

# Cancer negatively impacts on sexual function in adolescents and young adults: The AYA HOPE study

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## Abstract

**Objective:** This cohort study examined the impact of cancer on sexual function and intimate relationships in adolescents and young adults (AYAs). We also explored factors predicting an increased likelihood that cancer had negatively affected these outcomes.

**Methods:** Participants ( $n = 465$ , ages 15–39) in the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study completed two surveys approximately 1 and 2 years post-cancer diagnosis. We used multivariable logistic regression to determine factors negatively affected by perceptions of sexual function at 2 years post-diagnosis.

**Results:** Forty-nine percent of AYAs reported negative effects on sexual function at 1 year post-cancer diagnosis and 70% of those persisted in their negative perceptions 2 years after diagnosis. Those reporting a negative impact at 2 years were more likely to be 25 years or older (OR, 2.53; 95% CI, 1.44–4.42), currently not raising children (OR, 1.81; 95% CI, 1.06–3.08), experiencing fatigue (OR, 0.99; 95% CI, 0.975–0.998) and more likely to report that their diagnosis has had a negative effect on physical appearance (OR, 3.08; 95% CI, 1.97–4.81). Clinical factors and mental health were not significant predictors of negative effects on sexual function.

**Conclusions:** Many AYAs diagnosed with cancer experience a persistent negative impact on sexual life up to 2 years following diagnosis. The findings underscore the need to develop routine protocols to assess sexual function in AYAs with cancer and to provide comprehensive management in the clinical setting. Copyright © 2016 John Wiley & Sons, Ltd.

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## Background

Adolescents and young adults (AYAs) who are diagnosed with cancer and undergo treatment risk having detrimental effects on their psychosocial maturation, sexual behavior, identity development, and intimate relationships [1,2]. Cancer-related sexual dysfunction is caused by a combination of physiological changes induced by cancer and its treatment (surgery, radiation, and chemotherapy) [3]. Surgery, depending on the amount of tissue or organ removed, and radiation can result in changes to nerves and blood vessels in the genital area. Such changes can cause erectile dysfunction and problems with ejaculation in men and affect sexual sensitivity (both desire and orgasm) in women and men. Chemotherapy may affect hormones that control normal sexual function. Changes in hormone levels may result in symptoms of early menopause in women including vaginal dryness, shrinking, and

loss of elasticity [4]. The extent of these problems and resultant psychosocial challenges that accompany sexual problems are not well-understood for this age group. Early treatment complications such as fatigue and nausea may hinder intimacy and interest in sexual activity [5]. Late effects can include unfavorable changes in self-esteem and body image as well as physical complications and symptoms that may have enduring effects on sexual performance [6,7].

Addressing sexual problems for cancer survivors involves consideration and management of several biological, psychological, interpersonal, or social/cultural factors. Bober and Varela have presented an integrative biopsychosocial model on cancer-related sexual problems [3]. Biological factors proposed to influence sexual problems include hormonal alterations and changes in body integrity due to tissue loss that can cause desensitization, pain, and fatigue. Interpersonal factors include relationship

challenges such as lack of communication and fear of intimacy. Emotions, cognitions, and motivation are also suggested to impact on sexual problems. Social and cultural factors, such as religious beliefs, cultural values, and social norms, are additionally important to consider when understanding and addressing sexual problems. The Bober and Valera model is an attempt to integrate multidimensional factors related to sexual problem and identify points for possible intervention.

Estimated rates of sexual dysfunction among AYA vary by cancer diagnosis, treatment modality, time since diagnosis, and the aspect of sexual health being evaluated. Common reported problems include pain, lack of desire, orgasm, and arousal difficulties [8]. Additionally women may be bothered by vaginal dryness, and men may experience erectile and ejaculatory dysfunction [8]. It is difficult to determine prevalence of sexual dysfunction among those diagnosed as AYAs (age 15–39) because available data combine results with younger and older populations [9]. The majority of the existing reports are cross-sectional, and there is a lack of results from studies that have prospectively assessed sexual function among AYAs with cancer. The prevalence of sexual problems in AYAs newly diagnosed with cancer has not been established. Importantly, the implications of sexual dysfunction after cancer treatment are different for AYAs versus childhood cancer survivors [9], as AYAs are more likely to be establishing intimate partnerships and starting families while simultaneously navigating a diagnosis and treatment. However, we know very little about the needs and concerns of individuals diagnosed and treated with cancer during adolescence and young adulthood.

The population-based Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study in the United States (USA) was designed to identify indicators of potential health-related problems. Thus, broad domains were assessed with the intention of determining high priority areas for future study. The results have shown a strong impact of cancer on health-related quality of life (HRQOL) 1 year following diagnosis of cancer [10]. Additionally, AYAs reported that cancer negatively affected dating, sexual function, and plans for having children [11]. The current study compared the prevalence of adverse changes in sexual functioning in this cohort at 1 year and 2 years post-cancer diagnosis. It also explored factors associated with negative effects on sexual functioning and intimate relationships 2 years after diagnosis.

## Methods

### Sample and setting

The design, methods, and recruitment of the AYA HOPE study have been previously reported [12]. Incident cases of AYAs diagnosed with cancer were identified through

one of seven National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) registries (Detroit, Seattle/Puget Sound, Los Angeles County, San Francisco/Oakland, Greater California, Iowa, and Louisiana) between July 2007 and October 2008. Study approval was obtained by each of the registries' and NCI's institutional review boards. Eligible participants were 15–39 years old at time of their diagnosis, and diagnosed with non-Hodgkin lymphoma, Hodgkin lymphoma, acute lymphoblastic leukemia, germ cell tumor, or sarcoma (Ewing's, osteosarcoma or rhabdomyosarcoma). Before data collection, the items included in the survey underwent cognitive interviewing with patients to establish face validity and capture possible ambiguity or inappropriateness with content. All participants completed a first survey a median of 11 (range 6–14) months post-diagnosis and were re-contacted for a second survey (follow-up), 15–35 months, after diagnosis. Of the eligible participants, 525 agreed to participate by completing and returning the mailed survey (one survey was lost, resulting in 524 surveys), and 89% of them ( $n=465$ ) responded to both surveys. Informed consent was obtained from all individual participants included in the study. Medical records were received on 436 of these participants.

### Measures

The survey included questions about respondents' demographic characteristics, quality of health care, treatment and symptoms, insurance status, information, and service needs, the impact of cancer on various domains and HRQOL. Additionally, certain sociodemographics (age, race/ethnicity, sex, and marital status) and clinical characteristics (cancer type, type of treatment, and cancer stage) were collected from the SEER registries and patient's medical records. Because the cohort included individuals with different cancer diagnoses and associated treatments, we used a previously validated methodology to produce a treatment intensity variable based on cancer type, stage, and treatment [13,14]. Additionally, the follow-up survey included questions on whether respondents had finished their cancer treatment ('are you currently scheduled to receive future cancer treatment' and date for last cancer treatment). Current marital status was categorized to reflect those currently in a committed relationship (married or living as married) versus not in a committed relationship (single/divorced/separated).

### Sexual function

One item from the Life Impact Checklist [11,15] was used to record impact on sexual function. Participants were asked to 'indicate what kind of overall impact your cancer has had on sexual function/intimate relations'. Response choices were based on a 6-point scale: 0 (does not apply), 1 (very negative), 2 (somewhat negative), 3 (no impact), 4 (somewhat positive), and 5 (very positive). The distribution of this variable was

dichotomized into the following: any negative impact versus positive impact/no impact/does not apply. We additionally conducted a sensitivity analysis excluding all individuals who responded 'does not apply'. As the results did not differ when excluded from our analysis, we decided to include them in our final models to increase power.

### HRQOL

HRQOL was measured with the 12-item Short Form Health Survey (SF-12) [16] and the Pediatric Quality of Life Inventory (PedsQL™) [17]. The SF-12 (version 2) produces two normed summary measures of physical and mental health reflecting physical functioning, physical role limitations, bodily pain, general health, vitality, social functioning, emotional role limitations, and mental health; higher scores reflect better health. The SF-12 has demonstrated acceptable psychometric properties in adults [18]. The PedsQL was originally designed for children and adolescents, but there also exists a young adult version (4.0), which was used in the current study [19]. Additionally, results from the general fatigue subscale of the PedsQL™ Multidimensional Fatigue Scale [20] are reported. Responses were recorded on a 5-point scale (ranging from never to almost always) and subsequently linearly transformed to a 0–100 scale with higher scores reflecting fewer symptoms of fatigue.

### Covariates

Bober and Varela's integrative biopsychosocial model of cancer-related sexual problems was used to select covariates [3]. The model includes four interacting elements postulated as contributors to cancer-related sexual problems: biologic, interpersonal, psychological, and social/cultural. In the present study, *biologic* factors were measured by treatment intensity (a composite variable derived based on cancer type, stage, and treatment modalities) [11], ongoing cancer treatment, time from diagnosis to follow-up, and self-assessed fatigue severity and interference. We measured *Psychological* factors with the global mental component summary (MCS) score of the SF-12 [16] and satisfaction with one's body (i.e., perceived impact of cancer on physical appearance). *Social/Cultural* factors included race/ethnicity and level of education. Interpersonal factors were measured by relationship status and whether the respondent was raising children. Additionally, age at diagnosis (15–24 vs. 25–39 years) and gender were included in the modeling as covariates because prior research indicates that these are both prominent factors in shaping satisfaction with sexual functioning and intimate relationships [21].

### Statistical analysis

Sexual function concerns (frequency, proportion endorsing negative impact) were described for AYAs 1 and 2 years after diagnosis, and differences between the two surveys

were examined with the McNemar–Bowker test. For those concerns that statistically significantly changed between the two points of measurement, we investigated the number of individuals who persisted in reporting a negative impact at second assessment (2 years after diagnosis). We conducted multivariable logistic regression to examine associations between sexual function, and demographic and clinical characteristics as well as selected self-reported health outcomes, and dissatisfaction with physical appearance. Covariates (age at diagnosis, gender, race, education, partner-committed relationship, raising children, treatment intensity, ongoing cancer treatment, time from diagnosis to follow-up, self-reported fatigue, mental health, and physical appearance) were selected a priori, based on the conceptual model and the literature. All self-reported data included in the regression analysis were assessed at 2 years after diagnosis (i.e. fatigue, mental health, physical appearance, education, partner-committed relationship raising children, and ongoing cancer treatment). The model was evaluated using a significance level of  $p < 0.05$ , Nagelkerke's  $R^2$ , and the percentage of cases correctly classified.

Statistical analyses were performed with the IBM® SPSS® Statistics, version 21. All tests were two-tailed with values of  $p < .05$  considered significant.

### Results

Data on 465 participants were included in this analysis. Socio-demographic and clinical characteristics of participating patients are presented in Table 1. The majority of participants were men (62%), non-Hispanic white (60%), raised children under 18 years (59%), and had received treatment including chemotherapy (71%) [12].

One year after diagnosis, 49% of the respondents reported that cancer had a negative impact on their sexual function and intimacy, 59% held negative feelings about their physical appearance, and 46% negative impact on plans for having children (Table 2). At 2 years post-diagnosis, the proportion reporting a negative impact in specific domains had significantly declined (sexual function,  $p < 0.01$ ; physical appearance,  $p < 0.05$ ). However, a negative impact on sexual function (43%) and negative feelings of body appearance (50%) remained prevalent. Among those reporting a negative impact on sexual function or body appearance 1 year after diagnosis, 70% and 72%, respectively, persisted in their perceptions at 2 years. Additionally, some of those who did not report any negative impact on sexual function (9%) or on body appearance (7%) at 1 year (no impact/did not apply/positive impact) did so at 2 years after diagnosis.

### Factors associated with negative impact on sexual function

In a multivariable logistic regression analysis, older AYAs, those diagnosed at age 25–39 (OR, 2.53; 95%

**Table 1.** Sociodemographic and clinical characteristics of AYA HOPE sample (n = 465)

	n (%)
Sociodemographic variables	
Gender	
Female	178 (38.3)
Male	287 (61.7)
Age at diagnosis, years*	
15–19	62 (13.3)
20–24	81 (17.4)
25–29	98 (21.1)
30–34	104 (22.4)
35–39	104 (22.4)
Race/ethnicity*	
Hispanic	95 (20.4)
White, non-Hispanic	277 (59.6)
Black, non-Hispanic	38 (8.2)
Other, non-Hispanic	54 (11.6)
Marital/relationship status*	
Single/never married	228 (49.0)
Married/living as married	214 (46.0)
Divorced/separated	22 (4.7)
Raising children under 18 years*	
No	189 (40.7)
Yes	275 (59.3)
Level of completed education*	
High school or less	107 (23.0)
Some college	179 (38.5)
College graduate or higher	174 (37.4)
Disease-related variables	
Time from diagnosis to follow-up, median months (range)	24 (15–35)
Cancer type (baseline)	
Germ cell cancer	181 (38.9)
Hodgkin lymphoma	130 (28.0)
Non-Hodgkin lymphoma	113 (24.3)
Sarcoma	23 (4.9)
Acute lymphocytic leukemia	18 (3.9)
Treatment type	
Surgery only	50 (10.8)
Radiation	48 (10.3)
Chemotherapy	225 (48.4)
Combined modality chemoradiotherapy	107 (23.0)
Unknown/NA	35 (7.5)
Treatment intensity	
Least intensive	47 (10.1)
Moderately intensive	261 (56.1)
Very intensive	128 (27.5)
NA/No MR	29 (6.2)
Ongoing cancer treatment at follow-up*	
No or unknown	400 (86.0)
Yes	49 (10.5)
Self-reported Health	
PEDsQL fatigue, mean (SD)	62.76 (24.51)
Mental health component summary (MCS), mean (SD)	46.01 (11.18)

\*Does not sum to total due to missing data.  
NA, Not applicable; No MR, No medical records.

CI, 1.44–4.42) and those currently not raising children (OR, 1.81; 95% CI, 1.06–3.08) were more likely to report negative impact on sexual function/intimate relations (Table 3). Additionally, AYAs who reported fatigue (OR, .987; 95% CI, 0.975–0.998) and negative perception

**Table 2.** Sexual function and related concerns over 2 years following diagnosis of cancer for all participants responding at both occasions (n = 465)

	I year after diagnosis Survey I n = 465 (%)	2 years after diagnosis Survey II n = 465 (%)	X <sup>2</sup>	P <sup>a</sup>
Impact on sexual function/intimate relations*			29.66	0.009
Very or somewhat negative	227 (48.8)	202 (43.4)		
No impact	149 (32.0)	167 (35.9)		
Somewhat or very positive	20 (4.3)	38 (8.2)		
Does not apply	63 (13.5)	57 (12.3)		
Feelings about physical appearance*			27.34	0.026
Very or somewhat negative	275 (59.1)	234 (50.3)		
No impact	132 (28.4)	147 (31.6)		
Somewhat or very positive	45 (9.7)	64 (13.8)		
Does not apply	8 (1.7)	16 (3.4)		
Overall impact of cancer on dating*			24.0	0.090
Very or somewhat negative	83 (17.8)	86 (18.5)		
No impact	93 (20.0)	109 (23.4)		
Somewhat or very positive	18 (3.9)	26 (5.6)		
Does not apply	264 (56.8)	240 (51.6)		
Impact on relationship with spouse/partner*			24.0	0.090
Very or somewhat negative	73 (15.7)	90 (19.4)		
No impact	53 (11.4)	73 (15.7)		
Somewhat or very positive	232 (49.9)	214 (46.0)		
Does not apply	98 (21.1)	83 (17.8)		
Impact on plans for having children*			22.05	0.107
Very or somewhat negative	213 (45.8)	197 (42.4)		
No impact	116 (24.9)	112 (24.1)		
Somewhat or very positive	20 (4.3)	40 (8.6)		
Does not apply	111 (23.9)	115 (24.7)		

<sup>1</sup>McNemar–Bowker test.  
\*Does not sum to total due to missing data.

of their own physical appearance (OR, 3.08; 95% CI, 1.97–4.81) were more likely to report a negative impact on sexual function. Other variables examined were non-significant.

**Discussion**

In our cohort study, a large proportion of AYAs diagnosed with cancer in the USA reported a negative impact on their sexual life and intimate relations 2 years following diagnosis (43%), a prevalence that only had decreased slightly from 1 year following diagnosis. Seventy percent of those who reported negative impact at 1 year persisted in their perceptions 2 years post-diagnosis. Our results are somewhat comparable to the few AYA studies involving cancer that have been

**Table 3.** Factors predictive of negative effects of cancer treatment on sexual function/intimate relations at 2 years post-diagnosis (n = 449\*)

	Adjusted OR**	95% CI
Age at diagnosis, years		
15–24	Ref	
<b>25–39</b>	<b>2.526</b>	<b>1.443–4.419</b>
Sex		
Male	Ref	
Female	1.208	0.761–1.917
Race		
Hispanic	Ref	
Non-white, non-Hispanic	0.619	0.303–1.261
White	1.263	0.726–2.196
Committed relationship		
No	Ref	
Yes	1.643	0.969–2.788
Education		
High school or less	Ref	
Some college	1.480	0.832–2.634
College graduate	1.241	0.668–2.309
Raising children		
Raising children <18 years	Ref	
<b>Not raising children &lt;18 years</b>	<b>1.806</b>	<b>1.058–3.083</b>
Treatment intensity		
Less intense treatment	Ref	
Moderately intensive	1.004	0.479–2.103
Intense treatment	0.686	0.300–1.581
Ongoing cancer treatment		
No/unknown	Ref	
Yes	0.489	0.238–1.004
Time since diagnosis (months)	0.987	0.936–1.041
Mental health component summary (MCS) score <sup>a</sup>	0.985	0.961–1.010
<b>PEDsQL Fatigue score<sup>a</sup></b>	<b>0.987</b>	<b>0.975–0.998</b>
Physical appearance		
No negative impact	Ref	
<b>Negative impact</b>	<b>3.077</b>	<b>1.968–4.810</b>

Model summary  $\chi^2$  96.812  $p < 0.0005$ , Nagelkerke  $R^2 = 0.260$ ; 70.2% classified. The variables bolded are those that are significant.

\*Difference in sample size due to missing item responses for 16 participants.

\*\*Odds ratios are adjusted for all other variables in the table.

<sup>a</sup>MCS and PEDsQL are treated as continuous variables in the model.

published. A systematic review of sexual functioning among male survivors of lymphoma (mean ages across studies ranged from 31 to 45 years) found that 20–54% experienced sexual problems [22]. Among testicular cancer patients, a meta-analysis of empirical studies showed that among those assessed prospectively, the extent of reported problems varied by dysfunction, from 11% (loss of desire) to 51% (ejaculation disorder) [23]. Among young breast cancer patients (22–52 years), research suggests that 16–52% of them report sexual problems the first year following diagnosis [6,24]. The percentage of the general population in the USA reporting sexual problems was recently investigated using a similar general screening item and found to be significantly lower (10% and 15% of women and men endorsed sexual problems, respectively) [25] than among the AYAs we studied.

Our results confirm that cancer-related sexual problems include the elements presented in the Bober and Valera conceptual model. Indeed, AYAs who were diagnosed between ages 25 and 39, were not raising children, were fatigued or perceived their physical appearance to be impacted by the cancer were observed to be more likely to report a negative impact on sexual function and intimate relations. These findings underscore the need to routinely assess sexual problems in clinical practice and to develop interventions for patients who indicate a negative impact on sexual function. According to the model, biological factors may be addressed through medical consultations and rehabilitation, and interpersonal problems (relationship issues) may be dealt within support groups and couples therapy. Recommendations for how to intervene on psychological problems vary according to the specific problem and may include individual counseling, cognitive-behavioral therapy, and sex therapy. Even though the Bober and Varela's model was useful for understanding sexual problems in the study population, there may be other factors relevant for AYAs that are not addressed in the model. One potential issue could be having your sexual debut with the cancer experience. Communication in partner relationships may also be different in AYAs, who are more likely to have a shorter common history. Furthermore, whether the integrative biopsychosocial model's suggested approaches to overcome sexual problems are suitable for the AYA population needs to be further studied and recommended to be explored in future studies.

It is well known that sexual problems often are neglected in clinical care due to patients feeling embarrassed to discuss the topic and care providers being likewise uncomfortable and often lacking training for such discussions [26,27]. There is a need to find approaches that are easily followed to address sexual issues in clinical settings. One such approach is the PLISSIT model, which can be used to determine different levels of intervention for treatment of sexual problems. The model consists of four steps (Permission, Limited Information, Specific Suggestions, and Intensive Therapy) with increasing intervention and interaction to the client, related to each step [28]. Park *et al.* [29] adapted the PLISSIT model for use in oncology practice including some straightforward questions about sexual functions, which has been suggested to be posed to cancer survivors at routine visits [8,29]. Specific interventions addressing sexual issues in the AYA cancer population are almost nonexistent, as most programs have been directed toward older adults. One exception is a pilot study testing a psychoeducational intervention in a sample of 15–25 year olds [30]. Results showed positive effects on body image, decreases in anxiety and psychological distress, and increased cancer-specific

knowledge regarding sexual issues. The study, however, had difficulties recruiting patients, and only those experiencing significant emotional distress chose to participate. The reason for the high non-participation rate was explained by the stigma associated with treatment of mental health issues, and the authors suggest that trained nurses or physician assistants should deliver such an intervention rather than a mental health provider [30]. Applying this to our results, systematic assessment of sexual function and intimate partner relationships in the delivery of survivorship care of AYAs diagnosed with cancer is recommended.

In our study, the association we observed between fatigue and a negative impact on sexual function may indicate that AYAs more troubled by their disease and treatment lacked energy to engage in sexual activities [5,31]. We do not know whether fatigue in female participants was related to abrupt menopause induced by the cancer treatment, which could also accentuate sexual problems [4]. Furthermore, those who were not raising children were more likely to report sexual problems. One possible explanation is that those without children were worried about the risk of being infertile because of the cancer treatment and that this worry interfered with sexual function. Another explanation could be that in relationships without children, there are greater expectations of intimacy and sexual activity. Further study beyond the scope of the AYA HOPE dataset is warranted to test these hypotheses. Even with 46% of AYAs reporting a positive impact of cancer on their relationship with spouse 2 years after diagnosis (Table 2), 20% indicated that the cancer experience had a negative impact on the relationship with their spouse or partner. It may be difficult for healthcare providers to communicate about sexual issues in the context of cancer care [26,29], and our results emphasize the need to reach out to couples at the time of follow-up care to address sexual life expectations following cancer treatment [29].

Those perceiving that disease and treatment had a negative impact on physical appearance were three times more likely to report a negative impact on sexual function, an association also described in previous reports [5,31]. The association between sexual function and body image is supported by the Bober and Valera model and has been suggested to be stronger in younger-aged adult women [32]. In a recent study on sexually active heterosexual women, body image concerns (evaluative, affective, and behavioral) was shown to predict decrements in young women's sexual function, specifically desire and arousal [33]. The study authors concluded that interventions to improve body image could have benefits related to sexual experience. The relationship between body image and sexual function in AYAs with cancer needs further study to better understand interplay between body image and sexual function.

Interestingly, clinical variables did not appear to be associated with sexual function among AYAs, neither time since diagnosis nor treatment intensity were significantly associated with a negative impact on sexual function and intimate relations. Still, the variable ongoing cancer treatment almost reached statistical significance, which suggests that treatment may have immediate negative effects on sexual function. The role of diagnosis and treatment has been discussed in the literature, and it has been suggested that other factors may play a larger role in maintaining sexual function following cancer, as our results suggest [3]. Issues suggested to play a larger role than clinical factors include general health, personal characteristics, and quality of the partner relationship.

We did not find that gender was associated with impact on sexual function. Few studies among AYAs have analyzed sexual issues in both genders. However, among the general population, women report more problems than men [21,34], and results among childhood cancer survivors show a similar pattern [35]. Given that almost 40% of the participants in our study had germ cell cancers, which present and are treated differently in men (testicular cancer) and women (ovarian cancer), the results related to the association between gender and sexual problems should be interpreted with caution. The sparse data available on race and ethnicity on sexual function outcomes suggest that race, religion, and ethnic background may influence the willingness of patients to discuss issues pertaining to sexuality [36]. Further study is warranted.

Even though mental health was not significantly associated with a negative impact on sexual function, mental health together with fatigue and physical health should be closely monitored in survivorship care, and rehabilitation recommended for those in need (e.g., persistent fatigue) [37]. Given the high proportion of patients indicating sexual problems, providing educational materials can be helpful and particularly appropriate for patients who may be reticent to discuss their sexual problems.

Several caveats should be considered in interpreting our study results. First, although comparable with other studies of children and young adults with cancer, our response rate was low. Additionally, we were not able to evaluate an extensive array of issues related to sexual function or dysfunction. The AYA HOPE study was designed to be a feasibility study to determine whether we could gather data from AYA cancer patients using population-based registries. The survey goals were to identify indicators of problems in health care and outcomes that require more in-depth study. Therefore, we only had a single item to assess sexual function. Interestingly, Flynn *et al.* recently validated

a single-item self-report screener to capture sexual problems and concerns for men and women in the USA [25]. They compared results from three possible single-items with scores on the comprehensive Patient-Reported Outcomes Measurement Information System Sexual Function and Satisfaction measures (PROMIS SexFS) and found promising results. They argue that even without being able to identify particular sexual problems, a general screener only asking for 'any sexual problems' identifies patients who may benefit from further discussion with a health care provider. We still recommend future studies to include a more comprehensive measure to be able to identify specific sexual problems in AYAs [38]. The measure we used to record mental health, the MCS of the SF-12, was developed for adults and has therefore not been validated in study subjects under age 18; however, only few AYAs were that young at 1 year ( $n=23$ ) and 2 years ( $n=11$ ) post-diagnosis, and we did not observe difficulties with the items when pilot testing the survey. Strengths of this study include that our results are based on a large population-based sample of AYAs with five different cancer types, including men and women, and surveyed twice over the two first years after diagnosis.

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## Conclusions

In our study, a large proportion of AYAs diagnosed with cancer in the USA reported a negative impact on their sexual life and intimate relations extending through the first 2 years following diagnosis. We also identified predictors of AYAs who were more likely to report a negative impact on sexual function and intimate relations. This subgroup was older, not raising children, fatigued, and perceived their physical appearance to be negatively impacted by treatment. Our findings underscore the need to incorporate periodic systematic assessment of sexual function and intimate partner relationships in the delivery of survivorship care of AYAs following a diagnosis of cancer.

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## Conflict of interest

The authors declare that they have no conflict of interest.

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