

# Sexual function in adolescents and young adults diagnosed with cancer: A systematic review

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## Abstract

**Purpose** The purpose of this systematic review was to identify, with supporting evidence, the impact of cancer and its treatment on the sexual function of adolescents and young adults.

**Methods** PubMed, CINAHL, and PsycINFO articles were searched for relevant studies published in English. Fifteen studies, 13 quantitative and two qualitative, were included in this review.

**Results** Results indicated that cancer during the adolescent and young adult period has a significant negative impact on certain domains of sexual function in both men and women.

**Conclusions** Among adolescent and young adult males, there is evidence that cancer has detrimental effects on erection, ejaculation, and orgasm. Among adolescent and young adult females, cancer is associated with decreased desire, but there appear to be mixed findings with respect to arousal, orgasm, and satisfaction. Directions for future research are discussed.

**Implications for Cancer Survivors** A better understanding of the effects of cancer and its treatment during adolescence and young adulthood on sexual function could increase attention paid to sexual health in oncology settings and lead to improved psychosexual services for this population.

**Keywords** Sexual function · Adolescents and young adults · Cancer · Survivorship · Sexual health

Nearly 70,000 adolescents and young adults were diagnosed with cancer in 2011 [1]. According to the National Cancer Institute, adolescent and young adult (AYA) patients are individuals who were between the ages of 15 and 39 years at the time of their cancer diagnosis [2]. Though children (aged < 15 years) diagnosed with cancer have historically been the focus of most research and treatment, increased attention has been paid in the last decade to the long-term physical and psychological effects of cancer and its treatment in AYAs. Although it has been well established that various treatments for cancer often negatively impact sexual function [3–5], sexual function in AYA patients is not well understood.

Adolescence and young adulthood is a crucial time for navigating the simultaneous development of physical sexual maturation, romantic relationships, and psychosexual identity. During this time, individuals experience a number of physical changes, and they often begin interacting with potential romantic partners and forming new relationships, especially intimate and sexual relationships [6–8]. Masturbation, an important aspect of sexuality, typically begins early on in the AYA period; indeed, masturbation is more frequently engaged in than any other sexual activity during adolescence [9]. Other milestones that typically occur somewhat later on during the AYA period include marriage [10] and starting a family [11]. It is clear from the wide range of sexual and relational experiences that are typical of this age group that the AYA period is a particularly sensitive time for psychosexual development and for the formation of intimacy more generally.

Given the importance of adolescence and young adulthood in typical psychosexual development, the implications of sexual dysfunction in AYA individuals who have been diagnosed with and treated for cancer are likely different than those of patients in other age groups. AYAs diagnosed with cancer may experience sexual difficulties, due either to the illness itself or to its treatments, which may then lead to delays in achieving

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these important psychosexual milestones. In addition, spending large amounts of time in the hospital may interrupt dating and other forms of relationship building, which may in turn affect sexual activity and sexual function. Other psychological outcomes associated with the cancer experience that likely also affect sexual function in this population include negative body image, loss of self-confidence, and anxiety regarding sexual activity [12, 13].

Estimated rates of sexual dysfunction in individuals with cancer vary by disease, treatment modality, and time since diagnosis, but the most commonly reported problems include low desire, orgasm, pain, and arousal difficulties [14, 15]. These effects are most likely due to an interaction of physiological and psychological factors. The physiological effects of cancer treatment may thoroughly disrupt sexual function [16]. Some treatment plans involve surgery, which, depending on the amount of tissue or the organ removed, can result in damage to nerves and blood vessels in the genitals [17]. Similar effects have been noted for radiation, which has been associated with erectile dysfunction in men and changes in sexual sensitivity in women [17]. Chemotherapy may affect the hormones that govern sexual function, leading to symptoms of early menopause in women, such as vaginal dryness and loss of elasticity [18]. Early on in the treatment process, fatigue and nausea may affect interest in sexual activity [19]. Self-esteem, body image, and feelings of sexual attractiveness, which are generally known to affect sexual function, have been shown to decrease after diagnosis and treatment [20].

Given the documented impact of cancer on sexual function, and the importance of adolescence and young adulthood in sexual development, it is important to examine the literature in this area. A comprehensive, systematic review of the effects of cancer and its treatment on sexual function in AYAs has not yet been conducted.

## Aim and objective

The objective of this review of the relevant literature is to identify, with supporting evidence, the effect of cancer and its various treatment modalities on the sexual functioning of AYA men and women.

## Method

### Information sources

A comprehensive search was conducted of the electronic databases of PubMed, CINAHL, and PsycINFO for papers that focused specifically on sexual function after cancer in AYAs. Combinations of the following search terms were used to

search all databases: adolescents, young adults, teen(s), cancer, neoplasm, oncology, sexual function, sexual satisfaction, sexual desire, sexual arousal, sexual pain, lubrication, and orgasm. Results from the databases were compiled and duplicates were removed. The titles and abstracts of the remaining articles were independently reviewed by the first two authors. The authors compared their results and made agreements on their discrepancies. The full texts of the remaining articles were read and assessed for eligibility. Studies were eligible for inclusion if they (a) were published in peer-reviewed journals, (b) were published in English, (c) presented original findings, (d) used validated measures, and (e) included men and/or women who were diagnosed with cancer between the ages of 15–39 years (Table 1).

### Quality assessment

The two reviewers independently rated the quality of all quantitative studies according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [35]. The STROBE statement is a set of guidelines for rating the quality of observational studies in various domains related to article abstract, method, results, and discussion. The STROBE statement consists of 22 items worth one point each; scores of 22–17 are considered to be of high quality, scores of 16–11 are of moderate quality, and scores of 10 and under are considered to be of low quality.

The quality of each of the qualitative studies was rated according to the criteria set forth by the Evidence-Based Nursing Guide to evaluating qualitative research studies [36]. This guide includes nine criteria, each worth one point. Studies that scored 50% or more of the maximum attainable score (i.e., nine points) were considered to be of high quality, whereas studies with scores lower than 50% of the maximum score were considered to be of low quality. See Tables 2 and 3 for quality assessments of articles included in this review.

Additional data was extracted from each of the studies using a pre-determined, author-constructed form, including information on the literature, study design, sample size, gender of patients, and measurement of sexual function.

## Results

A total of 2975 papers were retrieved. After duplicate studies were removed, 1578 articles remained. Titles and abstracts of the 1578 articles were screened according to the criteria for inclusion. Following the blinded reviews performed by the two authors, 1428 papers were removed. Excluded articles were not on sexual function ( $n = 735$ ) or cancer ( $n = 219$ ), related to HPV ( $n = 392$ ), were not within the correct age range ( $n = 52$ ), used animal models ( $n = 16$ ), or were review articles ( $n = 14$ ).

**Table 1** Age and other demographic information from reviewed studies

Reference	Age range at time of data collection (years)	Age at diagnosis ( <i>M</i> or range)	Time since diagnosis/treatment
Aksoy et al. 2008 [21]	Participants included in review were aged 18–39		At least 6 months post-treatment
Bae and Park 2016 [22]	Participants included in review were aged 20–39		At least 1 month post-radiotherapy and at least 2 months post-surgery
Blackmore 1988 [23]	20–37		< 2 years post-diagnosis and treatment
Campos et al. 2012 [24]	23–41	22–39	< 1 year post-diagnosis = 38%; < 2 years, > 1 = 31%; > 2 years = 31%
Dahl et al. 2007 [25]	Participants included in review were aged 20–39		
Dubashi et al. 2010 [26]	< 35	30	At least 18 months post-treatment
Eeltink et al. 2013 [27]	18–40		Median time since treatment = 70 months
Geue et al. 2015 [28]	18–45	18–39	Mean time since treatment = 30 months
Hoyt et al. 2015 [29]	18–29		Mean time since diagnosis = 32.4 months; mean time since treatment = 30.1 months
Rosenberg et al. 2014 [30]	18–40	35.6	Mean time since diagnosis = 12.7 months
Robertson et al. 2016 [31]	18–26	11–25	< 24 months post-treatment
Sendur et al. 2014 [32]	Participants included in review were aged 18–39		At least 6 months post-treatment
de Souza Melo 2006 [33]	18–27		Patients were hospitalized for treatment during data collection
Surbeck et al. 2015 [34]	Participants included in review were aged 18–39		Mean time since treatment = 38.3 months
Wettergren et al. 2016 [17]	15–39		Participants completed two surveys at approx. 1 and 2 years post-diagnosis

Not all studies provided participant age at diagnosis or time since diagnosis. The cells for these studies are empty

One hundred and thirty-five papers were removed following a review of the full texts of 150 papers. The excluded studies were not on sexual function ( $n = 9$ ), not on cancer ( $n = 2$ ), not within the correct age range ( $n = 101$ ), not in English ( $n = 6$ ), not peer-reviewed ( $n = 1$ ), did not present original findings ( $n = 5$ ), did not use validated measures ( $n = 4$ ), or were review articles ( $n = 7$ ). Ultimately, 15 studies (two qualitative and 13 quantitative) remained and were included in this review. See Fig. 1 for an illustration of the search process involved in identifying the relevant literature and for comprehensive categorization of removed articles.

### Characteristics of the selected studies

All of the 15 studies included in this review presented original research findings and were published in peer-reviewed journals. There were two qualitative studies and 13 quantitative studies. The designs of the quantitative studies varied; there were two case-control studies, one cohort study, and ten cross-sectional studies. The studies represent a diverse population, being conducted in 11 different countries, with one conducted in Australia, one in Korea, one conducted in Brazil, six conducted in Europe (France, Germany, Netherlands, Norway, Turkey, UK), one conducted in India, and four conducted in the USA.

There were 2289 total participants in the selected studies (873 females), with sample sizes ranging from nine to 793. Five studies recruited both men and women, whereas five studies recruited only men and five studies recruited only women. The age ranges of the participants (both at the time of data collection and at the time of treatment) in these studies varied, as did time since diagnosis and/or treatment (see Table 1).

### Effect of cancer on sexual function

Sexual function is typically conceptualized as the combined domains of desire, arousal/erection, orgasm, ejaculation (for men), lubrication (for women), satisfaction, and pain (for women). There are two measures that are considered to be the gold-standard indices of sexual function: the International Index of Erectile Function (IIEF) [37] assesses sexual function in men, and the Female Sexual Function Index (FSFI) [38] is the equivalent measure for women. Both of these assessment tools offer unique scores for each domain of sexual function and provide a total score, which is reflective of overall sexual function. Other, shorter measures have been developed to assess overall sexual function, some of which are used in studies that are included in this review. These include the Brief Male Sexual Function Inventory (BFSI) [39], an 11-item scale that measures five domains of sexual function, and the Arizona Sexual

**Table 2** Summary of overall result for all studies containing male participants

Reference	Sexual function	Desire	Erection	Ejaculation	Orgasm	Satisfaction	Quality of evidence	Score
Aksoy et al. 2008 <sup>a</sup> [21]			X				High	18
Blackmore 1988 <sup>a</sup> [23]		X				X	Moderate	15
Dahl et al. 2007 <sup>a</sup> [25]	X	X	X	X		X	High	20
de Souza Melo et al. 2006 <sup>b</sup> [33]		X	X		X		High	7
Geue et al. 2015 <sup>a</sup> [28]		X				X	High	18
Hoyt et al. 2015 <sup>a</sup> [29]	X						High	17
Robertson et al. 2016 <sup>b</sup> [31]		X					High	8
Sendur et al. 2014 <sup>a</sup> [32]			X				High	19
Surbeck et al. 2015 <sup>a</sup> [34]	X	X	X		X	X	Moderate	16
Wettergren et al. 2016 <sup>a</sup> [17]	X						High	19

No study containing male participants measured enjoyment

<sup>a</sup> Quantitative studies

<sup>b</sup> Qualitative studies

Experiences Scale (ASEX) [40], a five-item index designed to assess the core elements of sexual function. Some of the studies reviewed here assessed sexual function via individual subscales of established cancer-specific inventories, including the Cancer Rehabilitation Evaluation System (CARES) [41] and the Cancer Assessment for Young Adults (CAYA) [42], a scale designed specifically to assess health-related quality of life in young men with cancer.

Two studies examining sexual function in AYAs did not provide separate results for men and women [17, 31]. Wettergren et al. [17] assessed sexual function using the Life Impact Checklist in a large cohort ( $N = 465$ ) of AYAs with diverse cancer diagnoses. They found that, 1 year after diagnosis, half (49%) of participants felt as though cancer had negatively impacted their sexual function. This percentage was found to decrease to 43% 2 years following diagnosis. Older AYAs (aged 25–39 years) were more likely to report having experienced a negative impact on sexual function compared to

younger AYAs (aged 15–24 years). Interestingly, the authors did not find any differences in sexual function based on gender; in the general population, rates of sexual problems are known to be higher in women than in men.

#### AYA men

Five studies investigated the effect of cancer on overall sexual functioning in men (see Table 4). Two of these studies focused exclusively on men, while three focused on both men and women (one, which did not separate results by gender, is discussed above). Dahl and colleagues [25] administered the BSFI, and Hoyt and colleagues [29] administered the five-item sexual function subscale of the CAYA. Surbeck and colleagues [34] used the ASEX to assess overall sexual function.

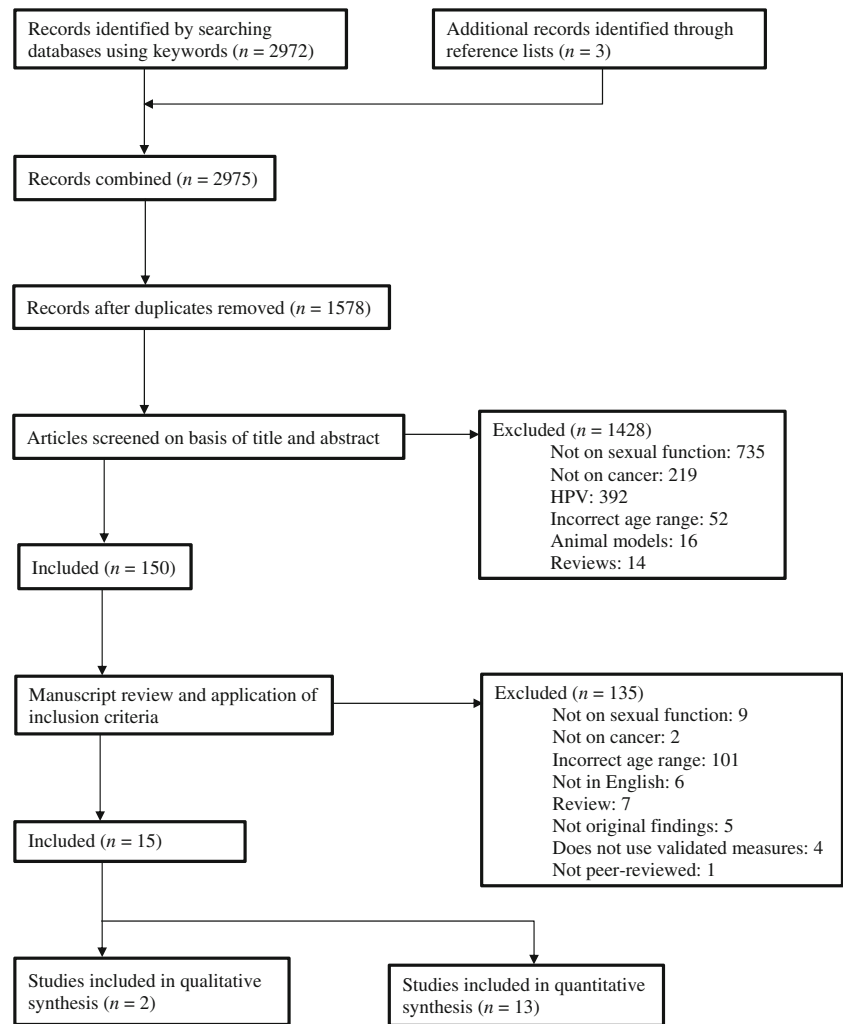
Dahl and colleagues [25] found that 35% of AYA men diagnosed with testicular cancer reported problems with sexual functioning, a comparable rate to what was found in the

**Table 3** Summary of overall results for all studies including female participants

References	Sexual function	Desire	Arousal	Lubrication	Orgasm	Satisfaction	Pain	Quality of evidence	Score
Bae and Park 2016 <sup>a</sup> [22]	X							Moderate	14
Campos et al. 2012 <sup>a</sup> [24]		X				X	X	Moderate	14
de Souza Melo et al. 2006 <sup>b</sup> [33]		X		X	X			High	7
Dubashi et al. 2010 <sup>a</sup> [26]	X					X		Low	10
Eeltink et al. 2013 <sup>a</sup> [27]	X	X	X	X	X	X	X	High	18
Geue et al. 2015 <sup>a</sup> [28]		X				X		High	18
Robertson et al. 2016 <sup>b</sup> [31]		X						High	8
Rosenberg et al. 2014 <sup>a</sup> [30]	X	X						High	21
Surbeck et al. 2015 <sup>a</sup> [34]	X	X	X	X	X	X		Moderate	16
Wettergren et al. 2016 <sup>a</sup> [17]	X							High	19

<sup>a</sup> Quantitative studies

<sup>b</sup> Qualitative studies

**Fig. 1** Flow diagram on identifying literature

control group. Neither time since treatment nor treatment modality was significantly associated with overall sexual problems, though treatment modality was related to ejaculation (to be discussed). When comparing AYA men to an older age range of men within this study (aged 40–59 years), sexual problems increased as age increased. The authors note that this finding is consistent with epidemiological studies of male sexual function.

Similarly, Surbeck and colleagues [34] found that 30% of a sample of men treated for diffuse low-grade glioma met criteria for sexual dysfunction according to the ASEX, and 45.4% reported that their sexual experiences have deteriorated since treatment. It was also found that remaining on antiepileptic drugs (AEDs) after right-side resectioning was related to poor sexual function in men as opposed to women. However, for those remaining on AEDs after left-side resectioning, sexual function was superior in men than in women. The authors note that the rates of sexual dysfunction found in this study were inconsistent with those of other studies examining sexual function after brain surgery. They posit that this may be related to the psychological distress associated with the incurable nature of gliomas.

Hoyt and colleagues [29] attempted to assess psychological variables that may be contributing to sexual dysfunction in this population. They found that, in a sample of 171 AYA men diagnosed with testicular cancer, a high level of interpersonal sensitivity was associated with lower sexual functioning scores. In other words, men who were more likely to perceive criticism, rejection, or negative evaluation from others reported poorer sexual functioning. However, coping style moderated this relationship; individuals with high interpersonal sensitivity and strong approach-oriented coping skills reported better sexual functioning than individuals with high interpersonal sensitivity and weak approach-oriented coping skills. The authors suggest that enhancing coping skills related to problem solving may protect against the negative impact of interpersonal sensitivity in this population.

#### *AYA women*

Seven studies measured the effect of cancer on sexual function in women, but only five provided detailed results pertaining specifically to women (see Table 4). These studies used a

**Table 4** Summary of the effect of cancer on AYA sexual function

Reference	Design	Sample size	Instrument	Findings
<b>Females</b>				
Bae and Park 2016 [22]	Cross-sectional	24 females (subset of <i>N</i> (137) within AYA age range)	FSFI	AYAs reported significantly greater levels of overall sexual function compared to their older peers (ages 40–59 years)
Dubashi et al. 2010 [26]	Cross-sectional	51 females	EORTC BR23	AYAs reported low sexual function, though women in the mastectomy group reported greater sexual function than those in the conservation group.
Eeltink et al. 2013 [27]	Cross-sectional	36 females	FSFI	31.4% of AYAs met criteria for sexual dysfunction. FSFI scores were not related to treatment modality or age.
Rosenberg et al. 2014 [30]	Cross-sectional	461 females	CARES	Sexual dysfunction was highest among AYAs who received chemotherapy and had treatment-induced amenorrhea.
<b>Males</b>				
Dahl et al. 2007 [25]	Case-control	429 cases, 364 controls (subset of <i>N</i> (2013) within AYA age range)	BSFI	Overall sexual problems were comparable between cases and controls, with 35% of cases and 29% of controls reporting such problems.
Hoyt et al. 2015 [29]	Cross-sectional	171 males	CAYA	Higher levels of interpersonal sensitivity were significantly related to lower sexual functioning, but coping skills moderated this relationship.
<b>Males and females</b>				
Robertson et al. 2016 [31]	Qualitative	21 males, 22 females	Psychosocial Adjustment to Illness Scale (PAIS) interview	Of the 16 AYAs who were in a relationship, 50% reported sexual difficulties.
Surbeck et al. 2015 [34]	Cross-sectional	11 males, 10 females (subset of <i>N</i> (32) within AYA age range)	ASEX	64% of female and 30% of male AYAs met criteria for sexual dysfunction.
Wettergren et al. 2016 [17]	Cohort	287 males, 178 females	LIC	Older AYAs who were fatigued and had a negative perception of their appearance were more likely to report that cancer negatively impacted their sexual function.

variety of assessment tools to measure sexual function, including the EORTC BR23 [43], the breast cancer-specific health-related quality of life module used by Dubashi and colleagues [26], and the FSFI, which was used by Bae and Park [22] as well as by Eeltink and colleagues [27]. Rosenberg and colleagues [30] administered the CARES to document the number, type, and severity of difficulties that may result from a cancer diagnosis, whereas Surbeck and colleagues [34] used the ASEX.

In their cross-sectional examination of quality of life among young women with breast cancer, Dubashi and colleagues [26] found an effect of treatment type on sexual function. All of the patients in this sample underwent surgery, but 35% of the women chose breast conservation surgery as opposed to mastectomy. In 43.1% of the cases, doctors performed bilateral salpingo-oophorectomies to remove both ovaries and Fallopian tubes. The authors reported that sexual functioning was significantly greater in the mastectomy group compared to the breast conservation group; however, they also

found that sexual function was significantly greater among women who had their ovaries preserved as opposed to ablated. To explain these somewhat contradictory findings, the authors noted that there may be confounding factors leading to poorer sexual function in the breast conservation group as compared to the mastectomy group. Specifically, they suggest that breast conservation and mastectomy are gross categories that do not highlight other adjuvant therapies that may have been involved in the treatment process, such as chemotherapy, radiotherapy, and hormone therapy. However, adjuvant treatments fail to discriminate women who receive lumpectomies from women who receive mastectomies because no adjuvant treatment or combination of treatments is specifically associated with one or the other type of surgery. It is therefore unclear how adjuvant treatment could explain differences in sexual function between women receiving mastectomies and women receiving lumpectomies. It is possible that other individual factors may compromise sexual function more so for some women than for others.



Eeltink and colleagues [27] assessed the association between perceived fertility status and sexual function in young women with Hodgkin's lymphoma (HL). They found that 31% of HL survivors met the clinical cutoff for sexual dysfunction. The sample was separated into six groups by age (30 years and older, under 30 years) and perceived fertility status (infertile, fertile, and not aware). Women over the age of 30 years who perceived themselves to be infertile had the lowest FSFI scores compared to the other groups. It is important to note, however, that some of these groups had very small sample sizes (e.g.,  $n = 1$  in the infertile, aged less than 30 years group). When participants were asked an open-ended question about whether or not they had a sexual problem, 39% of the sample reported one or more sexual problems, and none of the patients reported recovery from these problems.

Rosenberg and colleagues [30] examined the effects of treatment and other factors on sexual functioning in a large sample of women ( $n = 461$ ) who were diagnosed with breast cancer at age 40 or younger. They found that treatment-induced amenorrhea was a strong predictor of sexual dysfunction in these women. Amenorrheic women reported significantly worse sexual functioning compared with women who had received chemotherapy but continued to menstruate. However, after accounting for vaginal pain, body image, and fatigue, treatment-related amenorrhea was no longer an independent predictor of sexual dysfunction. Other results indicated that tamoxifen may be related to sexual function in this population. Amenorrheic women who were not on tamoxifen had more symptoms of sexual dysfunction compared to amenorrheic women who were on tamoxifen. The authors found that, in the short term, tamoxifen did not appear to adversely affect sexual function, and they point to a study indicating that tamoxifen may actually improve lubrication [44]. However, they note that their data does not indicate that the drug will not have detrimental effects on sexual function in the long term.

Surbeck and colleagues [34] administered the ASEX to patients ( $n = 32$ ) who underwent surgery for diffuse low-grade glioma. They provided separate results for women and men, and of the 15 women included in their sample, nine fell within the AYA age range. Six (66.7%) of these young women met criteria for sexual dysfunction. Participants were asked about the subjective impact of the surgery on their sexual experience, specifically if their sexual experience has improved, deteriorated, or remained unchanged. Some women reported that their sexual experience has not changed since the surgery (44.4%), whereas others indicated that their overall sexual experience has deteriorated (44.4%). Based on these findings, the authors suggested that sexual dysfunction is common among patients who undergo surgery for this type of cancer.

Bae and Park [22] assessed sexual function, depression, and overall quality of life in 137 Korean women with cervical cancer. Though the authors did not specifically recruit AYAs, they provided FSFI scores for participants across three age

groups: ages 20–39, 40–49, and 50–59 years. The mean FSFI score for the AYA women (aged 20–39 years) was 10.75 (SD = 4.62), which is well under the clinical cutoff of 26.55 [38] and thus indicative of poor sexual function. However, women in the older age groups (40–49 and 50–59 years) reported significantly greater sexual problems; the mean FSFI score among women aged 40–49 years was 4.70 (SD = 3.45), and women aged 50–59 years had an average score of 2.70 (SD = 1.57). Though it is clear from this data that sexual function among AYA women with a history of cervical cancer is poor, sexual function appears to decrease with age.

### Effect of cancer on desire

Sexual desire is typically defined as the motivation to engage in sexual activity. Desire may also be referred to as “interest” or “sex drive,” and it describes the feelings that compel an individual to seek out some type of sexual activity, either partnered or solitary. The majority of the studies reviewed below assessed sexual desire using one desire-specific item on a validated measure (e.g., the ASEX) or the desire domain score of a measure that assesses multiple domains of sexual function (e.g., the FSFI).

Two studies [31, 33] assessed sexual desire via qualitative interviews and did not separate results by gender. In the first of these studies [33], sexual desire concerns affected 60% of the sample. Among participants who indicated a decrease in sexual desire, four reported that, before they were diagnosed, they typically initiated sexual activity; following treatment, their partners initiated. The second study [31] assessed the quality and satisfaction of sexual/romantic relationships in 43 young males and females who had recently received treatment for cancer. Of those who were in a relationship at the time of the interview ( $n = 16$ ), eight (50%) endorsed sexual difficulties (e.g., sexual interest, frequency of sexual activity). One of the most commonly cited issues was a loss of sexual interest (62.5%). Five participants (31.3%) attributed their loss of sexual interest to feeling unwell during treatment; notably, the majority of these individuals (80%) reported that their sexual difficulties resolved post-treatment. However, low sexual interest was also reported post-treatment by seven participants, who indicated that these effects were likely due to medication-related side effects (2/7, 28.6%), emotional fluctuations (2/7, 28.6%), and body-image concerns (3/7, 42.9%). Findings from these two qualitative studies suggest that a cancer diagnosis during the AYA period is associated with decreased sexual interest and reduced frequency of sexual activities.

### AYA men

Six studies examined the effect of cancer on sexual desire in men (see Table 5). Three studies focused exclusively on men and one study focused on men and women, providing unique

results for each participant. Two were qualitative and did not separate results by gender (discussed above). Blackmore [23] assessed sexual desire using the drive subscale of the Derogatis Interview for Sexual Functioning (DISF) [45], a measure designed to capture ten major domains of sexuality. Dahl and colleagues [25] administered the BSFI, which includes an interest subscale, and Surbeck and colleagues [34] administered the ASEX, which has a single item pertaining to desire.

Blackmore [23] found that, in men who had undergone orchiectomy for treatment of testicular cancer, levels of sexual desire did not differ from controls. However, this study did identify that men retrospectively reported a significant decrease in sexual desire from pre- to post-treatment. Blackmore [23] speculates that patients may perceive that their sexuality has suffered as a result of their orchiectomy, despite their levels of postoperative sexual desire mirroring those of their healthy counterparts.

Similarly, Dahl and colleagues [25] found no differences in levels of sexual desire in men treated for testicular cancer and healthy controls. In this study, 10% of patients and 12% of controls reported problems with sexual desire. When examining the effect of age on sexual desire, similar declines in desire were found in patients and controls, with AYA men reporting greater sexual desire than their older counterparts (aged 40–59 years). The authors also noted that their desire findings closely match those of the general American population [46].

When examining men treated for diffuse low-grade gliomas, Surbeck and colleagues [34] found that 63.6% of men described their level of sexual desire as being “somewhat strong,” 18.1% described it as “somewhat weak,” and 18.1% reported having “no sex drive.” Taken together, results from these studies suggest that, while there is a very real possibility of experiencing decreased desire after treatment for cancer, low sexual interest was only evident in a small portion of participants.

Sexual frequency is typically considered to be a component of sexual desire. One study investigated the frequency of sexual activity in men. Geue and colleagues [28] used the Questionnaire on Stress in Cancer Patients-Revised (QSC-R23) [47] to assess changes in sexual activity since cancer diagnosis. Primary diagnoses in AYA men were hematological and testicular cancers. It was found that nearly half (45.5%) of the men in the sample reported decreased frequency in sexual activity since receiving their diagnoses. When asked to rate the strength of the decline in frequency on a scale of 1 (little) to 5 (very strong), 26.7% reported a “little” decrease in frequency. The authors did note, however, that the cross-sectional design of the study challenges the ability to properly compare sexual frequency pre- to post-diagnosis.

#### *AYA women*

There were seven studies that examined sexual desire in women (see Table 5). Four of these studies focused exclusively on

women, one included both men and women, and two were qualitative (discussed above).

Campos and colleagues [24] examined the effects of fertility-sparing surgery for ovarian neoplasms, the leading cause of death in gynecological malignancies, on certain domains of sexual function in a small sample ( $n = 16$ ) of young women. One item on the Sexual Activity Questionnaire [48] (“Did you desire to have sex with your partner this month?”) pertained specifically to desire. The majority of women (38%) endorsed that they “somewhat” desired to have sex with their partners. A relatively similar number of women (31%) reported that they “very much” desired to have sex. Among the nine AYA women who received surgery for low-grade glioma [34], 44.4% reported that their sex drive was somewhat strong, while 55.6% reported that their sex drive was somewhat weak.

In their assessment of sexual function in young females with a history of HL ( $n = 36$ ), Eeltink and colleagues [27] found that 28% of the sample reported a lack of desire in response to an open-ended question pertaining to sexual problems. The authors also administered the FSFI and compared the domain scores of their sample to those of a healthy Dutch sample [49]. The only significant difference between the HL group and the healthy controls was on the desire subscale, as the HL group reported experiencing a lack of desire significantly more often than the group without a history of cancer. The authors suggest that these results may be driven, in part, by the potential distress of impaired fertility in the HL group.

Rosenberg and colleagues [30] found a specific relationship between treatment-related amenorrhea and sexual interest in young women with breast cancer. Amenorrhea due to chemotherapy or surgery was significantly associated with decreased sexual desire. When body image, weight problems, and vaginal pain symptoms were added to the model, treatment-related amenorrhea retained its significant association with sexual interest.

Two studies specifically addressed the effect of a cancer diagnosis on frequency of sexual activity, which is generally conceptualized as a marker of sexual desire. In their sample of women with ovarian neoplasms, Campos and colleagues [24] found that 25% did not engage in sexual activity at all over the last month, 31% reported that they engaged in sexual activity 1–2 times per month, and 31% endorsed engaging in sexual activity 3–4 times per month. In a separate sample of adolescent and young adult women with a variety of different types of cancer [28], 72.7% reported that they have had less sexual intercourse since their diagnosis. When asked to rate the strength of the decline in sexual frequency on a scale of 1 (little) to 5 (very strong), most of the women reported the strength of the decrease to be “very strong” (29.2%). Approximately 13% reported the strength of the decline to be a 4 on the 1 to 5 scale, and the rest of the women reported that the strength of their decline fell either at 1, 2, or 3.



Overall, the findings from these five studies indicate that a cancer diagnosis among young women may have significant negative effects on sexual desire and that low desire is more prevalent in AYA populations than in healthy controls. Similarly, the frequency of engaging in sexual activity appears to decline after treatment. It is possible that decreased desire may be linked to treatment-related amenorrhea. However, though diminished or weakened sexual desire following treatment for cancer does often occur, desire may remain somewhat strong during this period.

### Effect of cancer on arousal

Sexual arousal is conceptualized as mental and physical readiness for sexual activity. In men, sexual arousal is typically equated with erectile function. In women, sexual arousal has been broken down into two key components, a physiological genital response and a psychological appraisal of a sexual stimulus as “arousing” [50, 51]. The physiological genital response involves changes that occur in the body to prepare for a sexual interaction (vaginal swelling, genital warmth, and lubrication). The cognitive appraisal of the sexual stimulus is often referred to as psychological, mental, or subjective sexual arousal, and it reflects the state of feeling “turned on.” Studies that assess sexual arousal in women often fail to distinguish between physiological and psychological arousal. If physiological arousal is measured, self-report tools focus primarily on vaginal lubrication, whereas assessments of psychological arousal usually include items that gauge mental excitement. Validated questionnaires generally distinguish between the two components. For example, the FSFI includes a lubrication domain, which assesses an important aspect of physiological arousal, and an arousal domain, which probes feelings of mental arousal. Although none of the studies on AYA women reviewed below differentiated between physiological and psychological, some studies did differentiate lubrication from arousal.

#### *AYA men*

Five studies investigated erectile function in men after cancer treatment (see Table 6). Two studies used the IIEF, one study used the BSFI, one study used the ASEX, and one was qualitative. One study compared erectile function in patients and controls.

Aksoy and colleagues [21] measured erectile function in lymphoma patients using the IIEF. Two thirds of the sample reported experiencing some degree of erectile dysfunction (ED): 29.1% reported mild ED, 8.3% reported moderate ED, and 25% reported severe ED. No significant differences in age were found between men with and without ED. Hypertension, diabetes, cigarette consumption, and weight were not significantly related to the presence or severity of ED. The authors suggested that, given the increased prevalence of ED in

successfully treated patients, psychosocial problems related to cancer diagnosis and survivorship may result in sexual dysfunction in this population.

Similarly, Sendur and colleagues [32] found that three quarters (72.4%) of men treated for colorectal cancer reported some degree of ED. According to the IIEF, 41.3% of patients reported mild ED, 20.6% reported moderate ED, and 10.3% reported severe ED. For men under 30 years of age, nearly half (42.9%) reported mild and half (57.1%) reported moderate ED. For men aged 30–39 years, however, a greater range of erectile function was observed. Nearly a third (36.4%) of men aged 30–39 years reported no ED after treatment, 40.9% reported mild ED, 9.1% reported moderate ED, and 13.6% reported severe ED. The authors concluded that increasing age is linked with a significantly higher risk for developing ED in male colorectal cancer patients.

When using alternate forms of measurement, rates of erectile difficulties were not as high. With the BSFI, Dahl and colleagues [25] found that only 8% of patients diagnosed with testicular cancer reported erection problems, and rates of erection problems did not differ between patients and controls. Using the ASEX, Surbeck and colleagues [34] found that 9.1% of diffuse low-grade glioma patients described getting and keeping an erection as “very difficult” and 9.1% said that they were not able to do so. In addition, the majority (72.6%) of men in this sample reported that it was “very” to “somewhat” easy to become sexually aroused, whereas 9% reported that it was “somewhat difficult” and 18.1% reported not being able to become aroused [34]. Patients who underwent right-sided resectioning reported the greatest impairment in erectile functioning. Through interviews with 11 male AYA cancer patients, de Souza Melo and colleagues [33] found that 50% of the sample reported difficulties attaining or maintaining an erection. They theorized that these difficulties were likely related to decreases in testosterone resulting from the disease itself, changes in the vascular systems associated with erection, and negative psychological factors, including stress and fatigue.

#### *AYA women*

The effects of cancer and its treatment on psychological sexual arousal in women were measured in two studies. In the first study, 8% of women endorsed problems getting aroused in response to an open-ended question [27]. Eeltink and colleagues [27] also assessed arousal with the FSFI, and they reported that the FSFI arousal domain scores for young women with a history of HL did not differ from those of a healthy Dutch population [49]. The second study [34] assessed sexual arousal via one item on the ASEX. Among women in this sample, 22.2% reported that they are “very easily aroused” and 33.3% reported that they are “somewhat easily aroused.” However, the majority of the sample (44.4%) indicated that it is “somewhat difficult” to become aroused.

**Table 5** Summary of the effect of cancer on AYA sexual desire

Reference	Design	Sample size	Instrument	Findings
<b>Females</b>				
Campos et al. 2012 [24]	Cross-sectional	16 females	SAQ	31% of AYAs reported that they “very much” desire to have sex.
Eeltink et al. 2013 [27]	Cross-sectional	36 females	FSFI	Low sexual desire was the most prevalent sexual difficulty.
Rosenberg et al. 2014 [30]	Cross-sectional	461 females	CARES	AYAs who underwent breast reconstruction exhibited significantly more desire than did women who had mastectomies without reconstruction.
<b>Males</b>				
Blackmore 1988 [23]	Case-control	16 surgical cases, 10 surgical controls, 10 healthy controls	DSFI	There was no difference between groups even after controlling for age, marital status, and social class.
Dahl et al. 2007 [25]	Case-control	429 cases, 364 controls (subset of <i>N</i> (2013) within AYA age range)	BSFI	Desire problems were comparable between cases and controls, with 10% of cases and 12% of controls reporting such problems.
<b>Males and females</b>				
de Souza Melo et al. 2016	Qualitative	11 males, 9 females	Interviews	60% of AYAs indicated problems related to sexual desire.
Geue et al. 2015 [28]	Cross-sectional	33 males, 66 females	FLZ	45.5% of AYA men reported a decrease in the frequency of sexual activity since diagnosis. Among AYA women, 72.7% reported that they have engaged in sexual activity less frequently since their diagnosis.
Robertson et al. 2016 [31]	Qualitative	21 males, 22 females	Interviews	Of the 16 AYAs who reported being in a relationship, 5 (31.3%) reported a loss of sexual interest during treatment, and 7 (43.8%) reported decreased sexual interest post-treatment.
Surbeck et al. 2015 [34]	Cross-sectional	11 males, 10 females (subset of <i>N</i> (32) within AYA age range)	ASEX	52% of AYAs reported having “somewhat strong” desire, while 48% reported no to somewhat weak desire.

Three studies highlighted the impact of cancer on vaginal lubrication, a key component of physiological sexual arousal, in young women. In response to an open-ended question about sexual problems following treatment, 8% of women reported problems getting lubricated [27]. Similarly, in the same sample, 8% of participants endorsed problems with vaginal dryness. The authors noted that their sample did not have significantly lower FSFI lubrication domain scores compared to a healthy control group [49]. Surbeck and colleagues [34] examined lubrication among nine young women who were surgically treated for low-grade glioma. These participants completed the ASEX questionnaire, which includes one lubrication item. In this small sample, 22.2% of women reported that it was “somewhat difficult” to become wet or moist during sex, 22.2% reported that vaginal lubrication was achieved “somewhat easily”, and 33.3% reported that lubrication came either “very easily” or “extremely easily.” However, de Souza Melo and associates [33] found that, among women, lack of lubrication was a primary sexual concern during treatment. Women reported that insufficient lubrication often led to pain

during sexual activity. The authors suggested that difficulties with vaginal lubrication may have resulted from a reduction in estrogen (due to chemotherapy).

### Effect of cancer on ejaculation and orgasm

There is no widely accepted definition of orgasm, but most conceptualizations include both a physiological component and a subjective component [52]. In men, ejaculation often serves as an objective marker of orgasm, whereas women have no such marker. Researchers find that the subjective experience of orgasm and the physiological changes that accompany it are quite varied, especially among women [53, 54]. Problems with orgasm come in a variety of forms. Men may be unable to achieve orgasm despite the presence of adequate desire, arousal, and stimulation, or they may experience a persistent or recurrent pattern of orgasm and ejaculation immediately following penetration (i.e., before the individual wishes it). Additionally, some men may experience orgasm without ejaculation for various medical reasons such as

**Table 6** Summary of the effect of cancer on AYA erection

Reference	Design	Sample size	Instrument	Findings
<b>Males</b>				
Aksoy et al. 2008 [21]	Cross-sectional	24 males (subset of <i>N</i> (59) within AYA age range)	IIEF	62.5% of the AYA subset reported experiencing some degree of ED after treatment; a third of those participants (33.3%) had moderate to severe ED.
Dahl et al. 2007 [25]	Case-control	429 cases, 364 controls (subset of <i>N</i> (2013) within AYA age range)	BSFI	Erection problems were comparable between cases and controls, with 8% of men in each group reporting such problems.
Sendur et al. 2014 [32]	Cross-sectional	29 males (subset of <i>N</i> (61) within AYA age range)	IIEF	The majority (72.4%) of AYAs had some degrees of ED; almost a third of those participants (31.0%) had moderate to severe ED.
<b>Males and females</b>				
de Souza Melo et al. 2016	Qualitative	11 males (subset of <i>N</i> (20) within AYA age range)	Interviews	50% of AYA men reported difficulties reaching and maintaining an erection.
Surbeck et al. 2015 [34]	Cross-sectional	11 males, 10 females (subset of <i>N</i> (32) within AYA age range)	ASEX	81.8% of AYAs said that they could “very” or “somewhat easily” get and maintain an erection.

radiotherapy for prostate cancer [for a review, see 21]. Among women, problems in this domain may involve reduced intensity, delay, and/or absence of orgasm. A number of validated psychometric instruments designed to assess sexual function include single items or multiple items on orgasm and/or ejaculation. Some of these instruments, such as the BSFI, the ASEX, and the FSFI, were used in the reviewed studies.

One study addressed orgasm concerns in AYAs but did not interpret these results by gender. de Souza Melo and colleagues [33] interviewed 20 inpatients (11 males) with onco-hematological diseases to assess changes in sexuality post-diagnosis. Orgasm concerns were one of the most commonly cited sexual problems in this sample; 80% of the participants noted changes in their ability to achieve orgasm post-diagnosis.

#### *AYA men*

Two studies (one qualitative, discussed above) measured orgasm and one study measured ejaculation. Dahl et al. [25] found that male patients treated for testicular cancer reported significantly greater problems on the BSFI ejaculation domain (e.g., difficulty ejaculating, amount of semen ejaculated) than did their healthy counterparts. In Surbeck et al. [34], 81.8% of diffuse low-grade glioma patients described their ability to reach orgasm as “very” to “somewhat” easy, 9.1% said reaching an orgasm was “somewhat difficult,” and 9.1% said that they could “never reach orgasm.” Patients who received right-sided resections were more likely to experience impairment in this domain than those who received left-sided resections. This closely aligns with functional imaging studies showing right hemisphere lateralization of brain activity during orgasm [55].

#### *AYA women*

Three studies (one qualitative, discussed above) examined the effect of cancer on orgasm in AYA women. Eeltink and colleagues [27] measured the frequency of orgasm in this population via the FSFI. They found no differences in frequency of problems with orgasm between their sample of HL survivors and a healthy control group [49]. However, Surbeck and colleagues [34] found an effect of surgery to resect diffuse low-grade gliomas on orgasm in young women. The authors examined the single ASEX item pertaining to orgasm in relation to treatment. In response to this item, 33.3% reported that orgasm can be attained “somewhat easily”; however, 44.4% reported that reaching orgasm is “somewhat difficult,” and 22% reported that it is very difficult. The authors noted an interesting interaction effect of resection side (right or left hemisphere) on ability to reach orgasm; right-sided resections were associated with higher scores (i.e., greater difficulty) on the ASEX orgasm item. The authors indicated that this finding aligned well with recent imaging studies [for a review, see 56], which have revealed a right hemispheric dominance during orgasm.

#### **Effect of cancer on sexual satisfaction**

The most widely used definition of sexual satisfaction is that of Lawrance and Byers [57], who conceptualized the construct as an affective response arising from a subjective evaluation of both the positive and negative dimensions of a sexual relationship. Satisfaction is widely considered to be a domain of sexual function, and it is typically assessed via one or several items on validated sexual function inventories. Sexual satisfaction may also be assessed on measures of overall

quality of life. In this review, a number of studies measured sexual “enjoyment,” an alternative conceptualization of sexual satisfaction.

#### *AYA men*

Sexual satisfaction in AYA men was investigated in four studies (see Table 7), two focusing exclusively on men and two focusing on men and women, providing unique results for each gender. Sexual satisfaction was measured using the DISF [23], BSFI [25], the Life Satisfaction Questionnaire-Sexuality Scale (FLZ), a seven-item subscale of a larger questionnaire aimed at assessing ten domains of life satisfaction [28], and the ASEX [34].

Blackmore [23] assessed sexual satisfaction across three samples of men: those who had received surgical treatment for testicular cancer, those who had received testicular surgery for reasons other than cancer, and healthy controls. No significant differences were found among any groups in level of sexual satisfaction. Additionally, no significant relationships were identified after controlling for demographic variables such as age, marital status, and social status.

Geue and colleagues [28] found that, while many AYA men reported having sexuality-related concerns (e.g., feeling unattractive), they reported being satisfied with their sexual lives as a whole. Another study indicated that men frequently reported being “very” to “somewhat” satisfied with their sexual lives [34]. It should be noted, however, that these studies employed relatively small sample sizes, ranging from 11 to 16 men per group.

When utilizing a large sample of men, Dahl and colleagues [25] found different results. They assessed sexual satisfaction in men with ( $n = 429$ ) and without ( $n = 364$ ) a diagnosis of cancer. It was found that men with cancer reported significantly *greater* levels of satisfaction. The authors speculate that men may have reduced expectations regarding their post-treatment sexual function, which may inflate satisfaction with even suboptimal outcomes.

#### *AYA women*

The effect of a cancer diagnosis and its subsequent treatments on sexual satisfaction in AYA women was analyzed in five studies (see Table 7).

In a sample of women who underwent a fertility-sparing procedure for ovarian neoplasms [24], 37.5% reported that they were very much satisfied after sex. Similarly, 37.5% of the sample reported that they were either “somewhat” or “a little” satisfied after sex, while 12.5% indicated that they were “not at all” satisfied after sex. However, these authors did not include healthy women as a comparison group. Eeltink and colleagues [27] did compare the FSFI satisfaction domain scores of their sample of women with a history of HL to those

of healthy women in a previously published study [49], and they found no statistically significant differences.

In their examination of young females and males with cancer, Geue and colleagues [28] used the sexuality subscale of the FLZ to evaluate relationship quality and satisfaction. Among the 66 females included in the sample, 39.4% were “quite satisfied” with their relationship and/or sexuality 28.8% were “very satisfied.” Fewer women reported less sexual satisfaction; 12.1% indicated that they were “rather unsatisfied” with their relationship/sexuality, and 4.5% endorsed being “unsatisfied.”

Surbeck and colleagues [34] looked specifically at *orgasm* satisfaction in both males and females following surgery to resect low-grade gliomas. Among the nine women who fell within the AYA age range, 66% found their orgasms to be “somewhat satisfying,” and 34% reported that their orgasms were “somewhat unsatisfying.”

Sexual enjoyment is distinct from but highly related to sexual satisfaction. Two studies reported findings on sexual enjoyment. Campos and colleagues [24] found that 38% of their sample of women who underwent fertility-sparing surgery for ovarian neoplasms very much enjoyed sexual activity, 31% “somewhat” enjoyed sexual activity, and 12.5% enjoyed sexual activity “a little.” A relatively small proportion of the sample (6%) did not enjoy sexual activity “at all.” Using the BR 32, Dubashi and colleagues [26] found an effect of treatment type on sexual enjoyment. Specifically, sexual enjoyment was significantly higher among women in the mastectomy group compared to the breast conservation group. With respect to ovarian treatment, sexual enjoyment was significantly greater in the group of women who had their ovaries preserved compared to the women who were treated with ovarian ablations.

The results of these five studies suggest that sexual satisfaction may be compromised in young women diagnosed with cancer during the AYA period. However, women with cancer may be experiencing similar levels of sexual satisfaction compared to healthy women.

#### **Effect of cancer on sexual pain**

Sexual pain has typically been studied only in women. Genital pain often causes painful intercourse, and it can result from a variety of underlying physical pathologies, such as endometriosis, lichen sclerosis, and other genital infections, as well as childbirth and menopause [for a review, see 58]. Genital pain may also exist in the absence of identifiable organic causes; this type of pain, also known as vulvodynia, may be localized to a specific area of the vulva or generalized to the entire vulva. Pain is a distinct subscale of the FSFI, the most widely used index of female sexual function, and pain is also assessed as a single item or as multiple items on other measures.

Two studies examined the effect of cancer on sexual pain in women. Both studies were cross-sectional in design. Campos



and colleagues [24] used the Sexual Activity Questionnaire to measure sexual pain and Eeltink and colleagues [27] used a subscale of the FSFI. In the first study [24], the majority of the sample (56%) who were surgically treated for ovarian neoplasms did not report any sexual pain. About a fifth of the sample (19%) endorsed some pain during penetration, and 12.5% reported a little pain. When asked an open-ended question about sexual problems post-cancer diagnosis, 6% of women in a sample of young HL survivors reported pain or fear of pain during sexual intercourse [27]. Eeltink and colleagues [27] noted that the FSFI pain domain scores of this sample did not differ significantly from those of healthy sample published in another study [49].

## Discussion

Adolescents and young adults have unique developmental needs during cancer treatment. Not only do AYAs face specific psychosocial challenges ranging from increased dependence on their parents [59] to delayed achievement of professional and educational goals [60], they also experience disruptions in their psychosexual development [12, 13]. Sexual function is a key aspect of psychosexual development and an important component of quality of life. To our knowledge, this is the first systematic review to examine the effects of cancer and its treatments during the AYA period on sexual function.

The findings of this review indicate that the diagnosis and treatment of cancer in AYAs differentially affect the various domains of sexual function by gender. Among AYA men, erection, ejaculation, and orgasm appear to be most significantly impacted. The studies included in this review highlighted impairments in erectile function following diagnosis and treatment, though rates of dysfunction differed by assessment tool. Ejaculation and orgasm appear to be negatively impacted in this population, but more research is needed on those domains as they were both only assessed in one study. Among AYA women, sexual desire appears to be particularly compromised. There were mixed findings with respect to arousal, orgasm, and satisfaction. Of the studies that assessed arousal and orgasm, those that included a healthy control group showed no significant differences between AYAs with cancer and healthy controls. However, cross-sectional studies that did not include a control group showed some deficits in arousal and orgasm following diagnosis and treatment. With respect to sexual satisfaction, it appears that more AYAs are satisfied than unsatisfied, but that does not rule out the possibility that cancer may negatively affect sexual satisfaction among women in this age group.

Though the effects of infertility and sterility on sexual function were outside the scope of this review, they are highly relevant to sexual function, particularly among AYAs. One of the studies that we reviewed [33] found that fear

surrounding the possibility of infertility significantly affected the sexuality of AYAs. Infertility has a notable negative effect on marital relationships [61], sexual satisfaction [62], and psychosocial well-being [63], particularly among women, who tend to feel more stress surrounding their fertility status than do men [64]. Concerns related to conception likely span the entirety of the AYA age range, though they may be more pressing for individuals in the mid- to older end of the spectrum, when childbearing is more common. Future research should investigate the impact of infertility on sexual function across the full AYA population, highlighting the point at which age becomes a clinically meaningful variable for psychosexual outcomes.

Characterizing the sexual function of AYAs with cancer has important clinical applications. Several studies have documented that patients often report confusion regarding sexual issues experienced during and after treatment [28, 31]. Research suggests that healthcare professionals often neglect to address the impact of a cancer diagnosis on sexual health and romantic relationships with this population [28, 60, 65], possibly due to lack of information, training, or time. Although it is important for all individuals diagnosed with cancer, regardless of age, to receive information on the sexual implications of their treatment options from their providers, there is a strong need for resources and guidance on cancer-related sexuality that caters specifically to younger adults. It is possible that discussing sexual issues with adolescents and young adults during and after treatment would both improve knowledge of the sexual sequelae of cancer and help minimize sexual difficulties.

It is worth noting some limitations of this review. First, this review addressed the domains of sexual function that are affected by a variety of cancer diagnoses, ranging from testicular cancer to low-grade gliomas. Sexual dysfunction is likely to be more associated with certain cancers than with others [16]; however, the fact that sexual problems are associated with a heterogeneous, though not comprehensive, group of cancers does point to the strength of the relationship between cancer in the AYA period and sexual dysfunction. Second, the authors of this review assessed only English-language papers and papers that had been subjected to peer-review. Therefore, language selection may be a possible source of bias, as studies may be more likely to be published in English when results are significant. Third, the studies examined here used multiple different assessment tools to examine sexual function; some of these tools were developed specifically for populations with cancer, whereas others were not. Furthermore, certain measures assess all relevant domains of sexual function, while others fail to include items that pertain to one or more areas. Given the range of assessment tools used in these studies, the generalizability of these findings may be somewhat limited. Fourth, the studies varied in the amount of time between diagnosis/treatment and assessment, ranging from a mean of



**Table 7** Summary of the effect of cancer on AYA sexual satisfaction/enjoyment

Reference	Design	Sample size	Instrument	Findings
<b>Females</b>				
Campos et al. 2012 [24]	Cross-sectional	16 females	SAQ	Most AYA females very much (38%) or somewhat (31%) enjoyed sexual activity. Some women (6%) did not enjoy sexual activity at all.
Dubashi et al. 2010 [26]	Cross-sectional	51 females	EORTC BR23	Sexual enjoyment was affected by treatment type; it was higher for women who had mastectomies and ovary-sparing surgeries compared to women who had breast conservation procedures or ovarian ablations, respectively.
Eeltink et al. 2013 [27]	Cross-sectional	36 females, compared to 108 controls	FSFI	AYA females reported significantly lower sexual satisfaction than did women without a cancer diagnosis.
<b>Males</b>				
Blackmore 1988 [23]	Case-control	16 surgical cases, 10 surgical controls, 10 healthy controls	DISF	Found no differences in sexual satisfaction among AYA males who had surgery to treat their testicular cancer, males who had testicular surgery for other reasons, and healthy controls.
Dahl et al. 2007 [25]	Case-control	429 cases, 364 controls (subset of <i>N</i> (2013) within AYA age range)	BSFI	Men with cancer reported significantly greater sexual satisfaction than healthy controls.
<b>Males and females</b>				
Geue et al. 2015 [28]	Cross-sectional	33 males, 66 females	FLZ	About one third of AYA patients were not satisfied with the frequency of sexual activity or with their own sexual performance. Overall, AYA men were more sexually satisfied than AYA women.
Surbeck et al. 2015 [34]	Cross-sectional	9 males, 9 females (subset of <i>N</i> (32) within AYA age range)	ASEX	Of the 9 AYA women, 66% reported somewhat satisfying orgasms, and 34% reported their orgasms to be somewhat unsatisfying. The majority of the AYA men reported that their orgasms were either very satisfying or somewhat satisfying.

6 months post-treatment [21, 32] to a median of 70 months post-treatment [27]. In certain cases, patients who were assessed multiple years after receiving their initial diagnoses no longer fell within the AYA age range. This variability in time between diagnosis/treatment and assessment is a clear limitation that may have compromised our conclusions. Finally, though this review covered a heterogeneous group of cancers and wide range of sexual function concerns, the studies that met the inclusion criteria did not represent a diverse range of participants with respect to sexual orientation or gender identity. Given that the LGBT population is relatively understudied, particularly in the oncology literature, this is not unusual. However, it is possible that cancer and its treatment modalities may have unique effects on the sexual function of AYAs who identify as LGBT. Future research should address the relationship between sexual function and cancer in this important population.

Unfortunately, certain domains of sexual function were the focus of more attention than others. For example, among the studies that included or exclusively recruited female participants, there was more focus on sexual desire ( $n = 7$ ) and

sexual satisfaction ( $n = 5$ ) than on sexual arousal ( $n = 2$ ), sexual pain ( $n = 2$ ), and orgasm ( $n = 3$ ). The studies that examined sexual function post-cancer diagnosis in AYA men focused more on erection ( $n = 5$ ) and sexual satisfaction ( $n = 4$ ) than on ejaculation ( $n = 1$ ) and orgasm ( $n = 2$ ). Though these studies did address multiple domains of sexual function, it is evident that certain domains received less attention, which suggests that the relationship between cancer during the AYA period and orgasm, for instance, may warrant more attention in future research.

The AYA age range (15–39 years) that is currently accepted by the cancer survivorship field and was therefore used in this review may obscure important differences that are relevant to the study of sexual function. The developmental milestones that occur between the ages of 18 and 25 years, the time period that Arnett termed “emerging adulthood” [66], are largely distinct from those that take place around age 40 years. Arnett suggests that emerging adulthood is unique in that these individuals are exploring their identities; they are navigating the areas of love and work while also developing their worldviews. Historically, the focus of identity formation has centered on adolescence

[67]; though adolescents do date and work, their romantic relationships tend to be less serious and less likely to include sexual intercourse than those of emerging adults [68], and their work is less focused and more transient than that of their slightly older counterparts [66]. Adolescents start to experience sexual urges, accept themselves as sexual beings, and begin to think about emotional connections with a potential partner [69]. During emerging adulthood, individuals coordinate individual life goals with dyadic commitment [70]. With respect to sexuality, emerging adults are more likely than adolescents to be sexually active [71], and they are more accepting of casual sex than their younger peers [72]. Though a growing number of emerging adults are not in stable and committed relationships [70], many individuals in this age group are planning for and expecting to get married later on [73].

Emerging adults are not only distinct from adolescents. There are also notable differences in psychosexual milestones between emerging adults and “older” young adults (aged 26–39 years), particularly with respect to romantic and sexual relationships. Marriage is an important example. Over the past two decades, age at first marriage has increased to 27.4 years for women and 29.5 years for men in 2016 [74]. At these ages, men and women no longer fall within the age range of emerging adults; they have moved on to the next developmental stage. Similarly, the average age of mothers at first birth has increased from 24.9 years in 2000 to 26.3 years in 2014 [75]. For women, age at first birth is another important psychosexual milestone that is no longer occurring during the period of emerging adulthood. These distinctions that differentiate emerging adults from their older peers are critical for healthy sexual function. Indeed, the ability to function sexually—to experience sexual desire, arousal, satisfaction, etc.—is integral for entering long-lasting partnerships, which typically occurs during emerging adulthood, and sustaining these relationships over time [76], which is more characteristic of individuals aged 26–39 years.

The interaction between developmental stage and sexual function is particularly relevant for AYAs, as their age of diagnosis may impact the type and/or degree of impairment in sexual function. Wettergren and colleagues [17] chose to break down their participants into two groups based on age at diagnosis (15–24 vs. 25–39 years). In their study, the subgroup of AYAs that was most likely to report poor sexual function was older, not raising children, fatigued, and concerned about the negative impact of treatment on their physical appearance. A few other experiments included both AYAs and older participants; in one such study [34], more AYAs than older individuals met for sexual dysfunction (8 vs. 6); however, increased age was associated with greater overall sexual problems in a different study [25]. Sendur and colleagues [32] found that older participants met for severe ED more frequently than did AYAs (37.5 vs. 13.6%), but more AYAs than older participants endorsed moderate ED (20.7 vs. 12.5%). In a sample of

lymphoma survivors [21], just as many 18–29 year olds as 50–55 year olds met for ED. The data are clearly mixed, but it seems that *certain* sexual problems may be at least as common, or more common, in AYAs as in older cancer survivors. In order to develop more targeted interventions, future research should attempt to elaborate on the domains that are more compromised in AYAs than in older survivors.

Unfortunately, only one study included in this review [31] specifically targeted recruitment toward AYAs at the younger end of the age spectrum, so we know little about the effects of cancer on sexual function among participants in this age group. Given the societal taboos that limit discussions about sex and sexuality, especially with minors, it may be challenging to recruit younger participants for studies that focus on sexual function. However, failing to do so, and thus failing to produce strong empirical research on the sexuality of *all* AYAs, may signal to young patients that sexual outcomes are irrelevant to cancer survivorship.

The results of this review indicate a deleterious effect of cancer on the sexual function of AYA men and women. In particular, sexual desire and arousal appear to be most notably impacted by cancer in AYA women, whereas erection, ejaculation, and orgasm are most affected by cancer in AYA men. Additional research is needed to (1) assess sexual function following the diagnosis and treatment of *specific cancers* in AYAs; (2) ascertain the impact of age at diagnosis/treatment on specific domains of sexual function in AYAs, particularly among younger AYAs; and (3) break down the current AYA age range of 15–39 years into smaller subgroups that reflect the range of psychosexual milestones that occur during that time. To prevent future research from focusing primarily on AYA participants who fall at one end of the age spectrum, we suggest that researchers adopt three subcategories within the AYA age range: mid-late adolescence (15–17 years), emerging adulthood (18–25 years), and young adulthood (26–39 years). Indeed, some agencies have already adopted narrower definitions of the AYA age range; for example, Cancer Australia defines AYAs as individuals who were diagnosed with cancer between the ages of 15 and 25 years [77]. By defining more developmentally sensitive age brackets, researchers could help elucidate desired treatment outcomes that are age-appropriate, develop interventions that aim to improve sexual function in one or more of these targeted groups, and then integrate these treatments into clinical oncology settings, where sexual health is not currently a primary focus.

#### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** The article does not contain any studies with human participants or animals performed by any of the authors.

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