REVIEW

The Clinician’s Toolbox: Assessing the Sexual Impacts of Cancer on Adolescents and Young Adults with Cancer (AYAC)

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ABSTRACT

Introduction. Adolescents and young adults aged 15–39 years who have been diagnosed with cancer (AYAC) have unique medical and psychosocial needs. Following their cancer treatments, AYAC must learn to manage the sometimes irreversible general side effects of cancer treatments including side effects that impact their sexuality. These side effects include but are not limited to: infertility, altered body/physical appearance, and sexual dysfunction. Such effects may hinder AYAC efforts to date and experiment sexually, limiting sexual maturation and confidence, as well as the formation or maintenance of meaningful couple and sexual relationships. It is clear that we need to tailor our clinical approaches to ensure that we assess the unique needs and concerns faced by AYAC.

Aims. Based on consistent study findings substantiating the distinctive needs of AYAC, the main objective of this article is to present the core clinical components involved in assessing sexuality among AYAC.

Methods. The clinical recommendations are based on the authors and experts’ clinical experiences coupled with a thorough examination of the literature related to AYAC sexuality.

Main Outcome Measures. This article first describes the three components (clinical interview, review of chart notes, and self-report questionnaires) of a sexuality assessment and the seven core domains that highlight target areas of focus.

Results. A detailed outline of each of the core domains of assessment (socio-demographics; medical history; fertility and sexually transmitted infection; sexual functioning; sexual coping style; body and self-image; and sexual history and dating/couple experience) is presented. A “toolbox” table containing useful resources for clinicians (e.g., questionnaires and red flags) and direct resources for AYAC patients are included.

Conclusion. Cancer can have a significant impact on numerous domains of AYAC sexuality. The assessment of and attention to the impact of sexuality on AYAC is crucial in order to provide effective and comprehensive quality patient cancer care. Aubin S and Perez S. The clinician's toolbox: assessing the sexual impacts of cancer on adolescents and young adults with cancer (AYAC). Sex Med 2015;3:198–212.

Key Words. Adolescents and Young Adults with Cancer; Cancer; Sexuality; Sexual Health; Cancer and Sexual Problems
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Introduction

The 2013 LIVESTRONG and Institute of Medicine Workshop defines adolescents and young adults with cancer (AYAC) as individuals aged 15–39 years who have been diagnosed with cancer [1]. These individuals present unique medical and psychosocial needs that distinguish them from both younger and older cancer groups [1–6]. Studies confirm the disruptive impact of cancer on the achievement of critical developmental milestones associated with adolescence and emerging adulthood [1,7,8]. AYAC are at risk of experiencing delays or arrests in their sexual development that often include decreased or non-existent sexual experimentation and discovery. AYAC are not only faced with the pressure of “catching up with life,” but are also faced with a number of added challenges pertinent to their sexuality [9].

The literature emphasizes the importance of a sexuality assessment in cancer populations as a valuable and essential opportunity to provide comprehensive cancer care [10,11]. Nonetheless, sexuality remains a topic that clinicians rarely inquire about with cancer patients [12,13]. Sted et al. report that only one of four doctors and one of five nurses actually discuss sexual issues with ovarian cancer patients [14]. Similarly, Park et al. found that 62% of primary care physicians reported that they “never” or “rarely” address sexual dysfunction with their cancer patients, and 54% reported that they are “not at all likely” or “a little likely” to initiate conversations about sexual dysfunction with their patients [15].

There are numerous contributing factors for why sexuality is rarely discussed by clinicians with AYAC, which can include: (i) the clinician’s own embarrassment and fear (e.g., worries about invasion of privacy or legal consequences), (ii) the belief that sexuality is defined solely as sexual function [16], (iii) the belief that sexuality is not part of the presenting problem (cancer), and (iv) the clinician’s own lack of training in assessing sexuality [16,17].

Similar to professionals, cancer patients also report that they seldom remember discussing sexual risks pre-treatment or treatment options for sexual dysfunction post-treatment. Some of the barriers for patients include: (i) their own discomfort and embarrassment, (ii) time constraints during medically oriented visits, (iii) not being prompted or having the medical professional initiate the discussion, and (iv) a sense of hopelessness, helplessness, and/or pessimism that the sexual problem can be resolved or that interventions exist to help with their sexual difficulties [10,13,14]. Thus, sexuality is often overlooked or under-prioritized among cancer patients [16,17].

Such challenges are more pronounced with AYAC as the main focus is often on the young adults’ survival. The confrontation with mortality is extremely foreign and unexpected for this age group that sexuality often gets “swept under the rug” as one of the last priorities worthy of attention. Most of the literature examining sexuality and sexual health (herein referred to as sexuality) for AYAC comes from breast and gynecological cancer survivors and/or older adults (40+). Less is known about how clinicians working with AYAC (males and females, with all cancers) can effectively assess and evaluate their sexuality needs [18]. To the best of our knowledge, a sexuality assessment tailored for the AYAC population has not been described. Clinicians working with AYAC need to adapt their clinical evaluations to ensure that the unique sexuality concerns and needs are appropriately assessed and addressed among the AYAC population.

The goal of this article is to present useful and validated clinical information on key areas of focus when assessing AYAC sexuality. In addition, the authors highlight “red flag” tips that practitioners should keep in mind when assessing the sexuality of AYAC. These clinical recommendations are based primarily on the clinical experiences of the first author and consultation with experts in the field, coupled with a thorough examination of the literature related to AYAC sexuality. The article provides a toolbox of useful resources (e.g., self-report questionnaires, readings, and patient resources) to assist clinicians working with AYAC in the context of sexuality.

The authors first provide a framework and conventional format for assessing AYAC sexuality (i.e., clinical interview, review of chart notes, and questionnaires). Second, the authors outline seven core domains believed to be necessary for completing a thorough sexuality assessment with AYAC. Ultimately, a comprehensive and appropriate sexuality assessment will allow for improved allocation and provision of resources to AYAC.

Clinical Framework

The present sexuality assessment among AYAC follows the clinical guidelines and recommendations provided by the Adolescent and Young Adult Oncology Progress Review Group of the LIVESTRONG Young Adult Alliance (renamed
The topic of sexuality is both infrequently considered and challenging for health-care providers to address with AYAC [13,15,31]. Thus, the style and format of the assessment require the clinician to have the necessary skills to maintain the delicate balance between sexual investigation (e.g., asking questions) and ensuring the AYAC comfort and confidentiality. In order to conduct a comprehensive sexuality assessment for AYAC, the following format is recommended: 1. Clinical Interview, 2. Chart Review of clinical reports, and 3. Self-report questionnaires.

1. Clinical Interview

The clinical interview is the primary source of information about an AYAC’s sexuality. It allows for the identification of appropriate questionnaires for subsequent use and ultimately facilitates appropriate interventions. The clinician should use direct, open-ended, non-judgmental questions, engaging the AYAC via direct eye contact while trying to build a mutually interactive and dynamic relationship. Some opening questions can include: How has your cancer diagnosis or treatment affected the way you see yourself as a young man/woman/sexual being; as a single teen or young adult who dates and interacts with potential partners; as a wife/husband/partner; What aspects of your sexuality do you believe have been affected by your cancer diagnosis or treatment (negative or positive aspects); and How important is sexual intimacy to you [17]?

It is also essential to initially legitimize and normalize the sexuality discussion by making the conversation feel like a routine part of the clinic. The clinician can emphasize the importance of accurately assessing beliefs and concerns about sexuality. One of the best methods of beginning a discussion of this difficult and sensitive topic is to begin with a comment such as “When I am talking with any adolescent or young adult diagnosed with cancer or treated with (whatever treatment or medication that may impact sexuality), I usually ask about sexuality.” Following this opening comment, the clinician can focus the interview questions on the specific areas identified in either the questionnaire, the referral, or any area that is identified by a few subsequent direct questions that the clinician understands to be problematic or distressing to the AYAC.

The style and role of the clinician that AYAC best respond to is the mentorship/life coach intervention approach, which includes collaborating, goal setting, problem solving, sharing information, affirming, confidence building, and supporting. This approach integrates the principles of cognitive-behavioural and solution-focused interventions that foster a balance between teamwork and autonomy among the clinician and the AYAC [32]. This was consistently observed by the first author during her clinical work and preliminary study findings [33]. It is also important that clinicians are aware, examine, and appropriately manage their own beliefs, attitudes, and biases, such as sexism, ageism, or alternative sexual practices, which can affect the clinician’s ability to address sexuality with AYAC [17,34].

Many AYAC are routinely accompanied by parents during their medical visits [1]. As such, they may be quite concerned that information discussed in the assessment will be disclosed to their parents. This may be especially true for the early and late young adulthood cohorts. The authors stress the importance that clinical interviews be conducted in private with the AYAC, rather than with parent(s) present [31,35]. Adolescence and emerging early...
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young adulthood is often characterized as an intense process of physical and emotional development, coupled with the formation of close bonds with peer groups and the separation from parental authority. For this reason, the authors believe that a separate interview is needed to allow the AYAC to discuss private, intimate topics.

Providing AYAC with a “safe place” to discuss their sexuality without their parents present fosters trust between the patient and the clinician. One potential pitfall is the parent of the adolescent or early young adult who refuses to leave the room. With respect to the parent, the clinician can highlight that, regardless of the cancer, sexuality, and fertility are notoriously difficult issues for any young person to discuss with parental or authority figures present. An alternative solution is to reassure parents that although adolescents are more likely to disclose sensitive health topics if they are given assurance of confidentiality, these assurances seem not to impact the teens’ later discussions of these issues with their parents [36,37].

Although this might be different from other oncology appointments, it is necessary to establish boundaries with family members during the initial assessment. Coupled with this, reassuring the AYAC about patient confidentiality (e.g., information will not be shared with other professionals, unless permission is granted). With respect to confidentiality, the use of electronic medical records (EMRs) creates novel opportunities for improvements in healthcare, but also carries the unforeseen potential for inadvertent breaches of confidentiality. Security measures and appropriate safeguards should be put in place at the systems level to prevent breaches of patient confidentiality, as EMRs may actually offer more security than traditional paper-record systems.

Particularly for the early young adulthood and young adulthood cohort, sexuality may be a topic that they have infrequently or never been asked about during their cancer care. The first author has noted that it is not uncommon for younger AYAC to have less sexual knowledge or to have engaged in less sexual experimentation than their aged-matched peers [18,38]. Therefore, although the clinician will ask numerous questions during the assessment, the clinician should create an environment in which the AYAC should feel equally comfortable to ask questions. Strategies to increase the AYAC’s comfort include normalizing that sexuality is often an issue discussed by other AYAC, ensuring confidentiality, building rapport, and sharing with the AYAC that he or she is invited to ask any questions. The assessment can act as a space for the clinician to respond to the AYAC’s needs as well as an opportunity to provide some initial psycho-education to the AYAC.

With regard to logistics, the authors found that AYAC were most receptive to varying the timing and format of the meetings than conventional assessment. For example, having appointments later in the evening, and the opportunity to combine face-to-face meetings with other forms of interviews that would not require them to travel to the clinic/hospital. The first author has noted that AYAC generally appreciated the use of technological means (e.g., Skype—a video teleconferencing platform where the clinician and the AYAC can see one another) to facilitate meetings and allow for a more flexible relationship. Table 1 provides summary recommendations for the clinical interview.

2. Chart Review of Clinical Notes/Reports

Medical charts are excellent resources that can be used in conjunction with interviews for clinicians working with AYAC. These charts are a vital source of information given that they include reports from not only the oncology care team, but also from professionals whose expertise is highly relevant to sexuality (e.g., gynecologist, urologist, and couple/sex therapist). These reports can assist the clinician in identifying both medical and psychosocial factors that impact sexuality (e.g., rule out medical etiologies for sexual dysfunctions).

3. Self-Report Questionnaires

Utilizing self-report questionnaires as a compliment to the interview and chart review can provide many benefits, especially in circumstances where time is coveted. Numerous instruments [39] are available for general assessment of the ability to

| Table 1 | Key points for conducting a clinical interview with AYAC |
|---------|----------------------------------------------------------|
| ✓ Use a direct, open, non-judgmental, interactive communication style |
| ✓ Utilize a mentorship/life coach approach, balancing teamwork and autonomy |
| ✓ Meet AYAC alone as opposed to with their parents |
| ✓ Ensure confidentiality of information, highlighting that nothing will be shared with parents and/or other team members (unless permission is granted by AYAC) |
| ✓ Allow AYAC to ask questions, and clinicians can provide psycho-education |
| ✓ Validate and normalize AYAC concerns that may be related to sexual inexperience |
function sexually, level of sexual satisfaction, and evaluation of sexual beliefs and values such as the Derogatis Sexual Functioning Inventory [40,41] and Global Sexual Functioning [39]. There are also many instruments designed specifically to assess sexuality in men and in women that can be found through the Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID) website [42].

A recent systematic review of questionnaires used in psychosocial oncology indicated that very few were validated using AYAC and none were specific to the area of sexuality [43]. Suggested questionnaires related to each core domain of assessment are provided in Table 2. The authors have made every attempt to choose questionnaires that are either empirically validated (i.e., extensive psychometric validation) with a cancer population [54–60,72,73] and/or AYAC population [43,45,46], or which the authors believe to be clinically appropriate (and if possible, supported by applied research) to assess sexuality among AYAC.

Core Domains for Assessing Sexuality with AYAC

Given the complex interplay between an AYAC’s sexuality and his or her mental and physical health, it is important that sexuality assessments are not conducted in isolation. The following domains may be best understood as contributing variables that can either influence or maintain sexual function, adjustment, and relationship difficulties. Sexuality assessments should be considered a crucial element for a better understanding of an AYAC overall life functioning.

The authors will present seven core domains that they suggest need to be thoroughly evaluated in any comprehensive AYAC sexuality assessment:

I. Socio-Demographics

The sexuality assessment should be considered in the context of a variety of socio-demographic factors, such as age, gender, and relationship status. The existential reality and needs of younger vs. older, male vs. female, as well as single vs. coupled AYAC may significantly differ [74]. The authors suggest beginning the sexuality assessment by assessing the patient’s socio-demographics (e.g., age, culture, financial, relationship status, family, and social support). This is often important because distinct socio-demographics can result in certain developmental interruptions (e.g., identifying and pursuing a vocational goal) that have meaningful consequences on the AYAC growth [18]. As an example, the development of setbacks in the financial independence of early young adulthood AYAC may have multiple repercussions, including moving back home with one’s parents. This may not only be hard on AYAC self-image/esteem but also compromise the desire of the single AYAC to date and experiment sexually.

Furthermore, being a member of a sexual minority exposes AYAC to a higher risk of emotional distress and isolation, including an increase in suicidal risk [75]. For these AYAC, the risk may be twofold: (i) identifying as a young adult with cancer or cancer survivor, and (ii) identifying as part of a sexual minority [76]. These two factors likely compound to further increase the risk for distress. Special attention should be paid to assessing the sexual as well as the emotional repercussions of cancer for AYAC who identify as part of the sexual minority population.

For lesbian, gay, bisexual, transgender, and queer individuals (LGBTQ) living with cancer, sexual orientation introduces unique challenges, particularly when considering discrimination and other healthcare-related inequities that are routinely experienced by many LGBTQ individuals [77]. Providers may be less likely to address sexuality and sexual healthcare due to discomfort and lack of knowledge about the sexual practices and needs of the population, particularly with transgendered individuals [78]. Issues for LGBTQ living with cancer include but are not limited to: (i) LGBTQ wariness of the healthcare system due to past experience with stigma, (ii) pressure to adhere to gender expectations, (iii) clinician assumes heterosexuality as orientation, and (iv) clinician lacks respect for LGBTQ support system (e.g., partners who have been together for many years but are not legally married). As such, there is a need to being culturally responsible and competent with unique populations. This involves approaching all AYAC with appropriate, nonheterosexist language [76]. Training for healthcare providers to provide more culturally competent, safe, and welcoming care is available from the National LGBT Cancer Network [44].

II. Medical History

A comprehensive assessment of an AYAC medical history (i.e., during the interview combined with the chart review) further adds to a comprehensive picture of the AYAC sexuality. In the assessment, the clinician must conceptualize where the patient identifies on the cancer trajectory (i.e., at diagnosis, during or post-treatment, survivorship). In
Table 2 Red flags and selected clinician and patient resources for core domains of AYAC sexuality assessment

| Core domain                  | Key tips/red flags                                                                 | Resources for clinician                                                                 | Resources for patient                                                                 |
|------------------------------|------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| I. Socio-demographics        | Contextualize sexual impact as a function of socio-demographics (e.g., age, culture, family, single or couple) | National LGBT Cancer Network [44].                                                     | www.youngadultcancer.ca/our-stories#links†                                                                                   |
|                              | Consider financial factors and changes in living situation that impact sexuality (e.g., moving back home with parents) | Quality of Life-Cancers Survivors** [45] and Peds QL* [46]                              | http://www.huffingtonpost.com/news/generation-why/‡                                                                                  |
|                              | Assess and consider sexual orientation                                              | Functional Assessment of Cancer Therapies—General (FACT-G)** [47]                      | shannonstoolbox.com/cancer/                                                                                                        |
|                              | Use appropriate, non-heterosexist language to ensure cultural responsibility and competency |                                                                                       | www.cancer.gov/types/aya (see organizations serving AYAs such as planet cancer and stupid cancer.org) |
| II. Medical History          | Comprehensive inquiry of AYAC medical history (e.g., history of cancer diagnosis/recurrence, concomitant illnesses’ treatment with medications) |                                                                                       |                                                                                                                                    |
| III. Fertility and STIs      | Review clinical notes/reports from fertility specialists                             | Fertility Quality of Life Tool (FertilQol) [48]                                         | Information on sexuality and reproductive issues (PDQ®)—Patient Version—National Cancer Institute: http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/Patient |
|                              | Consider HRQL                                                                       | [49]: excellent source on infertility and reproductive health issues for AYAC, e.g., fertility preservation options for males and females, contraception, pregnancy, nontraditional family planning [50–53] | Fertility Hope referral guide http://www.fertilhope.org/tool-bar/referral-guide.cfm                                               |
|                              | Educate about safe sex practices (e.g., contraception, STIs, HPV vaccination)       | Information on sexuality and reproductive issues (PRD®)—Health Professional Version—National Cancer Institute: http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/HealthProfessional | http://www.cancer.gov/cancertopics/causes-prevention/risk-factors/infectious-agents/hpv-vaccine-fact-sheet |
| IV. Sexual Functioning       | Assess direct impacts of treatment (e.g., chemotherapy, surgery) on sexual functioning | Fertile Hope for health professionals http://www.fertilehope.org/index.cfm              | Hope for Two: The Pregnant with Cancer Network: http://www.pregnantwithcancer.org and http://www.livestrong.org/we-can-help/fertility-services/ |
|                              | Special attention directed at negative impacts of treatments on genito-urinary, pelvic, or hormonal areas |                                                                                       |                                                                                                                                    |
|                              | Consider common sexual complaints such as issues related to desire, arousal, orgasm, pain during intercourse |                                                                                       |                                                                                                                                    |
|                              | Referral to specialists (e.g., gyno-oncologist, uro-oncologist) to rule out medical etiology of sexual complaints |                                                                                       |                                                                                                                                    |

Menopause Guidebook [61]
addition, special attention should be paid to: history of cancer diagnosis(es) and recurrence; treatment(s) and medications; and concomitant illness’ treatment(s) with medications, as these may have a direct impact on AYAC fertility and sexual response.

Furthermore, health-related quality of life (HRQL) features an important medical correlate of sexuality due to the negative effect that some HRQL areas have on sexual function and well-being. The HRQL areas that may influence sexuality range from physical function to mental health and relationship issues, reflecting the multifaceted impacts of cancer [47,79]. The clinician must assess for the presence and severity of common side effects such as fatigue, loss of energy, insomnia, and nausea and their relationship with sexuality. HRQL may be assessed using the Quality of Life-Cancer Survivors (QOL-CS) [45], the only validated instrument using AYAC as the population sample.

### III. Fertility and Sexually Transmitted Infections (STIs)

Fertility is a significant source of concern and distress for the majority of AYAC and is highly recommended as a part of a comprehensive sexuality assessment. Managing the effects of cancer treatment on fertility can be as emotionally painful as the cancer itself [4,9]. Compromised fertility was found to significantly threaten young women’s self-esteem, as well as men’s mental/emotional health.

#### Table 2

| Core domain | Key tips/red flags | Resources for clinician | Resources for patient |
|-------------|--------------------|-------------------------|-----------------------|
| V. Sexual Coping Style | - Assess the short vs. long-term repercussions of sexual avoidance for AYAC  
- Assess use of substances to alleviate sexual anxiety or enhance sexual performance  
- Inform AYAC about the effect of drugs/alcohol on sexuality | Body Image Scale [64]  
Sexuality Scale [65]  
Sexual Beliefs and Information Questionnaire (SBIQ) [66]  
Negative Thoughts During Sex Questionnaire (NTDSQ) [67] | [62,63]  
http://www.youngadultcancer.ca/body-image-issues-are-tough-but-worth-working-on/ |
| VI. Body and Self Image | - Assess changes to physical appearance that can impact self-esteem, sexual assertiveness, sexual experimentation, and significant sexual/couple experience  
- Assess AYAC’s frame of mind during sex  
- Inquire about “sexual hypervigilence” to any affected areas | Cancer rehabilitation evaluation system (CARES) Dating Subscale [68]  
Dyadic Adjustment Scale (DAS) [69,70]  
Personal Assessment of Intimacy in Relationships (PAIR) [71] | http://www.youngcancerspouses.org  
http://www.livestrong.org/we-can-help/preparing-yourself/communicating-with-your-partner/  
Understanding relationships, sex, and fertility for young people affected by cancer booklet by Macmillan Cancer. http://be.macmillan.org.uk/be/p-298-relationships-sex-and-fertility-for-young-people-affected-by-cancer.aspx |
| VII. Sexual History and Dating/Couple Experience | - Assess if and how cancer impacted:  
  ○ Sexual experimentation and experiences (number and type of partners)  
  ○ First sexual encounter and anal/vaginal intercourse  
  ○ Identification of sexual preferences (partners and types of sexually arousing activities)  
  For couples and partners, consider high risk factors for relationship loss or troubles  
  ○ Consider the length of relationship  
  ○ Consider that the partner may ill-equipped or not ready/willing to take on the responsibilities of the caregiver role | Cancer rehabilitation evaluation system (CARES) Dating Subscale [68]  
Dyadic Adjustment Scale (DAS) [69,70]  
Personal Assessment of Intimacy in Relationships (PAIR) [71] | http://www.youngcancerspouses.org  
http://www.livestrong.org/we-can-help/preparing-yourself/communicating-with-your-partner/  
Understanding relationships, sex, and fertility for young people affected by cancer booklet by Macmillan Cancer. http://be.macmillan.org.uk/be/p-298-relationships-sex-and-fertility-for-young-people-affected-by-cancer.aspx |

*Validated instrument using AYAC as the population sample  
**Validated instrument in oncology population  
†Cancer Blogs from AYAC, relevant to all seven core domains  
‡The Huffington Post’s hub of young adult cancer content, from recurring survivor blogs, to what’s new in the medical world  
ープ Represents a “red-flag” tip for the clinician to assess  
 apprép Represents a self-report questionnaire  
reprp Represents an online resource  
reprp Represents a reading, e.g., a book, article or pamphlet
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The first author’s own clinical experience supports these findings, as infertility greatly affected her patients’ abilities to form and maintain meaningful relationships. Furthermore, single AYAC patients often cited fertility issues as either a barrier to dating, in that many often believed they are less desirable as mates when compared with same-aged available singles. Couples AYAC report that infertility difficulties pose a serious threat to the survival of existing relationships.

Study results confirm that treatment effects range from complete infertility to reduced or temporary infertility for AYAC [50,51,83,84]. Discussions of fertility risks prior to initiating treatment are not routinely performed with AYAC [85–87]. As a result, AYAC lose the “window of time” where fertility preservation must take place either because they were never informed or options were only presented to them too late in their treatment, or often explained that treatment could not be delayed. In other cases, fertility preservation was not possible because the AYAC could not afford fertility preservation. These aforementioned “let-downs” can be discussed when the clinicians asks about fertility.

A full, extensive review of the effects of treatment on fertility among AYAC is beyond the scope of this article [49,84]; however, the authors draw attention to a number of fertility resources that may assist the clinician’s understanding and assessment of AYAC fertility issues and their subsequent effects on sexuality (e.g. [51,83,88,89]). Additionally, the clinician can first review the clinical notes from care-team members and fertility specialists concerning past and upcoming cancer treatment(s), and review their recommendations specific to the safety and timing of conception. In cases where the status of an AYAC’s reproductive functioning is unknown, the authors suggest that the AYAC be referred to a fertility specialist. Second, the provision of valuable AYAC-specific websites and programs pertaining to fertility, such as the LIVESTRONG’s Fertile Hope Program and CanTeen, provides information and support for both AYAC and clinicians. Third, to better understand the scope of the emotional repercussions of infertility, the FertilQol self-report questionnaire is recommended [48].

Parallel to assessing fertility, discussions concerning safe sex practices provide a fruitful opportunity to educate AYAC about the more general benefits of contraception, such as protection against STIs, unwanted pregnancies, and post-chemotherapy side effects that can put both partners at risk. As an example, clinicians may inform older adolescents and young early adulthood AYAC about the human papillomavirus (HPV), the most common STI, and the HPV vaccine that prevents against cervical, head, and neck cancers and HPV-associated diseases [90].

IV. Sexual Functioning

A comprehensive assessment should also include inquiring about treatment-related effects on both objective sexual functioning (e.g., physiological arousal such as lubrication, orgasm, and ejaculation) and subjective functioning (e.g., having desire, experiencing pleasure and enjoyment). Special attention should be paid to the direct negative impacts of treatments on the genito-urinary, pelvic, or hormonal areas (e.g., surgery to remove testes, ovaries or cervix; pelvic or brain radiation near the pituitary or thyroid glands; hormonal suppression medications) [10,52,53]. Similarly, chemotherapy, including allo/autostem cell transplants, can cause adverse sexual effects such as low sexual desire, delayed orgasm, and erectile dysfunction [61,91,92]. To help rule out the direct treatment impacts underlying sexual complaints, we recommend referring AYAC to providers with a specialty practice in gyno-oncology or uro-oncology.

Common sexual complaints of female AYAC include lowered or loss of sexual desire or arousal, problems with orgasm response (e.g., frequency and intensity). Sexual complaints most commonly reported by young women also include sexual pain during penetration that may be associated with treatment-induced structural changes to the labial/vaginal areas (e.g., thinning/loss rugae, tightening, shortening) [52,93–97]. For example, women with breast cancer treated with hormonal ablation may experience early menopause and are at risk for facing a complete loss of desire and vaginal atrophy [98–100]. Moreover, breast surgery can often result in a significant decrease in arousal stemming from the loss of sensitivity in breast and nipple areas. As a consequence, it is crucial for clinicians to validate these young women’s sexual distress and to provide them with literature such as the Menopause Guidebook from the North American Menopause Society [101]. For women with gynecological cancers treated with surgery (e.g., removal of the cervix) and/or brachytherapy, treatment-induced changes may include alterations in vaginal structure such as the depth, width, elasticity, and consistency of the vaginal walls, all of which are suspected causes of bleeding and pain during intercourse [52,102]. Lastly, for women...
treated with hysterectomies, a significant loss in the intensity of their orgasm response may be experienced mainly due to the loss of uterine contractions [53,103–105].

Although the majority of young men do not report changes in sexual function post-chemotherapy, some have reported experiencing short-term sexual impacts that are usually resolved within the first year following treatment [106,107]. Domains of sexual functioning that should be assessed in young men treated for testicular cancer and lymphomas include lowered sexual desire and difficulties in getting and/or maintaining erections [108,109]. Changes in the orgasm response may also be reported and are likely attributable to a decrease in the ejaculate, semen, and/or sensation of orgasm [106,110,111]. Despite being transient, any of these changes in sexual functioning can significantly threaten men’s sense of masculinity and self/body image and, in turn, also their sexual proactivity (e.g., seeking sexual partners and making sexual advances) [50,109,112].

The degree of sexual side effects from cancer on AYAC remains somewhat unknown mainly due to scant research in sexual oncology (particularly among the AYAC population). To obtain a fuller clinical picture of the range of sexual consequences for both women and men, we highly recommend the health professional and patient versions of booklets from the National Cancer Institute [1], as well as the works by Ofman and Brotto [52,53]. The model of predictive factors of sexual health specific to women with breast cancer by Ganz et al. [113] is also useful for identifying survivors at risk of developing sexual problems.

V. Sexual Coping Style
Assessing an AYAC’s coping style in response to cancer—specifically, how he or she deals with sexual repercussions—needs to be assessed, as it may maintain sexual difficulties and/or compromise the development of the sexual self. An AYAC’s passive or avoidant sexual coping style should also be considered in relation to the cancer continuum. Timing is thus a key determinant of an AYAC’s willingness to address sexual impairments as well as a key indicator of adaptive vs. maladaptive sexual avoidance. Avoiding sex to deal with the stress of active treatment constitutes not only a common, but also an adaptive coping response. As such, the avoidance of sexual activities for years beyond treatment not only maintains but worsens sexual anxieties and poses a serious threat to the developing sexual self of an AYAC.

Determining AYAC sexual coping styles may also include inquiring about a range of negative/avoidant strategies that reflect their unique sexual realities. A passive coping style may include avoidance strategies such as refraining from engaging in sexual activities with or without the partner, the use of technology (e.g., Internet and sexting) to avoid partner-related sexual activities, and consumption of potentially problematic substances to either alleviate anxiety (e.g., alcohol and drugs) or enhance sexual response (e.g., ecstasy) [114–116]. Asking about the frequency, context, and underlying reasons for substance use tends to be a sensitive area of questioning but presents the clinician with an opportunity to combine sexual questioning with education. As an example, the older adolescent may not be informed about the potential adverse effects of certain substances on sexual response [114,115] and this thus presents an optimal moment for the clinician to address and provide resources for substance problems.

VI. Body and Self-Image
Changes in body/physical appearance from cancer treatments constitute a major source of concern and distress for AYAC [5,9,22,117–119]. Upsetting changes may include hair loss, weight loss or gain, and body disfigurements such as scarring and asymmetry due to the loss or alteration of a body part (e.g., breast or testicle) [18,74,117]. Any visible physical changes may significantly affect the development of sexual self-esteem, including delayed sexual maturation and formation of meaningful couple relationships [18,85,118]. Indeed, impaired body/self-image has been shown to not only affect decision making about dating, but also AYAC participation in social events, which provide opportunities to engage in dating and sexual experiences [4,18].

It is important for the clinician to assess an AYAC’s frame of mind during sex, and more specifically to inquire about “sexual hypervigilence” to an affected area (e.g., a scar, a missing body part) as well as arousal and orgasm responses, as this may trap the AYAC into a negative self-fulfilling prophecy cycle [64–67]. Indeed, we found that “sexual hypervigilance” not only distracted AYAC attention to the negative, unarousing aspects of the sexual encounter, but also inhibited their sexual responses, thus reinforcing their fear of sexual performance failure.
VII. Sexual History and Dating/Couple Experience

Evaluating the impact of cancer on AYAC sexual development includes examining how cancer can alter the course of sexual experimentation, a key component of sexual maturation and identity. We recommend getting a snapshot of an AYAC’s sexual life before cancer and, more specifically, his or her repertoire of sexual experimentation. The development of the sexual self takes place through a range of sexual experiences, which occur either alone or with a partner (including opposite and same sex partners). For older adolescents and early young adults, cancer may not only limit experimentation with different sexual partners, but also the experience of positive, sexually arousing, intimate sexual relationships that are necessary in order to build sexual self-esteem and confidence [18,118,120]. Our clinical reports confirm study results showing that AYAC significantly differ from their age-matched peers by reporting lower sexual experience, lower self-esteem, and higher sexual distress [18,93,120].

Dating

Assessing the sexuality of the single AYAC places a special emphasis on looking at the role of fear of rejection on willingness to date and on its multiple developmental repercussions. It is suggested to examine how fear of being rejected may delay sexual experimentation and dating and consequently the formation of meaningful couple and sexual relationships. Moreover, AYAC’s greater sensitivity to the fear of rejection, compared with aged-matched peers without cancer, can bring about distinctive dating fears and issues [1,18,74,112]. Older adolescent and early adulthood AYAC dating fears may differ from their peers due to disclosure regarding their cancer history (e.g., when to bring it up and how) [5,121], body image, and sexual dysfunctions caused by cancer. Dating issues may be assessed using the Comfort in Dating subscale of the CARES questionnaire [68].

Couple Relationships

Evaluating couple relationship adjustment also factors into the psychosexual development not only of AYAC as individuals, but also as romantic partners. Couple relationship factors play a critical role in the emergence and maintenance of sexual problems and may either facilitate or hinder AYAC efforts at resuming their sex lives [10,53].

Our clinical reports confirm study findings indicating that only a small percentage of couples of all ages with cancer separated or divorced following a cancer diagnosis [122,123]. However, adolescent and early young adulthood couples are at a higher risk of experiencing a break-up compared with healthy, age-matched couples [122]. In addition to partners’ age, other risk factors to assess include the degree of couple maturity (which we identified as relationship duration), partner relationship skills, and commitment prior to cancer. In our research, we found a positive relationship between relationship maturity and the likelihood that a relationship will successfully cope with cancer. More specifically, the longer the relationship prior to diagnosis, as well as better partner skills and a higher level of commitment, are positive predictors of relationship survival [109,120,124].

Cancer not only disrupts the development of the AYAC as an individual, but also the development of the AYAC as a member of a couple. When a member of a couple is diagnosed during the early months or years of a relationship, cancer cuts short or robs the AYAC couple of their “honeymoon” phase. Instead, they are forced to adjust to a major life event and to face a host of relationship changes that may in turn trigger a range of emotional repercussions. Among these, the fear of relationship loss features as a predominant emotion that is experienced by both partners. This is particularly challenging for new relationships (e.g., ranging from few months to 1–2 years), in which the partners might feel “trapped” by the cancer, as they may not have even felt secure/confident in the relationship prior to diagnosis.

For the AYAC, the fear of relationship loss may manifest as a fear of being rejected and guilt projected onto the “un-deserving partner.” This fear can be further exacerbated when framed as the availability of other healthy partners competing for a relationship, another painful reality unique to being young with cancer. For the AYAC’s partner, sadness in conjunction with significant anxiety may be experienced at the thought of losing the AYAC to death [53]. Although rarely expressed by the partner, this fear may be at the forefront of the his or her mind, or manifest itself as a distant thought. Also, the partner may feel helpless for not being able to help his or her loved one, or from wanting to escape his or her current couple reality, which can include thoughts of ending the relationship. It is not uncommon for the partner to feel guilty for being “the healthy one.” These issues are often influenced by the patient’s age, diagnosis (e.g., Stage 1 vs. Stage 4), and the age of the relationship (i.e., the time the couple has been together).
Irrespective of age, most couples affected by cancer experience the post-cancer dyadic role-shift from spouse/lover to patient/caregiver, which constitutes an exceptionally challenging adjustment period. This is especially difficult for the younger AYAC couple [62,63]. The adolescent and early young adulthood AYAC partner may feel overwhelmed, ill-equipped, or simply not ready/willing to take on the responsibilities of the caregiver role. It is possible that in young, budding couples, the partner decides to forego the relationship. Consequently, it is vital to assess partners’ reactive coping to the responsibilities of the patient/caregiver roles and to the changes in their couple intimacy and sexuality.

Shifting to the patient/caregiver roles can also significantly alter the sex lives of the young AYAC couple. Besides the obvious, disease-related reasons, the sharp drop in the frequency of sexual activities may be explained by the sexually “unarousing” roles of being a patient and a caregiver [53]. Giving and receiving illness-related care steers partners’ attention away from themselves as spouses/lovers and may alter their perceptions as sexual selves, increasing the likelihood of sexual avoidance. For the AYAC, being identified as a patient may evoke feelings of asexuality or an inherent sense that he or she have lost all desirability as a sexual partner.

Interestingly, some couples (likely among late early adulthood AYAC) find resilience by working together to fight cancer, which strengthens the couple’s intimacy both subjectively (i.e., how close or connected they feel to each other) and physically (e.g., how they mutually engage in physical displays of affection and love) [50,109,123,125]. Moreover, greater intimacy may positively impact an AYAC sex life. Our clinical reports validate study findings indicating that couples reporting a strong, intimate connection were more likely to develop alternate, non-performance–based sexual activities and to derive pleasure from these activities [10,53,62,109,126,127].

A number of questionnaires are currently available to assess either couple adjustment (e.g., Dyadic Adjustment Scale [69,70]) or couple intimacy (e.g., the Personal Assessment of Intimacy in Relationships [71]).

Conclusion

AYAC are now recognized as a distinctive population with unique biomedical as well as psychosocial needs [2,6,19,23]. Cancer not only disrupts the development of AYAC as emerging adults but also as emerging sexual adults. AYAC face a host of cancer repercussions that affect multiple areas closely tied to their sexuality, and as a result delay their psychosexual development. The cancer experience directly affects fertility; sexual functioning; body and self image; and dating and couple relationships.

It is thus important to tailor the clinical assessment to capture the special, distinctive sexual needs of this population, which will allow for more tailored interventions. On the basis of existing AYAC-specific clinical guidelines and recommendations, the main objective of this article was to present a tailored approach to assessing the sexuality of AYAC and the core domains that are important to assess. Furthermore, it is extremely beneficial to assess sexuality and consider the unique concerns among AYAC rather than to treat all cancer patients in cookbook fashion based on cancer site norms. The article also aimed at presenting specific resources and clinical tools to either assist the clinician or act as direct resources for their AYAC patients. Bringing attention to the unique needs of the AYAC population can ideally impact provision of the best quality of patient care.

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