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Taboo Topics in Adolescent and Young Adult Oncology: Strategies for Managing Challenging but Important Conversations Central to Adolescent and Young Adult Cancer Survivorship

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Abstract

Research on adolescents and young adults (AYAs) with cancer has flourished over the past decade, underscoring the unique medical and psychosocial needs of this vulnerable group. A cancer diagnosis during adolescence and young adulthood intersects with the developmental trajectory of AYAs, derailing critical physical, social, and emotional development. AYAs face these abrupt life changes needing age-appropriate information and resources to offset these challenges. Greater attention is needed to address AYA-specific concerns on reproductive and sexual health, financial security and independence, emotional well-being, social support, and end-of-life care. If these unique needs are unaddressed, this can adversely affect AYAs' health care engagement and overall quality of life, increasing their risk for cancer-related morbidity and early mortality. In particular, health care decisions made during treatment have important implications for AYA patients' future health. Oncology clinicians are well positioned to address AYA patients' concerns by anticipating and addressing the challenges this age group is likely to face. In this paper, we explore several core topics that affect AYAs' quality of life and that can be challenging to address. Starting from the moment of diagnosis, through cancer treatment and post-treatment survivorship, and into end of life, each section highlights critical developmental-centric life domains that are affected by the cancer experience. Specifically, we discuss resources, tools, and strategies to navigate these challenging conversations. Taking a risk-reduction approach that invites two-way communication

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and facilitates referral to age-appropriate resources would help destigmatize these experiences and, in turn, would support the provision of compassionate and effective age-concordant care to this vulnerable group.

INTRODUCTION

Sparked by a landmark report from the National Cancer Institute in 2006,[1] research on cancer diagnosed during AYA ages has flourished over the past decade. This work has been fueled by observed disparities in cancer outcomes among this group, highlighting individuals diagnosed with cancer between ages 15 and 39 as a high-priority group. This phenomenon, termed the "AYA gap,"[1] referred to the dearth in improvements in survival rates for individuals diagnosed during this life stage compared with those diagnosed in childhood (younger than age 15) and adulthood (older than age 40). Multiple factors have been proposed to contribute to this survival gap, including differences in the biologic and genetic features of their cancer, delays in diagnosis, low participation in cancer clinical trials (leading to delays in the development of novel therapies), lack of targeted treatments, and treatment noncompliance.[2–5]

AYAs comprise approximately 5% of cancer diagnoses in the United States, which equates to approximately 70,000 new diagnoses each year.[5] Much of what we have learned about AYAs to date has been extrapolated from work done with childhood survivors who have grown to become AYAs. Yet, what sets AYAs apart from their younger and older counterparts are their distinct medical and psychosocial needs during and after treatment. The timing of their diagnosis intersects with a period of substantial physical, social, and emotional development.[6,7] This sets the stage for unique and complex needs that are largely under-addressed.[8] A cancer diagnosis during the AYA life stage exacerbates typical developmental challenges and interferes with the attainment of important age-specific milestones, including establishing autonomy, moving away to college, developing romantic relationships, launching a career, becoming financially independent, and starting a family.[5,6] Straddling the pediatric and adult world, AYAs face the cancer experience with the cognitive capacity to understand the gravity of their illness; yet, underdeveloped emotional coping and decision-making processes may challenge their adjustment and adversely affect their overall well-being.[6]

Despite growing appreciation for the unique needs of this age group, there remains a need to focus on how best to deliver comprehensive cancer care to AYAs. Part of this work involves a willingness and ability to initiate conversations about difficult topics that are critical to the emotional and physical health of AYAs. This is important because the way clinicians communicate with and tackle the needs of AYAs has been shown to affect the doctor-patient relationship, AYAs' treatment satisfaction, and ultimately their overall quality of life.[9] In this paper, we explore several "taboo" topics that affect AYA quality of life and that are perhaps challenging for clinicians to address. Importantly, although the challenge to oncology clinicians is similarly multifactorial and largely unmet, our goal is to highlight oppportunitites to address these topics during the limited time allotted for a clinical encounter. Starting with concerns that emerge at the moment of diagnosis, throughout treatment, transitioning into end-of-cancer care and into end of life, each section briefly summarizes what is known about the topic and provides strategies and techniques to tackle these often-difficult conversations with AYA patients. Our goal is to provide oncology clinicians with resources and tools to engage in this important aspect of their work, in turn supporting their AYA patients' well-being.

ADDRESSING INFERTILITY AND OPTIONS FOR ITS PRESERVATION: CANCER DOES NOT STOP PATIENTS FROM WANTING TO BE PARENTS

Cancer treatments often have temporary or permanent gonadotoxic side effects among AYAs.[10–13] Due in part to the distressing and overwhelming nature of a cancer diagnosis, which occurs before patients are considering fertility issues, many AYAs do not fully understand or remember the potential adverse implications of their current or future fertility.[14,15] Yet, others are left tackling questions around cancer-related infertility even before they have begun to consider if and when they want to have a family of their own. AYAs who experience cancer-related infertility are more likely to report lower physical and emotional quality of life and clinically significant levels of distress in relation to loss of/impaired fertility.[16–18] In recent studies, as many as 51% of newly diagnosed female AYA patients and 44% of newly diagnosed male AYA patients reported fertility-related concerns.[19,20] Not surprisingly, information about infertility risks and options for having children is a common unmet need among AYAs.[21–23]

Organizations such as ASCO,[24] the National Comprehensive Cancer Network (NCCN),[25] and the American Society for Reproductive Medicine (ASRM)[26] have established professional guidelines to enhance the likelihood that AYAs receive timely and actionable information about cancer-related infertility. These guidelines essentially highlight two key issues: (1) AYAs should be informed about the potential gonadotoxic effects of their cancer or its treatment as early as possible, and (2) if AYAs are interested in learning more about options for preserving their fertility, they should be referred to reproductive specialists. AYAs desire to be fully informed about their options,[27] and clinicians often underestimate the importance of these discussions.[28] Moreover, studies show that less than 50% of oncologists follow recommended ASCO/NCCN/ASRM guidelines, rarely referring patients to fertility preservation specialists. Additionally, less than 25% of oncologists are aware of or distribute written educational materials to their patients.[29,30] Guideline-concordant care remains suboptimal even in resource-rich settings; specifically, a random review of clinical charts from four National Cancer Institute–designated comprehensive cancer centers determined that only 26% of AYA patient records had documentation of infertility risk discussions.[31] Additionally, only 13% of charts had documented referral to a reproductive specialist.[31] Of note, as is common with AYA research, it's important to acknowledge the varied age range used to define the AYA population in each of these studies when interpreting findings.

There are multiple barriers that hinder clinician adherence to guideline-concordant care in this area: institutional-level, clinician-level, and patient-level.[29,32] At the institutional level, there are resource limitations. Across National Cancer Institute–designated comprehensive cancer centers, a 2013 study revealed that only 27% of participating sites (8/30) had staff with time dedicated to fertility preservation, and institutional policies regarding consistent provision of fertility preservation information were rare (13%, 4/30). Unfortunately, because a majority of AYAs are treated in community-based practices, their access to fertility preservation information and resources is likely even more limited.[33] Clinicians also face many communication barriers, including time demands, comfort level with conversations about fertility, and limited awareness of fertility preservation options.[30,34–40] AYA concerns are further multilayered: patients are managing their own distress; navigating cultural/familial or religious perspectives on assisted reproduction; and balancing priorities, including cost of fertility preservation procedures.[36,41–43] Collectively, these barriers compromise the ability of clinicians to deliver optimal care for their AYAs in this important patient-centered domain.

Attempts to educate and empower patients and to educate oncology clinicians has resulted in a growing number of promising resources (Table 1), including strategies aimed at helping clinicians initiate conversations about infertility (Table 2). The resource list is neither exhaustive nor an endorsement of a particular resource; we include it because it provides a range of emerging and useful tools to enhance patient-centered care for AYAs who want timely and helpful information about options to preserve their fertility.

ADDRESSING AYA SEXUAL HEALTH: AWARENESS, SENSITIVITY, AND DEVELOPMENTALLY INFORMED CARE

Sexual health is a critical yet often overlooked aspect of care for AYAs with cancer, potentially compromising their physical health and quality of life.[45–47] Specifically, sexual health refers to one's state of well-being in relation to one's sexual identity, preferences, behavior, and relationships. During adolescence and young adulthood, exploring sexuality, romantic relationships, and psychosexual identity are important aspects of development.[48] Indeed, a common unmet need is the acknowledgment of an AYA patient's preferred sexual orientation and gender identity.[49] This is particularly important during adolescence and young adulthood. Lesbian, gay, bisexual, transgender, and other sexual/gender minority patients tend to be marginalized despite their elevated risk for certain cancers and their lower participation in routine cancer screening.[50,51] Sexual/gender minority survivors of cancer tend to report higher rates of psychological distress and discrimination than their heterosexual and cisgender peers.[52–54]

In contrast to common misconceptions that having cancer precludes exploration of sexual identity and corresponding sexual behaviors, AYAs with cancer engage in these processes at similar rates to nonill peers.[55,56] However, AYAs with cancer of all sexual orientations have additional, unique sexual health needs that require specialized care. Many AYAs experience sexual dysfunction during and after treatment,[55,57–59] with over one-half reporting problems with sexual functioning during the first 2 years after diagnosis.[57] Importantly, AYAs perceive that these issues negatively affect intimacy and their romantic relationships.[45,60,61] AYAs receiving treatment face additional risks associated with unprotected sex, including increased susceptibility to sexually transmitted infections and potential for severe pregnancy complications.[62,63] To mitigate these concerns and provide whole-patient care, clinicians must be prepared to consistently and appropriately address sexual health needs for AYAs with cancer.

Although AYAs with cancer desire and benefit from receiving sexual health information,[46,63,64] clinicians do not consistently recognize sexual health as an unmet need.[46] Many also lack confidence in querying sexual/gender identity and providing appropriate care focused on sexual health.[63,65] Additional barriers to sexual health conversations include clinicians' misconceptions that AYAs with cancer are too sick to engage in sexual behaviors[66]; AYAs' unwillingness to initiate conversations or ask questions[67,68]; and clinicians' discomfort broaching sexual health topics,[63,65,67] particularly when family members are present.[69] Indeed, discussing sexual health is complex. Clinicians must be prepared to navigate issues around sexual/gender identity, patient/family and cultural values, and, particularly for adolescents, confidentiality and parental consent. Critically, however, these conversations are associated with positive outcomes. AYAs who discuss sexual health and contraception practices with clinicians report increased contraception use, better knowledge of risks, and more confidence in their relationships with their clinician.[63,64]

Currently, there are no standard practices for addressing AYA sexual needs, and care is inconsistent.[66,70] To address this gap, the Global Adolescent and Young Adult Cancer Congress recently developed guidelines to help clinicians screen and intervene on sexual health issues, particularly concerns related to sexual dysfunction and contraception.[70] Building on this work, we offer additional guidance for addressing these complex topics, including initiating conversations, asking and eliciting important questions, normalizing and validating experiences, and creating a safe space (Table 3). Ultimately, it is critical for clinicians to acknowledge that AYAs with cancer engage in sexual behavior during and after treatment, to appropriately assess sexual health needs and risk-taking through creating a safe environment for AYAs to ask questions and share concerns, to and provide individualized information that empowers AYAs to take control of their sexual health.

FINANCIAL TOXICITY: AN UNADDRESSED SIDE EFFECT FOR AYAs WITH CANCER

AYAs tend to be healthy prior to diagnosis and have little experience with the health care system, insurance, and medical bills.[71,72] Across studies, AYAs with cancer consistently report financial burden, reduced access to care, limitations in their ability to work, and worse quality of life due to their cancer treatment.[73–76] Differences in financial burden exist by age within the AYA population.[73] In one study, AYAs diagnosed with cancer at age 26 to 39 reported that cancer negatively affected their finances more than those diagnosed at age 15 to 25 (77.8% vs. 37.5%).[77]

How patient financial burden can be addressed and how cost conversations should happen in oncology are emerging areas of research. Although improving patients' understanding of cancer care costs is part of providing high-quality cancer care,[78] clinicians and patients do not often consider this to be the role of oncologists.[79] Instead, social workers, navigators, and financial advocates are seen as best equipped to discuss costs with patients.[79] Common cost concerns raised by patients with cancer across studies include clinician's lack of time to attend to insurance eligibility/coverage, worries that costs may affect a clinician's decision-making and the patient-clinician relationship, and the cost of specific tests and visits.[80–82] Many of these are concerns common to AYA patients with cancer, who can feel lost in an unfamiliar health care system, and are complicated by AYA patients' insurance coverage.

Financial toxicity, which encompasses the problems a patient faces due to the cost of their medical care, can be a concern for patients of any age.[83] Yet AYAs with cancer tend to have unique resource and social experiences while going through cancer treatment that can place them at added risk for financial issues.[84,85] A typical AYA diagnosed with cancer lacks the financial security of older adults.[86] Younger AYAs are often establishing independence from their parents while undergoing formative educational and work experiences.[87] Although many patients in this age range are covered by their parents' health insurance, certain groups, such as His-panic AYAs have lower insurance access.[88] Even with insurance, out-of-pocket medical expenses can still be high.[89] By age 26, AYAs no longer have access to dependent health insurance coverage and experience limited employer-sponsored insurance coverage options.[90,91] At the same time, AYAs may face additional financial strains not experienced by older patients with cancer, such as the costs of oncofertility services, which are often not covered by insurance.[92,93]

As a result, financial concerns are common among AYAs with cancer and are often left unaddressed. In the AYA Hope study, financial advice was the most commonly reported unmet need by AYAs.[94] AYA patients with cancer want to understand their cancer costs, including how their insurance works.[71] For clinicians, finances can be a delicate topic, and few oncologists feel comfortable discussing costs or feel it is their role to do so.[95,96]

Cost discussions are recommended as part of high-quality patient-clinician communication in oncology.[97] To meet this goal, organizational commitment is required to address patient cost concerns.[82] Few patients with cancer report having cost conversations with their medical clinicians, and for those who do, conversations are often brief and occur at a single point in time.[80,98] Although there is limited evidence, patients who discuss costs with their oncology clinicians do report lower out-of-pocket costs.[99] Specifically, clinicians can help by starting a cost conversation with patients to understand if financial concerns are affecting patient decision-making around care. Clinicians can problem-solve regarding modifying treatment options or working with insurers to ensure preauthorization of services. Additionally, they can refer patients to internal resources, such as financial assistance, or to external resources, such as Triage Cancer. Effective cost-of-care conversations should thus include raising concerns with patients, integrating conversations into the clinical workflow, and assisting AYAs (through referral) with addressing financial issues (Table 4).

Clinicians should also be aware of the social and developmental factors that may affect their AYA patients' financial toxicity that differ from older patients.[85,102] One example of a common but underappreciated financial burden experienced by AYAs with cancer is their dual caregiver roles; AYA patients with cancer, for example, may have caregiving responsibilities both for young children and aging parents or grandparents, which can be costly. At the same time, due to their unique life stage, AYAs with cancer may face greater structural vulnerabilities or social risk that affects their access to care, treatment adherence, and financial toxicity, such as housing instability, food insecurity, and educational barriers (e.g., student loans).[92] As such, screening AYAs for social and economic determinants in the oncology context should encompass resource needs (e.g., childcare costs, student debt) extending beyond insurance and medical costs.[103] Screening for social and economic determinants of health may allow oncology clinicians to reduce barriers to care.[104] Ultimately, AYA patients need the opportunity to have their financial cost concerns heard and addressed in efforts to minimize experiences of cost burden.

TRANSITIONING INTO POST-TREATMENT SURVIVORSHIP: ADDRESSING PSYCHOSOCIAL NEEDS THAT BEGIN WHEN TREATMENT ENDS

The transition from end-of-treatment to post-treatment survivorship brings about a new set of challenges for AYAs[105]; however, limited attention has been placed on this sensitive re-entry period. This is noteworthy because post-treatment survivorship represents an important phase in the life trajectory of AYAs that carries additional emotional, social, and practical considerations. Like the timing of diagnosis, the end-of-treatment transition occurs abruptly and intersects with the normative developmental transitions that define this age group.[6,106] The difference here, however, is that at this juncture AYAs are forced to resume a life that has been profoundly transformed by the cancer experience.[105] Indeed, AYAs report feeling confused, unprepared, and alone as they strive to achieve a sense of normalcy.[7,22,105,107] Typical normative developmental concerns, such as dating, getting married, and having a family, are now observed through a new lens—one filled by uncertainty and self-doubt. Their sense of self and the world, now divided into a "before-cancer" and "after-cancer" self,[108] may become enshrouded by a desire for control, integration, and meaning. Physical aftereffects of treatment, such as pain or fatigue, may interfere with efforts to resume social, work, or school activities.[105] Making any life decision, big or small, becomes an arduous task as they grapple with making the "right" choice. A desire to "catch up" at work, for instance, may be met with the opposing impulse to change careers or live life fully for fear of an uncertain tomorrow. Others may cope with trying to explain vocational gaps to avoid discrimination. They may also experience difficulty separating themselves from their cancer experience, feeling isolated in their fears as others urge them to move on. As a whole, the aftermath of cancer treatment can lead to quality-of-life impairments that span multiple life domains, interfering with AYA patients' social, familial, financial, professional, spiritual, and emotional well-being.[5,22,105]

Not surprisingly, the collective impact of these transitional challenges and the lack of survivorship preparation render AYAs at increased risk for poorer mental health outcomes. Indeed, studies document higher rates of distress in AYAs compared with individuals diagnosed as children or older adults.[5,109] Although reports on the prevalence of distress in AYAs vary widely, upward of one-third have been shown to endorse symptoms that meet clinical thresholds.[110,111] Specifically, 44% report having post-traumatic stress symptoms[5]; additionally, 31% endorse moderate to severe levels of anxiety and depression.[110] Fear of recurrence is also high, with up to 62% reporting elevated worry.[112] Notably, distress symptoms have been found to persist beyond treatment completion, with the highest levels documented within the first 2 years after treatment completion.[113] It is also important to note that, given the timing of their diagnosis, symptoms of distress may fluctuate and coincide with key developmental milestones affected by cancer. For instance, a young adult breast cancer survivor may experience elevated anxiety when she observes her daughter begin to develop breast buds. Overall, this suggests that the emotional well-being of AYAs should be assessed at regular intervals throughout post-treatment survivorship.

Despite these challenges, numerous studies identify psychosocial support as an unmet need among AYA cohorts, especially when treatment ends.[7,105,107] The barriers to psychosocial service use are multidimensional. For instance, clinicians may underestimate or misinterpret distress symptoms, thereby missing opportunities to refer. In the event that referrals are made, perceived stigma surrounding mental illness may discourage survivors from seeking care.[110,111] On an institutional level, there is a dearth of tailored, age-appropriate services for AYAs.[105,111]

AYAs may also hesitate to share their distress because they do not want to worry their families[114,115] or appear un-grateful to clinicians. However, most importantly, not all AYAs present with distress symptoms that meet clinical thresholds.[5] Many may also present with subthreshold symptoms yet still want strategies to cope with the quality-of-life challenges they face post-treatment. Instead, distress symptoms may manifest as physical or behavioral concerns, such as fatigue, pain, disrupted sleep, or impaired concentration.[5] Nonetheless, even AYAs considered “resilient” (i.e., those reporting minimal symptoms) have been shown to desire psychosocial support, identifying it as an unmet need.[110] In light of these findings, one solution to optimize AYA emotional health may be to consider referal to psychosocial support as part of standard care delivery.

AYAs want and need to discuss the end-of-treatment transition with their clinicians.[107] Clinicians have an opportunity to mitigate the adverse effects of post-treatment survivorship by preparing AYAs, referring them to age-appropriate resources and connecting them with much valued peer support (Table 5). As with other topics, these are conversations that are best had often, at each turning point in their care. Additionally, given their health risks and known informational needs, AYAs may also benefit from reviewing a comprehensive care plan once treatment ends to facilitate future screening and surveillance care needs.[116] This is particularly important given their likely shifts in health care clinicians (e.g., pediatric to primary care) and health care delivery systems (e.g., home clinic vs. school clinic; relocation).

DEATH: TACKLING THE ULTIMATE TABOO TOPIC

Regardless of their diagnosis or prognosis, many AYAs with cancer think about death and want to talk about it. Thirty-eight percent report wanting to talk about the possibility of dying from cancer at the time of diagnosis.[117] Among those with advanced cancer, 88% state that talking about prognosis would be important and/or helpful; however, only one-half report having an opportunity.[117,118] These missed opportunities translate to high intensity end-of-life care for 78% of AYAs who die of their cancer, despite the fact that 75% prefer to focus on comfort during their last month of life.[119]

For oncology clinicians, talking about death is almost always difficult.[120] Many may feel a sense of personal failure upon considering their patient's death.[121] Most refrain from talking about death because they recognize that it is distressing to patients and families.[122] Indeed, in the short term, AYAs who engage in advance care planning do report sadness, worry, anger, and a sense that their clinicians lack compassion.[123–125] However, they also report that the discussion is helpful and that it ultimately alleviates their distress.[123,124] This is because compassionate and truthful conversations about prognosis help AYAs make decisions concordant with their values.[126,127] Furthermore, patients whose oncologists talk about death report greater trust and confidence in their clinical teams, greater understanding of treatment options and consequences, and even greater hope.[125,128–130]

Additional barriers to end-of-life discussions include the perception that patients or their families have un-realistic expectations about a cure.[121,122] Indeed, patients and families tend to be more optimistic than clinicians.[131,132] For example, among adults with incurable cancer, only 49% verbally acknowledge their prognosis, and of those, 33% still report a goal of cure, regardless of its feasibility.[133] This seeming discordance does not necessarily mean a patient does not understand; rather, it may mean that people are more comfortable articulating their hopes than their fears, or even their perceived reality.[133,134]

How can clinicians improve prognostic understanding? A single pessimistic statement has been associated with improved patient understanding.[135] This might include a phrase such as "Unfortunately, it looks like the cancer has grown further, which tells me that the chemotherapy we gave you did not do what we had hoped" (Table 6). Similarly, responding to patients' distress with empathy allows them precious time to process news and emotions, leading to better understanding.[136–138] Last, clinicians should recall that understanding takes time and repetition. One conversation is rarely enough. Instead, clinicians must provide manageable amounts of information, allow for patients' emotional response and processing time, and then repeat the information or provide slightly more.[139] It is important to acknowledge and validate the concerns clinicians may face with the increased time needed to engage in these critical conversations. Although scheduling longer visits could help overcome time demands, these accommodations often require institutional and third-party payer support. In spite of these challenges, anticipating these needs and finding opportunities to communicate about these concerns will greatly support your patients during a time of need.

Subspecialty palliative care teams may provide an extra layer of support for both communication and symptom management beginning at the time of diagnosis and extending throughout the end of therapy and bereavement, if applicable. Indeed, limiting palliative care to the end of life may translate to missed opportunities to improve AYA patient quality of life. Nevertheless, oncologists should be skilled in "primary" palliative care delivery, including facile communication about end of life and goals of care.[140] Several communication techniques and resources have been proposed in the oncology literature, including programs offering in-person trainings focused on communication, web-based curricula, and quick guides with mnemonics or suggested phrases.[97,141–147] All of these are helpful when discussing the possibility or inevitability of a patient's death. As a rule, it is helpful to start with an assessment of a patient's need or understanding.[148,149] Although this way of beginning is helpful regardless of the patient's current prognosis or their prognostic understanding, particular phrases may be more effective both early and later in the patient's cancer trajectory (Table 6). For example, early assessments might invite discussions about hypothetical poor outcomes, whereas later queries might direct the conversation toward the delivery of specific news. Regardless of the timing or the patient's verbalized response, clinicians should recall that talking about death is necessarily difficult. Patients and families may feel distressed, and clinicians should be prepared to provide emotional support.

After the assessment of needs or understanding, the compassionate delivery of information, and the management of emotions, we recommend that clinicians resume the conversation with another question. This may be a request to explore the patient's goals, hopes, worries, and values. It may be a request to hear more about the patient's concerns and thoughts about the news that was just delivered. It may also be an assessment of the patient's willingness to keep talking versus a desire to talk more at a later time point. This cycle (ask/tell/ask, or ask/provide information/respond to emotion/ask) can continue as long as necessary.

Ultimately, closing a conversation about death should include a statement of the patient's understanding, a summary of what the clinician thinks is important, a statement of gratitude for the patient's participation, and a plan for next steps (Table 6). This model may provide a roadmap for clinicians to navigate conversations about death (or any taboo topic) in a way that helps support patients and families at the time when open, honest, and compassionate communication may matter most.

DISCUSSION

A cancer diagnosis during adolescence and young adulthood clashes with the developmental trajectory of AYAs, derailing critical physical, social, and emotional processes. AYAs face these abrupt life changes wanting, yet lacking, age-appropriate information and resources to offset these challenges. Concerns related to sexual and reproductive health, financial security and independence, emotional well-being, social support, and end-of-life care are just a few of the many AYA-specific needs affected by cancer that remain unmet. This represents an important un-addressed cause of cancer-related morbidity for this already vulnerable population. The stress associated with these adverse psychosocial experiences can contribute to distress, maladaptive health behaviors, lower health care engagement, stress-related decrements in immune functioning, and overall lower quality of life.[5]

Oncology clinicians are well positioned to address their AYA patients' concerns by anticipating and addressing the challenges this age group is likely to face. Although their physical and psychosocial care needs will likely vary based on their chronological age and timing of diagnosis and treatment, all AYAs can benefit from engaging in these difficult conversations with their clinicians. Taking a risk-reduction approach that systematically normalizes these experiences, invites two-way communication, and facilitates referral to age-appropriate resources will be essential to providing compassionate and effective age-concordant care to this otherwise vulnerable population. It is important to recognize that cancer may be a disease of the aging; however, with improvements in cancer care, our AYAs with cancer shall grow to become our aging population. This aging process may further interact with treatment-related late effects to yield a population that will potentially live with chronic quality-of-life impairments. Taking every opportunity to discuss and address key developmental needs in our medical treatment of AYAs now can enhance their quality of life and overall health outcomes for the future.

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PRACTICAL APPLICATIONS

- The needs of AYA patients with cancer differ widely due to the timing of their diagnosis relative to their development and the impact that cancer and cancer treatment have on the attainment of important developmental milestones.
- There is clear evidence that AYAs experience high unmet needs, which can adversely affect their health and experience with the medical system. As AYAs age into adulthood, they carry with them important quality-of-life impairments that can further negatively affect their health.
- Oncology clinicians are in a unique position to facilitate challenging discussions associated with AYA health. Taking every opportunity to connect their AYA patients with resources can help address their unmet needs. Simply asking, validating, and referring can potentially offset the physical, social, and emotional burden AYAs may otherwise face.

TABLE 1.

Fertility-Preservation Resources

Support Type	Resource
Institutional support	**FERTLINE:** National fertility preservation hotline and source for clinical care communication supported by the Oncofertility Consortium. http://oncofertility.northwestern.edu/resources/about-fertline
	Clinician Pocket Guides: Information and guidance to oncologists, endocrinologists, and other health care clinicians concerned with the reproductive health of patients and survivors. www.savemyfertility.org/pocket-guides/providers
Clinician support	**Patient Pocket Guides:** Resource for adult patients and the parents of children with cancer who want to learn more about preserving their fertility before and during cancer treatment and protecting their hormonal health after treatment. www.savemyfertility.org/pocket-guides/patients
	Oncofertility Consortium: The Consortium represents a nationwide, interdisciplinary, and interprofessional network of medical specialists, scientists, and scholars who are exploring the relationships between health, disease, survivorship, and fertility preservation in young patients with cancer. http://oncofertility.northwestern.edu/
	Enriching Communication skills for Health professionals in Oncofertility (ECHO): Web-based training program that includes psychosocial, biologic, clinical, and skill-building modules to help oncology health professionals communicate timely and relevant information regarding reproductive health to their AYA patients. https://echo.rhoinstitute.org/
Patient support	**Fertility Scout:** Online tool designed to help oncology health care clinicians and patients find fertility preservation services. www.allianceforfertilitypreservation.org/get-involved/fertility-scout
	Alliance for Fertility Preservation: A 501(c)(3) charitable organization focused on fertility preservation for patients with cancer and comprising professionals from oncology, oncology nursing, reproductive endocrinology, urology, psychology, and reproductive law. www.allianceforfertilitypreservation.org/index.htm
	ReproductiveFacts.org**:** A website for patients by the American Society for Reproductive Medicine. www.reproductivefacts.org/
	LIVESTRONG Fertility: Information on treatment and eligibility for discounted rates for fertility preservation interventions. www.livestrong.org/we-can-help/livestrong-fertility

TABLE 2.

An AIDED Approach to Talking With Your Patients About Their Fertility*

Central Components	Sample Probes/Talking Points
Assess patient’s general understanding of their diagnosis and its potential impact on fertility as well as current and future desires to have a child.	“Has anyone discussed how your cancer treatment may affect your ability to have children?” “I would like to discuss how your cancer treatment might affect your ability to have children. I’d like to understand your perspective so that we can discuss potential options.”
Introduce the topic of fertility and why you are discussing this topic.	“I know this is something you may not be thinking about right now, but do you think you may want to have (more) children in the future?” “I would like to talk with you about these issues. Is this something you would like to hear about?” “Is there someone you would like to have with you when we talk about this?”
Describe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biologic and nonbiological parenting options.	“Before I begin, tell me what you have already been told about the possible effect of treatment on your fertility.” “Risk(s) of infertility with patients depends on the disease type and planned treatment(s).” “The recommended treatment involves freezing fertilized eggs/your eggs/your sperm. Can I describe those to you now?”
Explain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists.	“The process for freezing an embryo/your eggs takes 2.5 to 3 weeks. When patients are interested in these options, we refer them to a specialist.” “The process for freezing your sperm takes a week to 10 days, and men usually give three separate specimens with 2 to 5 days between collections. When patients are interested in this option, we refer them to a specialist.”
Discuss and provide patients with information and offer support to facilitate decisions about fertility preservation.	“This can be a difficult decision. There is no “‘right’ decision, and we will support you whatever you decide. The goal is to provide all the information you need to make the best decision for yourself based on what you know and need right now.”

Abbreviation: AYA, adolescent and young adult.

[*] Communication tips adapted from Vadaparampil et al.[44] Detailed scripts and additional information are available for female patients, male patients, and post-treatment survivors.

TABLE 3.

Discussing Sexual Health

Central Components	Sample Probes/Talking Points
Initiating conversations	“I’d like to ask you some questions about your sexual health. Is that okay? You don’t have to answer any questions that you don’t want to.”
	“If it is okay with you, I’d like to share some information with you about how [cancer/treatment] may affect your sexual health. Even if this doesn’t feel relevant for you right now, it might be helpful information for you to have for the future.”
Asking and eliciting important questions	“It is important for me to know what is important to you. This includes your personal life like sex and intimacy. How would you describe your sexual orientation? Are you attracted to men, women, both, or neither? What about your gender identity? Do you identify as a man, woman, or non-binary?”
	“Sometimes young people with cancer feel like they don’t get enough information from their doctors/nurses about their sexual health, and I want to make sure I’mgiving you all the information you need. What else would you like to know?”
Normalizing and validating	“It’s common for teens and young adults to feel that cancer has affected their sense of intimacy or romantic relationships. Has this been true for you?”
	“Talking about sex and gender can feel awkward, and I confess I may not use or say the right words. I invite you to correct me or help me so that I can take better care of you.” Always ask how your patient would like to be referred to and their preferred language.
	“Many young people with cancer experience concerns with their sexual functioning. Often, they don’t realize that these issues can be related to their treatment, and in some cases, there are things we can do to help. We are here to answer any of your questions about what might be related to your cancer treatment.”
Creating a safe space	“Sometimes teens and young adults with cancer are curious about how their cancer treatment can affect their sexual health but don’t feel comfortable asking. Would it help if I share some information about it?”
	“I want to make sure I am giving you the best care I can and all the information you need to stay healthy. Is there anything about your sexuality or sex life that I haven’t asked about but you think it would be important for me to know?”
	To an adolescent: “I’d like to talk to you about your sexual health. I want you to know that this conversation will be confidential, which means that I won’t tell anyone else what you tell me.”
	To a parent: “As part of his/her cancer care, we routinely have conversations with your son/daughter about their sexual health. What should I know about how you have discussed this in your family so far?”
	“Sometimes teens and young adults feel more comfortable discussing their sexual health with a clinician of their same gender. Is that something you would prefer?”

TABLE 4.

Discussing Financial Concerns*

Cost Conversation Components	Implications for Clinicians of AYA Patients	Sample Talking Points
You won’t know if you don’t ask.	AYAs may lack the awareness to raise financial concerns in a health care context. Don’t wait to raise concerns only when you sense a patient is having financial difficulties; screen for financial hardship with all your AYA patients.	“I’d like to ask about any worries or concerns you have about the costs of your cancer care.”
Discuss the cost prognosis.	Clinicians report being worried that costs may affect what care a patient may agree to, but patients often see a cost conversation as helping them plan for their care.	“I know talking about costs can feel a bit stressful with everything you have going on, but our goal is to get you the best possible care.”
You can anticipate many, if not all, costs.	AYAs often worry about other costs in their lives, such as school tuition, student loans, and childcare. As such, the indirect costs of care may be a big source of stress for AYAs with cancer, meaning that clinicians should screen for indirect costs and direct medical cost burden.	“Are there any costs that you are worried about? Sometimes we hear from patients that finding childcare or traveling for their care causes worries about costs.”
Be systematic: Make exploration of out-of-pocket costs routine.	Financial issues may emerge over time for AYAs with cancer as they go through their cancer treatment; as such, clinicians should be systematic and regular when developing financial toxicity screening systems and ensure that these issues are discussed with AYAs throughout their treatment.	“Let’s keep checking in on this issue at each visit to make sure we are continually addressing costs and any concerns.”
Integrate cost conversations into your workflow in a way that works for you.	AYAs are an age group comfortable with technology, so identifying alternative ways to screen, such as through patient portals, can be an efficient way to ensure that their financial concerns are heard and addressed.	
Enlist your ancillary staff.	AYA oncology programs are increasingly emerging across the United States. Many of these programs have navigators or educators who work directly with AYA patients and can be an important resource to help you screen your AYA patients for cost concerns.	“I amgoing to bring in another member of my team who is an expert on such matters and can help us brainstorm for possible solutions.”
It gets easier and better.	Cost conversations are a key component of high-quality cancer care for AYAs with cancer. The more you have these discussions, the better your approach with young patients will be.	

Abbreviation: AYA, adolescent and young adult.

*Tips adapted from Sloan and Ubel[100] and the American College of Physicians Costs of Care Resources.[101]

TABLE 5.

Strategies to Discuss Common End-of-Treatment Transitional Concerns

Conversation Components	Important Considerations		Sample Talking Points
Prepare AYAs for the end-of-treatment transition.	**1**	Help AYAs understand that it’s common to experience a range of emotions when treatment ends. In fact, “normal” may now feel different.	“Everyone copes with treatment completion in different ways.” “It is totally normal for you to be uncertain/worried about recurrence.” “You may find that certain things trigger heightened worry/concerns—returning to the clinic, waiting for a scan (or scan results), learning a friend has been diagnosed…Identifying your triggers can help you prepare”
	2	Let AYAs know that its common to feel more scared after treatment than before it began. Inform them that they may experience changes in their values and their relationships.	
	3	Listen and normalize these experiences so they do not feel alone.	
Identify and refer to age-appropriate resources, including lifestyle and peer support.	**1**	AYAs want information to help them feel “normal.” This includes peer support, which is key for reducing feelings of isolation.	“Healthy eating and exercise can help you feel better, and it can also give you a sense of routine, structure, and control.” “Would you like me to connect you to a nutritionist?” “I support and encourage you to develop a plan to reintroduce exercise into your daily routine. Let me know how I can help get you started.”
	2	Resources should also include health/lifestyle support. Exercise, in particular, can improve mood and reduce fatigue; however, most AYAs don’t know how to return to an exercise routine after cancer treatment.[116]	
Take a well-being approach to screening, and refer.	**1**	Offer AYAs the opportunity to connect with psychosocial support, regardless of severity of distress. Consider this as part of their regular oncology care. Connecting AYAs with a psychologist, for instance, can prevent the emergence of mental health concerns in the future. It can support their overall quality of life and emotional well-being.	“Everyday life is stressful. Having cancer on top of that can make it even more stressful. There are tools we know are effective in managing daily life stress. May I connect you with someone who can help you address life stressors that may be worsened by the treatment transition process?” “During treatment patients are surrounded by people. So it’s not uncommon for people to feel lonely after cancer. We know how important it is to connect with others your age who have gone through the same thing. May I offer some resources?”
	2	Although distress after treatment is normal, it remains important to also screen regularly for elevated levels of anxiety and depression. The AYA life stage is a time frame when mental health concerns often emerge	

Abbreviation: AYA, adolescent and young adult.

TABLE 6.

Phrases to Help Initiate Difficult Conversations About Prognosis, Recurrence, and End of Life

Context	**Phrases That Help**
Improving prognostic understanding	Statement of pessimism: “Unfortunately, it looks like the cancer has grown further, which tells me that the chemotherapy we gave you did not do what we hoped for.”
	Empathic response to emotion: “I wish I had better news.”
	Empathic response to emotion: “I cannot imagine how difficult this has been for you.”
Early discussions about the possibility of death	“Many patients like you wonder about scary topics like the possibility of dying from their cancer. Is this something you ever think about?”
Later discussions, when prognosis is poor	“Please tell me, what you have heard about how likely it is that your cancer will be cured?”
Delivery of news that cancer is incurable	“I wish I had better news. I amworried we will not be able to cure your cancer and that the treatments we have may do more harm than good.”
Assessing the patient’s understanding of the conversation	“To make sure we are on the same page, can you please tell me what you are going to take away from this conversation?”
Sharing clinician understanding of the conversation	“Thank you for sharing. Can I add that I also heard you say you wanted time to talk to your partner about this news?”
Statement of gratitude for the patient’s participation	“This must have been a difficult conversation. I appreciate your taking the time to talk to me like this.”
Plan for next stepsc	“So, our next steps are that you are going to talk to your partner tonight, and then we will talk again on Wednesday about your questions.”