scales ($P < 0.05$). When these analyses were conducted separately by gender (Table 4), results on the BSI-18 were consistent, with both males and females who reported significant sexual dysfunction being more likely to report clinically elevated levels of anxiety and depression (scores ≥ 57 on the BSI-18) ($P < 0.01$). On the SF-12, both males and females with significant sexual dysfunction

Table 2 Five-item sexual functioning subscale from the Swedish Health-Related Quality of Life Survey, and responses

	Case N = 84		Noncase N = 207		Total N = 291	
	N	%	N	%	N	%
Number of survivors endorsing Swed-QUAL items:						
1. I am not interested in sex.	53	63.1	31	15.0	84	29.5
2. I have difficulties in relaxing and enjoying sex.	60	71.4	8	3.9	68	23.9
3. I have difficulties in becoming sexually aroused.	62	73.8	2	1.0	64	22.9
4. I am afraid of the physical effort involved in sexual intercourse.	26	31.0	0	0	26	12.4
5a (Men) I have difficulties in getting and/or keeping an erection.	23	27.4	3	1.4	26	18.7
5b (Women) I have difficulties in having an orgasm.	32	38.1	9	4.3	42	28.5
Number of endorsed items						
0 (noncase)	—	—	154	74.4	154	52.9
1 (noncase)	—	—	53	25.6	53	18.2
2 (case)	29	34.5	—	—	29	10.0
3 (case)	30	35.7	—	—	30	10.3
4 (case)	17	20.2	—	—	17	5.8
5 (case)	8	9.5	—	—	8	2.7

Noncase refers to survivors who endorsed <2 items on the Swed-QUAL sexual functioning subscale.

were more likely to report significantly impaired health-related quality of life. Of note, the pattern of association with SF-12 scales differed between genders and differed from the aggregated results when male and female survivors were analyzed together. Specifically, females' sexual health cases reported significant limitations on role-emotional, mental health, energy/fatigue, and social functioning scales ($P < 0.05$), while males with significant sexual dysfunction were more likely to report poor function on the role-physical and bodily pain scales ($P < 0.05$).

Discussion

Our results, showing that almost one third of pediatric cancer survivors report significant sexual problems, highlight the importance of attending to sexual dysfunction in this vulnerable group of young adults. Despite growing acknowledgment that long-term survivors of pediatric cancer are likely to suffer from a range of treatment-related chronic health conditions, little attention has been paid to their sexual functioning. Unlike previous studies of sexual symptoms in childhood survivors [22,23], we chose to implement a more stringent definition for sexual dysfunction in this study, with survivors considered to have significant sexual dysfunction only if they endorsed two or more symptoms with at least moderate level of agreement. Despite using this more stringent classification criteria to define sexual dysfunction, childhood cancer survivors were still three times more likely to report sexual problems when compared with general population studies of young adults under the age of 40 [35]. Further, it is striking that of the

survivors who met criteria for sexual dysfunction in this study, the majority (65%) endorsed three or more discrete sexual problems, underscoring the range and severity of difficulties facing these young survivors.

Factors Associated with Sexual Dysfunction

Female survivors in the study were twice as likely as their male counterparts to report marked sexual impairment. This result is consistent with previous studies of sexual dysfunction in the general population [36], though prior studies of childhood cancer survivors have not consistently reported more sexual problems among women [22,23]. It has been hypothesized that young women in the

Table 3 Comparison of psychosocial functioning (Brief Symptom Inventory-18 [BSI-18] and Short-Form-12 [SF-12]) between cases and noncases

	Case x̄	Noncase x̄	P value	Effect size
BSI-18				
Anxiety	50.9	45.5	0.005**	0.38
Depression	52.7	46.7	0.001**	0.46
SF-12				
Physical Function	50.4	52.7	0.029*	0.28
Role-Physical	48.9	53.1	<0.001**	0.47
General Health	48.4	52.3	0.002**	0.42
Energy/Fatigue	46.6	53.6	<0.001**	0.77
Social Function	48.4	52.5	<0.001**	0.45
Role-Emotional	46.4	51.5	<0.001**	0.58
Mental Health	46.9	52.7	<0.001**	0.67
Bodily Pain	52.1	53.8	0.16	0.19

*$P < 0.05$
**$P < 0.01$
Noncase refers to survivors who endorsed <2 items on the Swed-QUAL sexual functioning subscale. Higher scores on the BSI-18 indicate increased levels of anxiety and depression. Higher scores on the SF-12 indicate better quality of life.

Table 4 Percentage of cases and noncases of sexual dysfunction meeting clinical criteria for psychological distress and health status across gender

	Male N = 141		Female N = 150		Total N = 291	
	Sexual dysfunction %	No sexual dysfunction %	Sexual dysfunction %	No sexual dysfunction %	Sexual dysfunction %	No sexual dysfunction %
BSI-18						
Anxiety	46.4**	21.2**	30.4**	12.8**	35.7**	17.4**
Depression	57.1**	23.0**	30.4**	12.8**	39.3**	18.4**
SF-12						
Physical Function	21.4	8.8	19.6	13.8	20.2*	11.1*
Role-Physical	28.6**	5.3**	16.1	9.6	20.2**	7.2**
General Health	14.3	7.1	12.5	7.4	13.1	7.2
Energy/Fatigue	21.4	11.5	42.9**	13.8**	35.7**	12.6**
Social Function	14.3	13.3	25.0*	9.6*	21.4*	11.6*
Role-Emotional	21.4	11.5	28.6**	9.6**	26.2**	10.6**
Mental Health	21.4	14.2	32.1**	10.6**	28.6**	12.6**
Bodily Pain	14.3*	3.5*	7.1	7.4	9.5	5.3

*$P < 0.05$
**$P < 0.01$
Clinical cutoff criteria for BSI-18 (≥ 57) and clinical cutoff for SF-12 (≤ 40)
BSI-18 = Brief Symptom Inventory-18; SF-12 = Short-Form-12

general population may be at greater risk for sexual dysfunction than men because they are more vulnerable to stress and anxiety related to relationship problems, sexual inexperience, and periods of sexual inactivity [36]. In the childhood cancer survivor population, women have been shown to be more vulnerable to some physical, cognitive, and emotional late-effects of treatment, including being at greater risk for posttraumatic stress symptoms [37]. It has been posited that young women may perceive changes such as the impact of treatment on body image and psychosexual development as being more traumatic than male peers and that this is one reason why female survivors may be more vulnerable to consequent cancer-related sexual dysfunction [23]. Moreover, long-term effects of treatment on menopausal status and vaginal health (e.g., vaginal dryness or vaginal atrophy) may additionally be related to loss of sexual function in this group of young women. While findings from the current study do not specifically support any of these hypothesized mechanisms, they provide new evidence for the greater vulnerability of female survivors of childhood cancers, and underscore the need to prioritize this vulnerability in both clinical care and future research.

Like gender, age was found to be significantly related to sexual dysfunction in our sample of childhood cancer survivors. Survivors with sexual dysfunction were older than their unaffected peers. Although sexual dysfunction is reported to increase with age in the general population [38],

the average age of the survivors with significant sexual dysfunction in the study was only 30, well below the age symptoms of sexual dysfunction are seen in the general population [35]. Rather than being related to the effects of normative aging on sexual function, our findings suggest that sexual dysfunction may be part of a larger pattern of treatment-related health problems which emerge in childhood cancer survivors during young adulthood. As a group, these young adult survivors are at risk for a variety of treatment related late-effects that can negatively affect cardiac, pulmonary, hormonal, and neurological systems. As late-effects, many of these sequelae of therapy are not typically present at the conclusion of cancer treatment, but emerge over time [2,39]. Studies from the Childhood Cancer Survivors study show that as these survivors move into adulthood, 73% of them will face at least one chronic health condition, and 42% of them will have severe, disabling, or life-threatening conditions [2]. Our finding, in which increased age during young adulthood was related to increased sexual dysfunction, parallels this trajectory of medical late-effects, and suggests that sexual dysfunction may need to be understood as part of this broader picture of medical late-effects for survivors of childhood cancer.

While we had expected sexual dysfunction in this group to be associated with specific cancer treatments that can disrupt physiological systems important for sexual function, the results did not support this hypothesis. This is surprising, especially because sexual dysfunction in survivors of

adult cancers can be closely linked with specific treatments such as chemotherapy or radiation that induces early menopause in women [40–42], or surgical treatments that compromise erectile function in men [43,44]. This may reflect limitations in the way the treatments and treatment combinations were measured, but it may also reflect differences in the way cancer therapies affect sexual function in adults and children. In adults, with presumably normal premorbid physiology, the effects of cancer treatment on sexual function may be easily perceived if they result in immediate and profound disruption of sexual function. By contrast, children are sexually immature, and so cancer treatments can affect the maturational processes which give rise to mature sexual development, and function later in adulthood. Consequently, this relationship between cancer treatment in childhood and later sexual function may be more complex, and difficult to investigate. There are also significant individual differences that likely influence the long-term impact of cancer treatment on the severity and timing of medical late-effects. For example, treatments associated with gonadal failure may not do so in a way that is consistent and easy to capture across ages, genders, and ages of treatment. Furthermore, treatments not conventionally considered to have effects on sexual health may in fact do so by subtle effects on other organ systems. As noted, childhood cancer survivors are at risk for a variety of medical late-effects that emerge in adulthood, and these late-effects, including organ toxicities, or constitutional factors such as fatigue, may all contribute to sexual health problems. While our study did not directly measure specific medical late-effects, the fact that young adults with sexual dysfunction in our study reported poorer functioning across the range of SF-12 subscales including physical functioning, general health, fatigue, and mental health, is consistent with this hypothesis.

Survivors with significant sexual dysfunction also reported higher levels of anxiety and depression. This was seen not only in differences in scale elevations, but also when examining the likelihood of significantly elevated ratings of anxiety and depression. Looking at particular differences between men and women, we noted that men with sexual problems were more likely to endorse significantly worse physical functioning on the SF-12, whereas women with sexual dysfunction were more likely to endorse significantly worse emotional functioning on the BSI-18. Interestingly, our findings contrast with those of Zebrack and colleagues who found that women's report of physical impairment was more likely to be associated with sexual dysfunction, whereas men's report of mental health impairment was more likely to be associated with sexual dysfunction [23]. Certainly it has been well established that sexual problems in general are related to decrements in both physical and emotional functioning [36], and clinical implications from our findings underscore the need for clinicians to specifically address concerns about sexual function in all young adult survivors of childhood cancer, but especially those reporting symptoms of physical impairment and/or emotional distress.

Study Limitations

In evaluating the findings reported here, it is important to acknowledge the limitations of the study. While the sexual dysfunction measure used here, the Swed-QUAL, is a validated measure that has been used in previous studies of cancer survivors [23], it is a brief measure that may not capture important aspects of sexual function in our sample. A more in-depth measure that includes more detailed information about a broader range of symptoms as well assessment of sexual dysfunction-related distress would be useful to more fully characterize the sexual health problems experienced by this group of cancer survivors. In addition, because the study lacked a normative comparison group, we have had to rely on comparisons with previously reported normative data, but this can be difficult because past studies have used different measures of sexual dysfunction and different algorithms for defining sexual dysfunction. While we are confident that the 29% of survivors meeting the study definition of sexual dysfunction indicate an elevated risk of sexual dysfunction in this group, future research directly comparing childhood cancer survivors and controls will be useful for quantifying the increased risk in these survivors. As noted, because findings between sexual dysfunction and reports of emotional and physical impairment were correlational, further inquiry will be required in order to establish causal directionality of this relationship. Future inquiry may include assessing current medications (e.g., antidepressants) and evaluating how such medications may be related to current sexual function. Fortunately, the subjects in this study are enrolled in a prospective cohort study, which will allow us to follow them prospectively so that we can look at the relationship between physical health, emotional health, and sexual

functioning over time. In this longitudinal study we can also look more specifically at medical late-effects, including symptoms of fatigue, menopause, and chronic illness, to better understand how these factors affect the development of sexual health problems in childhood cancer survivors.

Implications and Future Directions

Despite these limitations, results of the study provide important information about the impact of childhood cancer treatment on sexual function in later life. The number of young adult cancer survivors who reported multiple sexual health problems was very high in this cohort of almost 300 childhood survivors. Our results underscore the stark reality that a significant number of young adult survivors of childhood cancer report the presence of multiple sexual problems and need effective intervention. Just as importantly, sexual dysfunction in this group does not appear to be tied to the specific treatment exposures that have been associated with gonadal toxicity or infertility in this group. This should caution clinicians against limiting their assessment of sexual health to survivors exposed to specific cancer treatments, but rather underscore the need to assess sexual health in childhood cancer survivors more broadly. Unfortunately, previous studies of sexual health indicate that both oncologists and primary care physicians may neglect to assess sexual health in their patients [45–47]. Although clinicians have recently become much more likely to address treatment-related reproductive functioning [48], this has not yet been the case regarding sexual function. Further study is warranted to better understand the barriers to addressing sexual dysfunction in this young population including how it may or may not be related to fertility-related concerns. Additional use of qualitative methodology may help illuminate these issues. In order to facilitate greater integration of sexual health in cancer survivorship care, new initiatives to promote better assessment, evaluation, and referral for sexual health problems will need to be developed.

Sexual health problems were observed to be related to problems in physical and emotional health, indicating that sexual problems may be tied to broader decrements in physical and emotional health that are well documented in this group of cancer survivors. While few studies have looked directly at sexual function in childhood cancer survivors, our results indicate that it is a common problem in this group. Future research examining the development of sexual dysfunction and the relationship to other medical late-effects will be needed to better understand the causes of sexual problems and to develop effective interventions that can address sexual symptoms in this group. Understanding the relationship of sexual problems to specific medical and psychological late-effects may be a particularly important area to investigate, as it may be that treatment of psychological distress and/or treatment-related physical impairment, such as fatigue or body pain, could be very effective in treating certain sexual symptoms. Additional investigation is also needed to more specifically understand how the psychosexual needs of cancer survivors diagnosed in childhood may or may not be similar to those cancer survivors who are diagnosed during their adolescent years. As we await the development of evidence-based treatments for sexual health problems in this group of survivors, existing sexual health treatments will need to be made available for the significant proportion of childhood cancer survivors who experience sexual health problems as young adults.

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