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Sexual functioning in young adult survivors of childhood cancer

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Abstract

***Background*: Studies of sexuality or sexual behavior in childhood cancer survivors tend to examine relationships or achievement of developmental milestones but not physiological response to cancer or treatment. The purpose of this study is to (1) identify prevalence and risk factors for sexual dysfunction in childhood cancer survivors, and (2) examine the extent to which sexual dysfunction may be associated with health-related quality of life (HRQOL) and psychosocial outcomes.**

***Methods*: Five hundred ninety-nine survivors age 18–39 years completed standardized measures of sexual functioning, HRQOL, psychological distress and life satisfaction. Descriptive statistics assessed prevalence of sexual symptoms. Bivariate analyses identified correlates of sexual symptoms and examined associations between symptoms and HRQOL/psychosocial outcomes.**

***Results*: Most survivors appear to be doing well, although 52% of female survivors and 32% of male survivors reported at least 'a little of a problem' in one or more areas of sexual functioning. Mean symptom score for females was more than twice that of males. Sexual symptoms were associated with reporting health problems. Significant associations between sexual functioning and HRQOL outcomes were observed, with gender differences in strengths of association suggesting that males find sexual symptoms more distressing than do females.**

***Conclusions*: While most survivors appear to be doing well in this important life domain, some young adult survivors report sexual concerns. While female survivors may report more sexual symptoms than male survivors, males may experience more distress associated with sexual difficulties. Better-specified measures of sexual function, behavior and outcomes are needed for this young adult population.**

Keywords: sexual functioning; cancer survivor; childhood cancer; quality of life; psychosocial; gender

Medical illness has an adverse effect on sexual health, most often due to physical symptoms or the sequelae of treatment [1,2]. Schover [3] summarizes the physiological impacts of cancer treatments on adult sexuality in that cancer treatments may damage one or more physiological systems needed for a healthy sexual response, including hormonal, vascular, neurologic and psychological elements of sexual function. As a result of these impacts, sexual dysfunction may be characterized by disturbances in sexual desire and/or in the psycho-physiological changes associated with the human sexual response cycle [4].

The National Health and Social Life Survey (NHSLS) conceptualizes sexual dysfunction as symptoms or problems associated with (1) desire for sex; (2) arousal difficulties (i.e. erection problems in men, lubrication in women); (3) inability to achieve climax or ejaculation; (4) anxiety about sexual performance; (5) climaxing or ejaculating too rapidly; (6) physical pain during intercourse and (7) not finding sex pleasurable [5]. Large-scale population-based studies of sexual health report prevalence of sexual dysfunction in the general population at 10–52% for men and 25–63% for women [6,7]. The NHSLS (inclusive of US adults age 18–59 years) suggests the prevalence of sexual dysfunction at 43% of women and 31% of men [5]. The NHSLS also found married men and women to be at lower risk of experiencing sexual symptoms when compared with non-married counterparts. Age also was a strong predictor of sexual difficulties, with younger persons reporting fewer symptoms. Others have

suggested that higher rates of sexual symptoms in older adults are attributable to morbidities associated with aging, and not with aging in and of itself [2,8,9].

Although it is important to note what sexual dysfunction is, it is equally important to recognize that many people experience 'dysfunction' but are not distressed. For example, women with anorgasmia who participated in a supportive care program to increase orgasm reported that the program made them more satisfied with their sex lives even though their anorgasmia remained unchanged [10]. In a study of non-distressed marriages many women indicated that sexual satisfaction was not related to desire, sexual activity frequency or number of orgasms, but to closeness in relationship, sexual attitudes and assertiveness [11]. In contrast, Ganz [12] reported that young adults with cancer (*not* young adult survivors of childhood cancer) experience greater distress as a result of sexual dysfunction or other reproductive effects associated with treatment when compared with older adults. Thus, it is important to examine sexual dysfunction to the extent that it is associated with distress, life satisfaction or health-related quality of life (HRQOL).

Research on sexual functioning in adult cancer patients and survivors is replete with studies focusing on biophysiological response (see, for example, Hollenbeck *et al*. [13]; Ganz *et al*. [14]; Miller *et al*. [15]), whereas studies of sexuality or sexual functioning in childhood cancer survivors tend to examine infertility or achievement of psychosexual milestones. For example, childhood cancer survivors experience delays in dating and initiating social contacts [16,17], in marriage [18–20] and in first time having sexual intercourse [21–23]. They may be less likely than peers to be sexually active and perhaps less satisfied with their interpersonal relationships and sex life [23–26]. A recent Dutch study [17] of 60 childhood cancer survivors indicated that half the sample reported being seldom or never able to feel themselves sexually attractive, felt almost no sexual attraction, and seldom or never satisfied with their sexual lives. Forty-one percent of the sample reported 'sexual problems' and 18% reported negative effects of their disease on their sexual life.

There appears to be a gap in the literature with regard to physiological aspects of sexuality in young adult survivors of childhood cancer. Apparently there are no reports of the extent to which cancer or treatment experienced as a child has any affect on young adult survivors' sexual interest, ability to relax and enjoy sex, arousal or ability to achieve orgasm. Furthermore, there appear to be no reports of how sexual dysfunction may be associated with psychosocial health status or HRQOL. Indeed, a recent review of the state of the science with regard to HRQOL in childhood cancer survivors did not identify any studies reporting on the potential role that sexual functioning may play as it relates or contributes to psychosocial function, well-being or HRQOL. [27]. Thus, the purpose of the study reported here is to (1) identify prevalence and risk factors for sexual dysfunction in young adult survivors of childhood cancer, and (2) examine the extent to which sexual dysfunction is associated with HRQOL, psychological distress and life satisfaction.

Methods

Participants and procedures

A potential pool of 2864 respondents was derived from electronic records maintained at two Southern California institutions that treat pediatric oncology patients and one mid-western United States children's hospital. Study eligibility criteria permitted inclusion of survivors who were off treatment and disease-free at the time of questionnaire completion, were between the ages of 18–39 years at time of study, and 21 years of age or younger when diagnosed with a malignancy. Potential subjects were mailed survey questionnaires, informed consent forms and a self-addressed stamped envelope. Investigators maintained logs of when surveys were mailed and returned. Subjects failing to return their survey after 2 weeks were mailed a reminder letter. After another 2 weeks, investigators mailed out a second survey to non-respondents as a final reminder. Unless the US postal service returned a survey to marked 'non-deliverable', a subject who did not return a survey was considered a non-responder. All returned surveys were reviewed for completeness. Missing data or items needing clarification were noted and a staff research assistant contacted subjects via US mail to obtain missing data. Missing data (e.g. age, age at diagnosis, cancer type) were supplemented by the reviews of institutional records to the extent possible. All protocols and questionnaires were approved by the Institutional Review Boards of all collaborating institutions.

Measures

The MOS Sexual Functioning [28] scale is a widely used and validated instrument that identifies sexual impairments and dysfunction associated with serious health conditions or side effects of treatments. The items focus on problems that respondents perceive in their capacity to achieve sexual arousal and orgasm. Four items for men and four items for women are administered on an ordinal scale ranging from 0 = 'not a problem' to 4 = 'very much a problem'. A fifth category permits respondents to indicate 'not applicable', which is to be

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interpreted as an indication of not being sexually active [29]. As per scoring instructions, the 'not applicable' category is to be recoded as zero ('not a problem') when scoring the measure. Summary scores are calculated for men and women separately by averaging items and then transforming the scores to a 0–100 range scale. Higher scores indicate more problems. Internal consistency reliability (Cronbach's alpha) in this sample was 0.90 for men and 0.90 for women.

HRQOL was assessed using the SF-36 [30], a widely used and well-validated instrument that assesses health status with regard to physical, social and psychological functioning. Psychological distress was assessed by the 18-item Brief Symptom Inventory (BSI-18) [31], an ordinal level scale assessing the severity of symptoms indicative of depression, anxiety and somatic distress. Life satisfaction was assessed by the Ladder of Life [32], a visual acuity scale ranging from 0–10 on which respondents indicate their satisfaction with life on a 'ladder' ranging from 'worst possible life' to 'best possible life' at three time points (past, present, future).

Analyses

Descriptive statistics were calculated for demographic and cancer-related health status variables. Means scores for the MOS Sexual Functioning measure were compared among study participants using general linear models adjusting for age at study and age at diagnosis. Pearson product–moment correlations were calculated to examine bivariate associations among sexual functioning scores and the SF-36 subscales, the BSI-subscales, the Ladder of Life scores, age at study and age at diagnosis. SPSS version 15.0 was used for analyses.

Results

From 2864 mailed surveys, the US postal service returned 576 (20.3%) unopened surveys, indicating they were undeliverable. An additional 22 returned surveys were marked 'deceased'. Among 2266 assumedly live subjects for whom surveys were not returned by the postal service, 666 (29.3%) consented to participate and completed a self-report questionnaire. The remaining 1600 subjects were deemed 'non-respondents'. Of the 666 respondents, 39 were eliminated from subsequent analyses due to surveys being completed by individuals who in fact did not fit eligibility criteria with regard to age at study (18–39 years old), age at diagnosis (21 years or younger) or treatment status (not currently receiving treatment), or because the questionnaire was completed by a surrogate. An additional 28 respondents did not complete portions of the survey necessary to examine the variables of interest for this analysis. Thus, the analyses reported here are based on responses from the 599 participants.

A comparison of these respondents to non-respondents showed that respondents were significantly more likely to be female ($p < 0.000$) (Table 1). Respondents and non-respondents also differed significantly in terms of cancer diagnoses, with a larger than expected proportion of leukemia survivors and smaller than expected proportion of brain tumor survivors comprising the respondent group ($p < 0.001$). No statistically significant differences were observed with regard to age at study, age at diagnosis or years since diagnosis. Sample characteristics are summarized in Table 1.

Sexual functioning

Frequencies for individual items are summarized in Table 2. Missing data for any given item was no more than 5%. For any given symptom, most survivors reported an absence of sexual problems. Fifty-two percent of females and 32% of males reported at least 'a little of a problem' in one or more areas of their sexual functioning. Overall, 42.7% of the entire sample endorsed at least one problematic symptom.

Overall mean symptom score (transformed) for females (21.6) was more than twice that of males (10.6) (Table 3). No statistically significant differences in sexual functioning were observed across education, race or type of cancer. Male survivors with incomes of less than $25 000 reported significantly higher symptom scores than did males earning more than $25 000. Scores for men and women reporting health problems were significantly greater than for those reporting no health problems. Married female survivors reported significantly greater sexual dysfunction than did non-married female survivors, whereas no significant differences (at $p < 0.05$) were seen for males. Age at study and age at diagnosis were associated with reporting symptoms, with symptom scores increasing among older survivors and those diagnosed at older ages (Table 4).

Life satisfaction

Statistically significant correlations between sexual dysfunction and life satisfaction were observed for both male and females. Current and past life satisfaction increased significantly as survivors reported less sexual dysfunction (Table 4). Only for males was future life satisfaction associated with sexual functioning in that an anticipated better life in the future was associated with less sexual dysfunction.

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Table I. Sample characteristics of respondents and non-respondents

Variables	Respondents $n = 599$	Non-respondents $n = 1600$
	Freq (%)	Freq (%)
*Gender****		
Female	316 (52.8)	612 (39.8)
Male	282 (47.2)	927 (60.2)
Race/ethnicity		
White	380 (64.7)	NA
Black	24 (4.1)	
API	36 (6.1)	
Hispanic/Latino	138 (23.5)	
AmerInd	7 (1.2)	
Employment status		
Unemployed[a]	73 (12.5)	NA
Employed/occupied[b]	510 (87.5)	
Education		
HS Grad or less	115 (19.7)	NA
Some college	270 (46.2)	
4-year college grad	199 (34.1)	
Marital status		
No	318 (54.0)	NA
Yes	271 (46.0)	
Income		
⩽$25K	201 (35.3)	NA
$25-$75K	234 (41.1)	
>$75K	135 (23.7)	
*Cancer Type****		
Leukemia	225 (37.7)	173 (21.1)
Hodgkins' disease	98 (16.4)	121 (14.8)
Non-Hodgkin's Lymphoma	54 (9.0)	74 (9.0)
CNS/Brain Tumor	79 (13.2)	191 (23.3)
Solid tumors/soft tissue tumors	73 (12.2)	74 (9.0)
Kidney (e.g. Wilm's)	25 (4.2)	34 (4.2)
Other[c]	43 (7.2)	152 (18.6)
Reports current health problems (other than cancer related)		
No	267 (45.7)	NA
Yes	317 (54.3)	
Age at study, in years		
Mean (SD)	27.0 (5.5)	26.5 (5.5)
Range: 18–39		
Age at diagnosis, in years		
Mean (SD)	11.0 (6.0)	10.8 (6.1)
Range: 0–21		
Years since diagnosis		
Mean (SD)	16.0 (7.0)	15.7 (6.9)
Range: 2–37		

NA = not available from participating institutions; frequencies do not always add up to 599 for survivors or 1600 for non-respondents due to missing data.
*Indicates statistically significant differences at $p<0.05$; ** $p<0.01$; *** $p<0.001$.
[a]includes those 'on leave/disability', 'unemployed' or 'permanently unable to work'.
[b]includes 'full-time employment', 'part-time employment', 'student', or 'homemaker'.
[c]Includes germ cell tumors, retinoblastoma, neuroblastoma and other tumors not specified.

Distress

Sexual functioning was significantly correlated with all subscale and global measures of distress for both males and females (Table 4). Those reporting more dysfunction also reported greater depressive symptoms, somatization and anxiety, as well as a greater overall symptom index score.

HRQOL

Both males and females reported significant negative associations between sexual dysfunction and six of the eight subscales comprising the SF-36 (Table 4). HRQOL with regard to bodily pain, general health, vitality, social functioning, role-emotional status and mental health was worse among those reporting greater sexual dysfunction. Greater sexual dysfunction also was significantly associated with lower role function-physical for females. In examining the two component scores of the SF-36, sexual dysfunction was significantly associated with worse mental health functioning (MCS) for both men and women. Sexual dysfunction was significantly associated with worse physical functioning (PCS) for females only. Overall, the strength of association for sexual symptoms and all HRQOL, life satisfaction and distress measures was greater for males than for females (Table 4).

Discussion

This manuscript reports the prevalence of sexual dysfunction in a moderately large sample of young adult survivors of childhood cancer. While most survivors appear to be doing well in this important life domain, some young adult survivors report sexual concerns. For some, sexual dysfunction appears associated with detriments in psychological health and quality of life.

The proportion of respondents reporting at least 'a little bit of a problem' (43%) is roughly comparable to the 41% of childhood cancer survivors indicating 'sexual problems' in the childhood cancer survivor study by van Dijk *et al.* [17]. In addition, a comparison of findings here to results from the NHSLS is informative when considered in the context of the difference in age ranges for these studies. For example, the NHSLS is inclusive of US adults age 18–59 years, whereas the age range for survivors in this study was 18–39. Using Sherbourne's [28] algorithm for determining sexual dysfunction, in which any response other than 'not at all' suggests some level of dysfunction, the proportion of young adult survivors of childhood cancer demonstrating sexual dysfunction in this study (53% for females; 31% for males) exceeds the 43% of women and 32% of men reported in the NHSLS [5]. Given that the rates of sexual dysfunction increase with age in the general population [2,5,33], one could argue that the proportion of those reporting sexual dysfunction in this younger childhood cancer survivor cohort should in fact *be less than* the proportions reported in the NHSLS. As it is not, and in the absence of

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Table 2. Descriptive statistics for MOS sexual functioning scale

	Frequency (%) of item response			
	Not a problem	**A little of a problem**	**Somewhat of a problem**	**Very much a problem**
Men				
Lack of sexual interest	219 (79.9)	28 (10.2)	15 (5.5)	12 (4.4)
Unable to relax and enjoy sex	218 (79.9)	24 (8.8)	24 (8.8)	7 (2.6)
Difficulty in becoming sexually aroused	232 (84.7)	22 (8.0)	12 (4.4)	8 (2.9)
Difficulty getting or keeping an erection	218 (79.6)	33 (12.1)	8 (2.9)	15 (5.5)
Women				
Lack of sexual interest	190 (62.7)	54 (17.8)	31 (10.2)	28 (9.2)
Unable to relax and enjoy sex	197 (65.2)	47 (15.6)	34 (11.3)	24 (7.9)
Difficulty in becoming sexually aroused	199 (65.9)	52 (17.2)	30 (9.9)	21 (6.6)
Difficulty in having an orgasm	182 (60.5)	44 (14.6)	41 (13.6)	34 (11.3)

Table 3. Sexual dysfunction scores by select sociodemographic and medical characteristics; means and standard errors adjusted for age at study and age at diagnosis

	Females		**Males**	
	Mean (se)	***F* (*p*-value)**	**Mean (se)**	***F* (*p*-value)**
Overall	21.6 (28.6)		10.6 (21.6)	
Race/ethnicity				
White	22.7 (2.0)	0.67	11.8 (1.6)	1.15
Non-White	19.8 (2.9)	(0.41)	8.9 (2.2)	(0.29)
Education				
HS Grad or less	20.4 (4.6)	0.05	10.6 (2.6)	0.20
Some college	22.1 (2.4)	(0.95)	10.0 (2.0)	(0.82)
4-year college grad	21.9 (2.7)		12.1 (2.6)	
Marital status				
No	17.7 (2.3)	6.48	12.9 (1.8)	3.10
Yes	26.1 (2.3)	(0.01)	8.0 (2.0)	(0.08)
Income				
<$25K	25.4 (2.8)	2.00	15.2 (2.3)	5.8
>$25K	20.4 (2.1)	(0.16)	8.5 (1.6)	(.02)
Cancer Type				
Leukemia	19.4 (2.8)	0.60	12.4 (2.1)	0.97
Hodgkin's disease	22.7 (4.1)	(0.73)	4.4 (3.3)	(.45)
NHL	31.6 (6.6)		11.7 (3.9)	
CNS/brain tumor	20.1 (4.7)		9.1 (3.8)	
Solid tumors/soft tissue tumors	24.6 (4.5)		12.0 (4.0)	
Kidney tumor (Wilm's)	18.2 (7.2)		6.3 (9.7)	
Other	23.4 (6.6)		15.5 (4.7)	
Reports health problems				
No	13.4 (2.5)	19.0	6.9 (1.8)	8.52
Yes	27.9 (2.1)	(0.000)	14.6 (1.9)	(0.004)

F-statistic derived from general linear models, adjusted for age at study and age at diagnosis.

normative population data on sexual dysfunction in adolescents and young adults, these findings suggest that childhood cancer survivors may be at increased risk for sexual dysfunction. It is possible, however, that these differences across studies are confounded by the use of different instruments to assess sexual problems.

Gender differences

Female survivors appear to be far more significantly affected in their sexual functioning than are male survivors, with a symptom score being twice that of males. Furthermore, much larger proportions of females (12%–19% per item) compared with males (6%–12% per item) endorsed the 'not applicable' response, suggesting less involvement in sexual activity. These findings in and of themselves do not necessarily mean that women's sexual lives are more problematic than those of men. Theory and research in sexuality distinguishes two different physiologic and cognitive processes underlying men's and women's sexual attitudes and behavior. Women tend to operate within a cognitive framework of 'Am I desirable', whereas men operate from a vantage point of 'What do I desire?' [34] Research on gender differences in patterns of genital sexual

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Table 4. Bivariate Pearson product-moment correlations (p. 60)

	Sexual function	
	Male	**Female**
Age at Dx	0.163**	0.140*
Age at study	0.228**	0.134*
Life satisfaction		
Now	−0.362**	−0.209**
In the past	−0.139*	−0.142*
In the future	−0.384**	−0.110
Distress		
Depressive symptoms	0.433**	0.291**
Somatization	0.335**	0.233**
Anxiety	0.408**	0.285**
Global Index Score	0.430**	0.311**
HRQOL		
Physical function	−0.076	−0.107
Role-physical	−0.080	−0.196**
Bodily pain	−0.179**	−0.122*
General health	−0.285**	−0.261**
Vitality	−0.369**	−0.248**
Social functioning	−0.386**	−0.225**
Role-emotional	−0.349**	−0.213**
Mental health	−0.407**	−0.201**
Physical Component Score	−0.039	−0.157**
Mental Component Score	−0.425**	−0.243**

*$p \leq 0.05$; **$p \leq 0.01$.

arousal suggest that physiological arousal for women, as measured by lubrication and swelling, is not associated (statistically correlated) with their subjective experience of feeling sexually aroused [35]. In contrast, men experience a strong positive correlation between subjective sexual arousal and physiological response. The meaning and significance of this difference is that sexual arousal in women is manifested as a psychological experience inclusive of awareness of both desire and being desired, and is not directly correlated with the physiological response of genital swelling and lubrication. It may be that cultural expectations for females to contextualize experience, along with the physiological differences in anatomic structures—literally that males can see their arousal and females cannot—form the basis for different experiences of desire and arousal. Thus, if female cancer survivors are not dating or in a serious intimate relationship then they are potentially less likely to be aware of desire and arousal since they are less likely to be engaging in sexual activity and intercourse. In the general population even masturbation begins at a later point in development for females than for males, in that women typically masturbate after they have reached their late teens/early twenties and usually after they have begun a sexual relationship [36].

Another reason why there might be twice the number of females indicating sexual symptoms as compared with males may be the potentially traumatizing nature of cancer treatment. Indeed, post-traumatic stress symptoms have been reported in both male and female children treated for childhood cancers [37,38], and female survivors have been identified as being at significantly greater risk for experiencing post-traumatic stress [39]. It may be that young women are more likely than young men to experience cancer-related physical changes, medical procedures and treatment as traumatic assaults impacting their physical being, psychosexual development and heightened awareness about body and body image. Given that research and theory on childhood development suggest that females are more vulnerable to being traumatized by abuse than are males [40–42], gender differences in sexual dysfunction may be attributable to how males and females differ in their experiences of cancer as traumatic or abusive. The differential impact of sexual dysfunction among male and female childhood cancer survivors may indeed be related to post-traumatic stress symptoms.

The gender differences in the associations between life satisfaction and HRQOL observed here are notable and further distinguish males from females with regard to the role that sex plays in their lives. The significant statistical relationship between sexual symptoms and lower life satisfaction in the future for males only suggests that males anticipate sex to be an important component of future life satisfaction, whereas females do not, or at least to a much lesser extent. With regard to HRQOL, sexual dysfunction was associated with physical limitations interfering with daily lives and overall physical functioning (as indicated by the Physical Component Score of the SF-36) only for women. For men, regardless of their physical health or functioning, their sexual capabilities and desires do not appear affected. In contrast, an examination of the magnitude of the correlation coefficients among the SF-36 subscale scores and sexual symptoms scores suggests that for men, *mental* health functioning appears more salient as it relates to reporting sexual symptoms, as sexual symptoms was correlated with the Mental Health Component Score of the SF-36 at $r = -0.43$ for males as compared with $r = -0.24$ for females. Overall, the gender differences in strengths of association observed between sexual symptoms and all HRQOL and distress measures suggest that male survivors report greater distress associated with sexual symptoms than do female survivors.

Other factors associated with sexual problems

The correlation coefficients reported here suggest that decrements in HRQOL and psychological well-being may be partially attributable to sexual problems, and perhaps that sexual problems are exacerbated by limitations in physical functioning

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and mental health status. Data suggested that respondents reporting health problems were significantly more likely to report sexual problems. Although a direction of causation cannot be determined at this time, due to the limits of a cross-sectional research design, it seems evident that sexual health plays an important role in the constellation of HRQOL in this population. Furthermore, given that the reporting of sexual symptoms appeared to increase with age at diagnosis, it is possible that treatment occurring during puberty may contribute negatively to physical and/or psychological development, thus having ramifications for sexual attitudes, behaviors and experiences.

Although no significant differences in sexual function scores were observed across cancer type, the scoring procedure obscures an important observation in that male survivors of brain tumors were 1.5–3.0 times more likely than male survivors of hematological cancers and solid tumors to leave an item response blank or else endorse the response category 'not applicable'. For example, 34.4% of male brain tumor survivors, compared with 10.2% of male hematological survivors and 12.3% of male solid tumor survivors, endorsed 'not applicable' for the item 'Unable to relax and enjoy sex'. Proportions of female brain tumor survivors endorsing 'not applicable' also were greater when compared with female survivors of other cancer types, but nowhere near the two- to three-fold increases observed for male brain tumor survivors. One may assume that missing data or an endorsement of 'not applicable' serves as an indication for not being sexually active. This is Stewart and Ware's [29] justification for why this response is recoded as 0 for 'not a problem'. Thus, the findings here suggest that male brain tumor survivors are less likely than male survivors of other pediatric malignancies to be sexually active, which would be consistent with studies suggesting excess debilitation in social involvement and integration for brain tumor survivors [43,44]. In contrast, female survivors' level of sexual activity (as inferred by endorsement of 'not applicable') across all cancer diagnostic categories included here was relatively the same.

With research indicating delays in childhood survivors' involvement in dating, intimate relationships and sexual behavior, these young adults are at risk for not learning or adopting healthy sexual behaviors. This may explain why, in contrast to studies of sexual functioning in the general population, married female cancer survivors were more, not less, likely to report sexual symptoms. It is possible that the delays in both dating and development of sexually intimate relationships resulted in females having even less knowledge of their psychosexual functioning and thus creating more sexual concerns that these female survivors then carry forth into their marriages or committed relationships. Simultaneously, if women are not dating, they are potentially not likely to be bothered or distressed as much by their lack of desire or inability to become sexually aroused, even if they have indicated within the context of a survey instrument that these sexual functions are problematic, since women tend to associate desire and arousal with partnered activity. Thus, it is important to interpret findings from studies of sexual functioning cautiously, and to examine the findings as they relate to other critical biopsychosocial outcomes and in the context of psychosexual development. Indeed, there could be many explanations alone or in combination as to why women may be experiencing more sexual problems, including low hormonal levels, self-image being more challenging for women who are disfigured or disabled by illness/treatment, infertility in the context of womanhood or lack of support from intimate partners.

Study limitations

The opportunity to make meaningful and clinically relevant comparisons of sexual function in these childhood cancer survivors to others is limited by a lack of reported empirical data derived from similarly aged samples using similar instrumentation. The algorithms used to determine sexual dysfunction in the MOS Sexual Functioning instrument and in the NHSLS are not only different but also represent liberal, and perhaps problematic, criteria for determining prevalence of sexual dysfunction, possibly suggesting problems when none exist [45,46]. Yet, the NHSLS stands as an oft-cited study used to emphasize proportions of the US population reporting sexual dysfunction [46]. In addition, extant research suggests that long-term effects of cancer treatment, including infertility and deleterious reproductive effects, are attributable to intensive treatment exposures [47]. Unfortunately, a lack of resources and inability to mine institutional records for objective health status details limited the ability to investigate this important relationship. Restricted to self-reported measures of perceived health status, this study at least uncovered the expected result that differences in reporting sexual problems would be partially a function of current health problems.

Finally, the relatively small response rate (29%) reflects the limitations of conducting retrospective studies of a young adult survivor population many years beyond their cancer experience and limits the generalizability of these findings. However, while small, the reported response rate is most likely an underestimation of the true response rate. First, assuming a 15% mortality rate (85% survival rate) for off-treatment survivors of childhood cancer [48], one could estimate that approximately 324

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individuals among the 2166 assumedly alive subjects would be deceased; however, we were only able to confirm 22 deceased patients. Decreasing the denominator by 324 persons theoretically improves the overall response rate to 36.2%. Secondly, although investigators provided participating institutions with eligibility parameters to produce an eligible sample pool, institutional restrictions and lack of available resources prohibited investigators from reviewing institutional records and actually confirming that all 2864 patients included in the potential sample pool in fact fit eligibility criteria. As self-report data from completed and returned surveys indicated that some respondents were too old for the study or too old at time of diagnosis, we can presume that some unknown percentage of non-respondents also did not fit eligibility criteria, thereby further reducing the denominator and improving the response rate. Obviously, the low response rate may suggest a response bias and limits the ability to generalize to a population of young adult survivors of childhood cancer. However, the findings reported here have utility in that no studies of sexual functioning in childhood cancer survivors have been reported, and these data may serve as a starting point by which to further examine sexual functioning in this population.

Implications for practice and research

More research is needed to identify possible contributors to sexual difficulties. The social life disruptions and emotional upheavals experienced by many cancer survivors may manifest as sexual dysfunction. Alternatively, or perhaps additionally, sexual difficulties in long-term survivors of childhood cancer may have a biological or organic basis that has as yet gone undetected or unreported. The long-term endocrine system changes or imbalances experienced by childhood survivors may be implicated in this regard, perhaps having direct impacts on libido, arousal or lubrication.

Better-specified measures of sexual function, behavior and outcomes are needed for this young adult population. We recognize the limitations of the MOS Sexual Functioning measure administered to this population of young people in that participants were not asked directly if they were sexually active. As a result, the scoring procedures, which assume and recode a response of 'not applicable' to mean 'not a problem', obscures the specificity of the challenges that some childhood cancer survivors may be having with regard to sexual function, behavior and intimacy. Comprehensive assessments of sexual outcomes need to evaluate physical function along with the extent to which functional 'limitations' are experienced as problematic or distressing. They also should distinguish issues related to sexuality from issues related to infertility. Finally, future research needs to determine how sexual symptom prevalence and experiences compare with same-age peers and gender-matched controls; and, multivariate statistical analytic models are needed to examine the multiple pathways by which sexual dysfunction, physical and mental health status, psychological distress and quality of life are interrelated.

With regard to clinical care, there is a need to provide sexual health assessment in survivor clinical visits that includes attention to functioning and the psychological components of health and well-being, including self-image, subjective attitude toward one's own sexuality and relationships with intimate partners. Clinicians must be skillful in their approach and informed of the developmental and psychosocial needs unique to young adults in general, and particularly among young adults with cancer [49]. Administration of screening tools, as well as clinical assessments and other therapeutic endeavors, must be geared toward making these young people comfortable discussing personal issues and providing referral for additional counseling when indicated. Psycho-educational programs and counseling that is age-appropriate and addresses sexual development and function explicitly have the potential to enhance patient–provider communication around these issues.

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