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Psychosexual Functioning in Cancer Survivorship: What the Pediatric Oncologist Needs to Know

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Abstract

Sexual health may be disrupted in adolescents and young adults (AYAs) both during and after cancer treatment, irrespective of whether they are diagnosed in childhood, adolescence or young adulthood. Unfortunately, oncology providers often underestimate the relevance of psychosexual issues for AYAs and under-prioritize sexual health throughout treatment and survivorship. The purpose of this narrative review is to provide information on (a) the etiology of psychosexual dysfunction in childhood, adolescent, and young adult cancer patients and young adult survivors of childhood cancer; (b) strategies for communicating and evaluating potential sexual health issues AYA patients/survivors; and (c) guidance for the practicing pediatric oncologist on how to address sexual health concerns with patients.

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Keywords

Sexual health; sexual dysfunction in pediatric cancer survivors; psychosexual health; adolescent and young adult cancer

I. Introduction

Sexual health is a domain extending across physical health, emotional health, and quality of life which may be disrupted in adolescents and young adults (AYAs) both during and after cancer treatment, irrespective of whether they are diagnosed in childhood, adolescence or young adulthood. The World Health Organization defines sexual health as “a state of physical, mental, and social well-being and not merely the absence of disease, dysfunction, or infirmity, in all matters relating to the reproductive system, its functions, and its processes.”(1) Adolescent and young adult (AYA) cancer patients and survivors may be particularly susceptible to impaired sexual health given the specific developmental tasks and sexual milestones which are typically attained during this life period which includes formation of intimate relationships with peers and romantic partners, development of body image, sexuality, sexual identity and orientation, consideration of fertility and family planning/contraception, and psychosexual adjustment, all while navigating the physical and psychological changes brought on by cancer treatment. This necessitates receipt of medically accurate, developmentally appropriate, and tailored sexual health education along with access to associated clinical services as relevant to the patient, cancer diagnosis and/or stage of treatment.(2) While the defined age range for AYAs varies by country and organization, in the United States this is generally includes those aged 15–39 years(3), and encompasses adolescence, emerging and young adulthood.(4)

Nearly half of AYA childhood cancer survivors (CCS) perceive negative impact of cancer on their sexual lives.(5–7) While CCS report engaging in sexual activity less frequently and have poorer sexual function following cancer treatment(8), some data support participation in risky sexual behaviors at rates similar to peers.(9) One large study found significant rates of sexual difficulty/dysfunction among young adult CCS in which 30% reported no/low sexual desire, 23% noted impaired arousal, and 29% reported orgasmic dysfunction.(10) Compared with same-age peers, young adult CCS tend to have delayed attainment of sexual milestones including older age at first intercourse,(5, 11) fewer lifetime sex partners,(12) and are less likely to marry.(13) Collectively, these data suggest that many young adult CCS may experience problems with their sexual health thereby warranting a need for oncology providers to be prepared to discuss sexual health-related issues with their patients.(10)

Oncology providers often underestimate the relevance of psychosexual issues among AYAs and are less likely to discuss sexual health across the course of cancer treatment and into survivorship.(14) The purpose of this narrative review is to provide information on (a) the etiology of psychosexual dysfunction in childhood, adolescent, and young adult cancer patients and young adult survivors of childhood cancer;(b) strategies for communicating and

evaluating potential sexual health issues AYA patients/survivors; and (c) guidance for the practicing pediatric oncologist on how to address sexual health concerns with patients.

II. How Cancer Treatment May Adversely Affect Sexual Function in Males

Sexual dysfunctions among males may include disorders of interest/desire, arousal, orgasm, and pain during sexual activity. Ten to thirty two percent of males surviving childhood cancer will experience sexual dysfunction in adulthood, (15–19) with survivors experiencing a 2.6-fold increased risk for erectile dysfunction (ED) relative to siblings. (20) Beyond these physical issues, problems with psychosexual dysfunction including poor body image, low sexual interest and satisfaction have also been reported. (16, 20–23) Sexual dysfunction in this population has also been associated with poorer physical and emotional functioning, (15) highlighting the need to address this topic more systematically in survivorship. (24) Male sexual function relies on an intact neuroendocrine axis, penile innervation, and penile vasculature; impairment in any/all of these physiologic processes may be a consequence of chemotherapy, radiation, and/or surgery. (24) Erectile or ejaculatory dysfunction can be caused by tumor compression, or surgery/radiation involving the lower spinal cord, pelvis, bladder, distal colon, or rectum. (25, 26) Targeted radiotherapy and nerve sparing approaches have been shown to help preserve post-operative function. (25, 27)

Sexual dysfunction may also be caused by secondary/central hypogonadism (i.e. low testosterone due to gonadotropin deficiency) or primary hypogonadism (i.e. low testosterone due to testicular dysfunction). Secondary/central hypogonadism may occur due to disruption of the hypothalamic-pituitary axis by tumor invasion, central nervous system surgery, or radiation 30 Gy, (28) though some studies have also shown gonadotropin deficiency in patients who received 22 Gy. (29) Primary hypogonadism most commonly occurs due to exposure to alkylating (cyclophosphamide equivalent dose >20 g/m² (30)) and/or platinum-derived agents, total body irradiation, testicular irradiation, or orchiectomy. (31) Dose-response relationships between testicular radiation and hypoandrogenism have not been clearly identified, with risk thresholds ranging from 12–30 Gy (28, 30) and prepubertal males appear more sensitive to effects of testicular irradiation. (32)

Several studies on gonadal function in testicular cancer survivors demonstrate impairment. One study showed survivors of stage I testicular germ cell carcinoma had insufficient Leydig cell function one year after unilateral orchiectomy, though it was unclear whether these men would develop permanent hypogonadism. (33) Pre-surgical hypogonadism and testicular microlithiasis are predictive factors for post-treatment hypogonadism; (34) age of survivors also needs to be taken into account, as primary hypogonadism is associated with aging in males. (35) Long-term satisfaction with testicular prostheses appears to be fair, though one study showed 15% indicated their prostheses interfered with sexual activity. (36) Despite the variety of interventions available (e.g., pharmacologic therapies, external erection-facilitating devices, surgical options, psychological intervention, etc.), fewer than 6% of survivors report receiving ED treatment (20).

III. How Cancer Treatment May Adversely Affect Sexual Function in Females

Sexual dysfunction among females includes disorders of interest/desire, arousal, orgasm, and pain during sexual activity. Approximately 20–29% of female CCS report impairment in sexual function (15, 37, 38) and, on average, report greater sexual dysfunction in survivorship relative to males. (15, 16, 37, 39) Risk factors for sexual dysfunction in this group include specific cancer types (e.g., germ cell tumors, renal tumors, and leukemia (38), and treatment factors (e.g., cranial, pelvic or total body irradiation, stem cell transplant) along with associated late effects (e.g., ovarian failure, untreated hypogonadism, LH/FSH deficiencies), and developmental factors (e.g., age and developmental stage at diagnosis and treatment factors (8, 40, 41). Chemotherapy, primarily alkylating agents and heavy metals, and radiation to the ovaries are associated with premature ovarian insufficiency and ovarian failure, both of which decrease estrogen, which has a significant negative impact on the vaginal tissue. (42–44) Central gonadotropin deficiency due to disruption of the hypothalamic-pituitary-axis is also a concern among female cancer patients whose tumor or cancer treatment involves the hypothalamus/pituitary, and central hypogonadism is seen with doses of cranial radiation ≥ 30 Gy. Females who receive high doses of alkylating agents (7.5 g/m² for post-pubertal and 12 g/m² for pre-pubertal) (personal communication with Dr. Lillian Meacham), radiation to the ovaries, hematopoietic stem cell transplant, or a combination of these therapies are at highest risk for hormonal disruption after cancer treatment. (45) Unilateral oophorectomy is associated with early menopause (46); bilateral oophorectomy is uncommon among children with cancer, but when indicated, results in a complete cessation of ovarian hormone production.

Vaginal dryness and pain during intercourse are common treatment sequelae reported by survivors of childhood cancer. (22) Radiation to the pelvis can result in vaginal dryness and/or scarring of the vulvar/vaginal tissue, all of which can lead to pain during intercourse. (47) Chronic graft-vs-host disease, a long-term complication of allogeneic hematopoietic cell transplant, can result in vulvar scarring or vaginal fibrosis/stenosis. (48) Surgeries, including spinal/neurosurgery and pelvic surgery, can place patients at risk for nerve damage and potential sexual dysfunction. (26, 49) Limited research has assessed the impact of therapeutic exposures and sexual dysfunction among CCS.

Sexual dysfunction in females surviving cancer is often treatable, and interventions will vary based on etiology and symptoms; therefore a biopsychosocial approach to assessment and treatment is recommended. (50, 51) Intervention approaches may be specific to a sub-specialty or multidisciplinary in nature and may involve medical (e.g., exogenous estrogen or estrogen receptor modulators, androgen or antidepressant therapy) or non-medical approaches (e.g., physical therapy, psychotherapy, lubricants, dilators/devices, etc.). Although 41% of female survivors perceive themselves at-risk for sexual dysfunction, fewer than 3% report having received any intervention. (38) Nevertheless, young adult survivors of childhood cancer describe clinically significant sexual health concerns as well as interruption of psychosexual development, altered perceptions of body image, physical and psychological problems. (22)

IV. The Potential Adverse Impact of Cancer on Psychosexual Development

Immediate and late effects of childhood cancer treatment can directly and/or indirectly affect young survivors' physical and emotional development via altered body image or cognitive difficulties, which may impair ability to engage in romantic and sexual relationships.

The development of one's sexual identity developsthrough adolescence, which leads to an understanding of the self as a sexual being. Physical attractiveness and positive self-esteem are key components in this process.(52) Thus,cancer treatment during early childhood while coping with potential long-term side effects can be different from being diagnosed throughout adolescence.(53, 54) Experiencing acute side effects like baldness, weight changes, or fatigue, as well as longer-term side effects, like scars, physical disability, and cognitive function, can negatively impact social/interpersonal relationships, diminish autonomy, and contribute to difficulties obtaining sexual health knowledge.Taken together, these can diminish sexual opportunities and delay or impair developmentally appropriate exploration of sexual identity.(55–57) Thus, apart from diverse physical side effects which can cause emotional and social difficulties, the time of diagnosis may indirectly affect psychosexual development.

Research on psychosexual development among CCS is sparse, and the heterogeneity of CSS, due to the wide age range at diagnosis and diverse types of diagnoses, represents an additional challenge for drawing specific conclusions. Early studies found thatCCS were less likely to marry(13, 58–62),have children(59, 63, 64), be sexually experienced (37, 58, 65, 66),and/or had lower numbers of different sex partners.(23, 67) However, more recent studies suggest that some survivors only delay certain milestones to a later age(63, 66, 68), while others may rush into romantic relationships to achieve normality.(69, 70)Studies also demonstrate that survivors of childhood cancer engage in risky sexual behaviors at rates similar to healthy peers.(9)Survivors have described the interruption of adolescence due to cancer therapy as negatively impacting relationship development.(37) AYA patients also report missing out on romantic and sexual milestones and feeling isolated from peers while undergoing cancer treatment.(22)

A considerable number of CCS identify concerns and/or struggles with romantic relationships and intimacy due to the belief that they are a less valuable dating partner. (22, 71) CCS expressed self-consciousness about their bodies that adversely affected being physically intimate with another person(22, 69, 72–74), and distress about disclosing a past cancer diagnoses to a potential partner(71, 74, 75), particularly if this also included disclosure of potential infertility.(74–77)Concerns about dating, finding a partner, and/or infertility may be more common among female survivors (77, 78), but it remains unclear if such concerns are indeed more prevalent among females or if they are more likely to express them.Nevertheless, many survivors also reported close emotional bonds with others and being appreciative of interpersonal relationships.(71, 77)

Given the limited numberof large-scale and in-depth studies on psychosexual developmental among CCS, few risk factors for impaired psychosexual development and sexual intimacy have been identified. Next to psychological phenomena like low self-esteem and negative body image, some studies indicate that brain tumor survivors(13, 59, 79) or any

survivor treated with high-dose neurotoxic treatment regimens, may be at risk for impaired psychosexual development.⁽⁸⁰⁾ Age at diagnosis may be another crucial factor, given that cancer during adolescence could directly hinder exploration of sexuality, resulting in survivors who are less sexually experienced.^(5, 54) Treatment during adolescence creates increased time in the hospital away from peers, and increased supervision from parents at a time when developing autonomy is crucial. Such lacking opportunities for exploration are not only limited to sexual intimacy, but also experimenting with sexual orientation.⁽⁸¹⁾

V. Considerations for AYAs on Active Treatment

Sexual health of AYAs undergoing cancer treatment may be overlooked by clinicians^(82, 83). Oncology providers may assume the patients will not feel well enough to be sexually active or may assume the adolescent is not yet sexually active. However, in the United States for example, nearly half (46.8%) of high school students have ever had sexual intercourse.⁽⁸⁴⁾ Although the literature is scant with regard to guidelines for sexual activity during active cancer treatment, there are several points of discussion that should be addressed prior to and during treatment.

First, inquiries about parenthood goals should be assessed before treatment so that referrals and counsel on fertility preservation can be offered. Second, addressing contraception is imperative as AYAs may assume a discussion about potential infertility means they are not capable of siring a pregnancy or becoming pregnant.⁽⁸⁵⁾ Contraception is important not only for the prevention of pregnancy but also for prevention of sexually transmitted infections. Moreover, providers should not assume a patient is heterosexual nor in an exclusive or monogamous relationship. Third, normalization of sex-related topics, refraining from judgement, and direct questions about AYAs' number of partners and type of sexual activity can guide discussions about what precautions should be taken, tailored to the AYA's type of cancer and treatment as well as activity and partners. Such conversations should take place without parents being present. Fourth, counsel should be offered about the risks associated with penetrative or oral sex for patients with low blood counts or who are neutropenic. Depending on the type of cancer treatment, some patients may be cautioned to always use condoms and/or dental dams during active treatment to prevent partner's exposure to the chemotherapeutic agents, but specific guidelines on the duration of using such protection is unclear.⁽⁸⁶⁾ In general, AYAs who wish to be sexually active while on treatment should be encouraged and anticipatory guidance should be offered in relation to managing common treatment side-effects such as fatigue, decreased desire, vaginal dryness or erectile dysfunction. Many AYAs fear losing a partner or the termination of relationship if they cannot perform sexually. In such cases where patients are concerned about the status of their intimate relationships, counsel may be offered on alternate ways to create intimacy with a partner.

VI. The Role of Pediatric Providers

Several leading organizations highlight the need for pediatric hematology/oncology clinicians to address sexual health with AYA patients. The American Academy of Pediatrics (AAP) recommends pediatricians provide confidential time during a visit to discuss

sexuality, sexual health promotion, and risk reduction.(87) The National Comprehensive Cancer Network (NCCN) states that “Fertility preservation as well as sexual health and function should be an essential part in the management of AYAs with cancer.” (88)The American Society for Clinical Oncology (ASCO) recommends that “there be a discussion with the patient, initiated by a member of the health care team, regarding sexual health and dysfunction resulting from cancer or its treatment. Psychosocial and/or psychosexual counseling should be offered to all patients with cancer, aiming to improve sexual response, body image, intimacy and relationship issues, and overall sexual functioning and satisfaction.”(51)

Despite these recommendations, sexual health conversations rarely take place.(22, 83) Research exploring AYA patient-reported barriers to communication show that current communication gaps are exacerbated by patient discomfort in initiating these conversations, along with the presence of family members.(83)Clinician-reported barriers include lack of knowledge/experience, lack of resources/referrals, low priority in the context of other cancer care needs, presence of parents/family members at visits, perceived patient discomfortwhen discussing sexual health issues, clinician discomfortin discussing sexual health topics, limited time, and lack of rapport between the AYA and clinician.(82)

While there is a clear need for clinician-centered education on common sexual health questions and problems faced by AYAs during and after cancer therapy, clinicians must also have a clear understanding of how to initiate sexual health conversations to appropriately identify issues and provide effective patient education and intervention.Research focused on promoting fertility and fertility preservation communication demonstrates the efficacy of using scripts to help facilitate clinician comfort with conversations.(89) Additionally, the use of pre-visit patient-centered screening forms or questionnaires may be successful in identifying sexual health communication needs of AYA patients, thereby providing guidance to the clinician prior to meeting with the patient.(90)The oncology clinician may partner with a psychologist, medical social worker, or nurse to help assist in the assessment process.

There are several evidence-based strategies developed to guide clinicians through sexual health conversations. One approach is the 5 As (Ask, Advise, Assess, Assist, and Arrange)communication model (Fig. 1), which is shown to be an effective strategy used in adult cancer patients for the purpose of discussing sexual health, and is potentially adaptable to the AYA patient population.(91) Additional communication models, such as the extended PLISSIT or 5 Ps models may also be considered for adaptation to the AYA patient population.(87, 92) These models are similar in that they start by guiding the clinician to introduce the topic of sexual health and ask the AYA for permission to proceed with the conversation. This is followed by providing patients with a brief overview on a specific sexual health topic which, depending on the patient, may include puberty/development, contraception, safe sex practices, and/or sexual function. The clinician will then ask the AYA additional questions to understand his or her education and support needs followed by provision of brief counseling and/or making referrals as appropriate (urology, OB/GYN, reproductive endocrinology, adolescent medicine, psychology, etc.). Finally, it is critical that the clinician schedule follow up visits to review the identified problems or concerns and ensure that they are being addressed.

Importantly, AYAs have also provided recommendations for clinicians on how to approach sexual health conversations. These recommendations include that the clinicians should initiate the conversation, offer time alone to speak privately without the presence of parents or other individuals, normalize the conversation, engage in ongoing conversation throughout cancer treatment and survivorship, tailor the conversation to the patient by considering his/her age and developmental stage, gender and gender identity, sexual orientation, sexual activity, cancer type and treatment course, and communicate directly with the AYA (i.e. do not rely on packets, websites, etc.) (83, 87).

While pediatric oncology clinicians may play a key role in providing general education and screening for sexual health issues in AYAs, it is important to consider a multidisciplinary approach that includes utilizing existing expertise within a hospital, available referral networks, and comfort and expertise of clinicians directly interacting with patients. Pediatric clinicians should be cautious in treating sexual dysfunction as this is generally outside their scope of care and carries potential for harm, underlining the importance of an appropriate referral network. However, as detailed above, it is incredibly important to start these conversations and allow patients to feel comfortable talking about sexual health questions and concerns. (91, 93, 94)

VII. Building a Multidisciplinary Support Team

There are a variety of ways to create teams but the best start may be with institutional/practice policy. (95) Such guidelines may also aid in development of consistent practice across teams and clinics. Identifying team members such as allied health professionals (e.g., nurses, social workers, psychologists, sexologists, physician assistants, physical therapists, etc.) who have the proper experience and skills to communicate about sexual health with AYAs may improve the likelihood that counsel is offered and reduce the burden of time from the oncologist. Resources for additional training among team members should also be available. (Table 1) To enhance patient care coordination of sexual health issues that may arise during and after cancer treatment, it may be helpful to document conversations and/or recommendations in the medical record. Prior research demonstrates that lack of documentation of fertility conversations, a key component of sexual health, correlates with poor patient-provider communication regarding fertility. (96) Further, such documentation can help with survivorship care planning. For example, discussions of contraception may be needed and may differ from time of diagnosis into survivorship. A standard approach to documentation may enhance communication amongst multiple team providers and highlights both short and long-term care needs of a patient regarding sexual health status, current issues or concerns, necessary referrals, and follow-up needs.

Finally, developing a list of resources and referrals such as peer support groups, endocrinologists, and therapists will also help streamline the ability to address each patient's specific needs. Having written material about sexual function and potential solutions that is developmentally appropriate and context-specific is also a key component of quality care. Such materials may be in the form of a brochure or available on a website. The information provided should be inclusive of all sexual orientations and gender identities and should seek

to normalize the idea that psychosexual dysfunction during and after cancer treatment is to be expected and that solutions and referrals are available.

VIII. Conclusions

Sexual health is a critical component of comprehensive care for the AYA oncology patient during treatment and through survivorship. Providers caring for these patients must have an understanding of not only how sexual health may be adversely impacted by cancer treatment, but the skillset to discuss developmentally appropriate aspects of sexual health, provide counsel, and address potential problems. This may require building a support network of clinical experts to assist in patient care and to make appropriate referrals and consistent documentation in the medical record. AYAs have repeatedly prioritized the need for improved sexual health care. There is ongoing need to re-visit established guidelines for preventative measures related to psychosexual health during and after treatment as well as consideration of new evidenced guidelines based on future research. Future research may explore optimal clinician training strategies to help overcome communication barriers and facilitate conversations around specific sexual health topics. Additional areas of exploration also include the development of educational materials and interventions to identify patients most at risk for and to prevent impairment of psychosexual development and sexual functioning.

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Abbreviation

| | |
|-------------|---------------------------------------|
| AAP | American Academy of Pediatrics |
| ASCO | American Society of Clinical Oncology |
| AYA | Adolescent and Young Adult |
| COG | Children's Oncology Group |
| NCCN | National Comprehensive Cancer Network |
| CCS | Childhood Cancer Survivors |

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The 5As Communication Model (91)

| Communication Step | Description | Sample Prompt |
|--------------------------|--|---|
| Ask | Introduce the topic of sexual health and ask the patient for permission to proceed with the conversation. | <i>“Many AYAs worry about how cancer will affect dating and relationships. I would like to take some time today to talk about this. Is this okay with you?”</i> |
| Advise | Provide a brief overview on a specific sexual health topic relevant to the patient. | <i>“While sexual and romantic relationships may still continue or develop during cancer therapy, there are a few things that are important for you to know.”</i> |
| Assess | Ask additional questions to understand patient education and support needs | <i>“The following questions are personal, however I ask them so that I may have the best understanding of your current health and to provide you with information that you need to keep yourself as healthy as possible through treatment.”</i> |
| Assist | <ul style="list-style-type: none"> • Provide brief counseling based on conversation/assessment. • Give appropriate handouts, pamphlets, website links, etc. • Make referrals as necessary | |
| Arrange follow-up | Schedule a follow-up visit to review identified problems or concerns. | |

Figure 1.
The 5As Communication Model

TABLE 1.

Resources for Further Education

| Resource | Summary | Website |
|--|---|---|
| American Society for Pediatric Hematology and Oncology Webinar: Addressing Sexual Health in AYA Patients with Cancer | Online webinar designed for the pediatric oncology provider to provide education on sexual health care issues faced by AYA patients and survivors and strategies for discussing sexual health with these patients. | http://aspho.org/knowledge-center/kc-overview |
| American Society of Clinical Oncology Clinical Guidelines | Guidelines on how to manage sexual function adverse effects that occur as a result of cancer diagnosis and/or treatment. Targets patients >18 years and excludes childhood cancer survivors. | https://ascopubs.org/doi/full/10.1200/JCO.2017.75.8995 |
| Enriching Communication in Reproductive Health and Oncofertility (ECHO) | An eLearning training program aimed to enhance knowledge and communication skills related to fertility and sexual health in cancer patients. This program is aimed at social workers, psychologists, nurses, and physician assistants. | https://echo.rhoinstitute.org/ |
| Will 2 Love | Online interactive website that aims to assist clinicians and health organizations manage patients with sexual health and fertility problems due to cancer and other conditions. Specific training available for oncology clinicians. Program currently targets adults. Annual fee \$600. | https://www.will2love.com/ |
| Scientific Network for Female Sexual Health in Cancer | A global interdisciplinary network of clinicians, researchers and healthcare professionals who work to promote sexual well-being in women and girls affected by cancer by advancing evidence-based education and practice. | http://www.cancersexnetwork.org/ |