

Understanding and Meeting the Unique Needs of Adolescents and Young Adults with Cancer

Insights from a multidisciplinary
AYA cancer program



Over the last 2 decades, there has been an increasing awareness in the United States of adolescents and young adults (AYAs) with cancer being a distinct population with unique needs and challenges. AYAs face poorer cancer outcomes and experiences compared with younger and older cancer patients, and they historically have been lost between pediatric and adult models of oncology care. Formally identified by the National Cancer Institute (NCI) as those aged 15 to 39 years who have been diagnosed with cancer, the AYA population includes approximately 90,000 young persons diagnosed annually in the US and 5% of the total annual cancer incidence in this country; it also involves more than 2.1 million current survivors,¹ many of whom face decades of late- and long-term treatment effects across biological, psychological, and social domains.^{2,3} AYAs with cancer have an average 5-year relative survival rate that exceeds 85%, yet they face unique cancer care needs including those related to disparities in health care access, clinical trial enrollment, treatment outcomes, and post-treatment quality of life (QOL) when compared with cancer patients who are not AYAs.⁴ Mobilized by a desire to improve outcomes and make developmentally appropriate cancer care accessible to all AYAs, many health care providers, patient coalitions, families, foundations, community advocates, and health systems across the country have stepped forward to advocate for care that recognizes and addresses the unique needs of AYAs with cancer.

Improved awareness of the need for AYA-specific care and advocacy has resulted in the development of a subspecialty aimed at improving cancer outcomes and experiences for this patient population. This movement has led to the creation of various hospital-based AYA cancer programs with dedicated staff providing developmentally appropriate, customized care to AYA patients. We have also seen the establishment of community advocacy and philanthropic organizations to support improved access to AYA cancer care and an increase in research examining both the biopsychosocial underpinnings of AYA cancer and the experiences of AYA patients with cancer across the treatment trajectory.

While early in development, efforts to formalize training in AYA oncology are underway. Work is still needed to ensure that AYAs have equitable access to tailored care and research opportunities; however, efforts thus far have changed the landscape of AYA cancer. Some successes include:

Clinical trial participation, which offers patients access to newer and potentially more effective treatments, is lower among AYAs than among both older and younger patients; some estimates suggest that just 2% to 5% of eligible AYAs participate in clinical trials.¹⁶⁻¹⁹

- Advanced treatment options to promote AYA-targeted therapies and the use of precision medicine to reduce treatment-related side effects
- Expanded recognition of the importance of survivorship care and the transition to post-treatment life
- Increased clinical trial access with AYA-inclusive age ranges
- Enhanced psychosocial support mechanisms through the integration of mental health services, peer support programs, and online communities into cancer care.

The UNC Lineberger Adolescent and Young Adult Cancer Program

Since its founding in 2015, the University of North Carolina at Chapel Hill (UNC) Lineberger Adolescent and Young Adult Cancer Program has grown from a team of 1 to a multidisciplinary group of 11 individuals who have the common goal of improving access, experiences, and outcomes for AYAs with cancer at the North Carolina Basnight Cancer Hospital, UNC Children's Hospital, and beyond. The reach of our program has grown consistently over the past decade thanks to increasingly operationalized partnerships with philanthropic partners (eg, Teen Cancer America, Be Loud! Sophie Foundation), other care teams, buy-in from leadership, community support, and recognition of the value of this program within UNC's hospital system



more broadly. Below, contextualized in an overview of AYAs' unique needs, we summarize the latest research and practices, clinical standards, and practical tips for working with this patient population. We also present ongoing efforts of our program, highlighting some ways we strive to better understand and support our patients. As a large, academic medical center that serves all 100 counties of North Carolina, we recognize that the context of our work may differ vastly from that of many community programs. We hope that the information presented here provides relevant evidence and actionable tips for providers caring for AYAs with cancer in any setting.

AYA's Unique Characteristics: Unified by Circumstantial Age

Our team members are often asked questions like, "Why is the AYA population defined by the ages of 15 to 39 years?" or "What does a 15-year-old high school student who lives with her parents have in common with a 35-year-old mother of 2 who works full-time?" There are significant variations in cancer experience across this age range, and many experts in the field are beginning to consider 3 distinct AYA subgroups—adolescents (age, \approx 15-19 years), emerging adults (age, \approx 20-29 years), and young adults (age, \approx 30-39 years)—all made up of young individuals diagnosed with cancer and struggling with the impact that their disease and its treatment has on core developmental milestones. In a seminal article considering how best to define the AYA population, Kristin McMaster, MSW, aptly used the term *circumstantial age*. McMaster argued that understanding the unique psychosocial needs of an individual with cancer is more informative than is consideration of chronological age.⁵ AYAs are bound by many unique life transitions: completing education, establishing a career, building social systems and personal relationships, achieving financial

and housing independence, and building a family. Cancer treatment can derail any and all of these milestones, creating a set of needs distinct from that of older or younger individuals.

For instance, as most AYAs have not achieved career and financial independence, a cancer diagnosis can lead to lifelong disruption of professional and financial well-being. Financial toxicity, which the NCI defines as the "problems a patient has related to the cost of medical care," impacts AYA patients at higher rates than it does older patients.⁶ Among AYAs, this financial hardship has been associated with skipping or delaying necessary medical, mental health, and survivorship care as well as having negative impacts on long-term financial health including reduction in credit scores, higher risk for bankruptcy, and increased debt burden.⁷ Like the disruption to other developmental milestones caused by a cancer diagnosis during formative years, AYAs with cancer may face delays, interruptions, or alterations to their educational pursuits, graduation timelines, and workforce entry/advancement, all of which inhibit the attainment of financial independence typically associated with young adulthood.

In addition to unique psychosocial impacts of a cancer diagnosis, there are distinct biological factors underpinning AYA cancers that may contribute to poorer outcomes.^{8,9} For instance, there is growing awareness of the increasing incidence of cancers such as those of the colorectal or breast earlier in life. As compared to cancers in older adults, young adult-onset cancers are disproportionately associated with high-risk biological or genetic features such as mucinous histology, signet ring presence, or mismatch gene repair mutations in colorectal cancer and triple-negative hormone receptor status in breast cancer, all of which are associated with poorer survival outcomes. Compared with younger children with acute lymphoblastic leukemia (ALL), AYAs are more likely to have a Philadelphia chromosome–



QUICK TIPS

For Working with Adolescents & Young Adults (AYAs)

Compassion
PLUS honesty is
the sweet spot

Acknowledge that it sucks to be an AYA dealing with cancer: “This is a lot to deal with. How are you doing?”

Share the AYA
specific resources
available to them

Direct patients to **national resources for AYA cancer survivors** to facilitate connection to validating and supportive spaces.

Ask about their
preferences for
receiving info

“What’s helpful for you to remember and understand the information we’re talking about?” For instance, some people like to write things down, record on their phones, relay things back to me out loud, etc.”

Discuss things
other than cancer

“What kind of things do you like to do **when you’re not here?**” or “Are you watching anything to pass the time during your appointment today?”

Involve non-
traditional
caregivers

AYAs’ primary caregivers **may include friends, roommates, siblings, etc.** Invite them into conversations - “who do you have with you today, and can I answer any questions they might have?”

Repeat, repeat,
repeat

Let AYAs know that **repetition is helpful**, and that people receive information differently at different points in their treatment: “You may hear me say this a bunch of times!”

Things that AYAs report are unhelpful or invalidating in their care experiences

Toxic positivity: “at least you have the good kind of cancer”

Assuming
who their
caregiver is

Sad,
“puppy
dog”
eyes

Talking down to them or only
speaking with caregivers

“You’re too young
to have cancer!”

Doing things to them without explaining what
is happening or asking their preferences

positive (Ph+) or Ph-like variant (gene expression similar to that of Ph+ without the BCR-ABL translocation), both of which are associated with higher mortality rates. Efforts to target these molecular changes (eg, inclusion of BCR-ABL tyrosine kinases for treatment of AYAs with Ph+ disease) have begun to improve outcomes. Additional work is needed to more comprehensively define the unique histological and genetic landscape of AYA cancers, to map these to the most appropriate therapies that target these biologically distinct diseases, and to better understand the interactions between tumor biology and outcomes among AYAs.

Adverse health outcomes are common in the growing population of AYA cancer survivors, leading to decades of impaired QOL, disability, morbidity, and early mortality. Although AYAs represent a small proportion of the overall cancer survivor population, they disproportionately experience poor outcomes including higher rates of cancer-related distress, mental health impairment, and severe and life-threatening conditions compared to other cancer survivor populations.¹⁰⁻¹² A 2013 Institute of Medicine report, *Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer*, recognized the improvement of survivorship care as a priority area; further, it specifically recommended that AYA survivor cohorts be established to facilitate the development of guidelines to follow this at-risk population over the long term.⁴ This is an area of active research to examine the health and well-being of survivors of AYA cancers that is distinct from efforts for childhood or older adult cancer survivors.

Considerations for Providers: Select Issues in AYA Care

Understanding the unique characteristics of the AYA population is an essential first step in providing them with excellent cancer care. Based on these unique biopsychosocial needs, we highlight select areas for consideration below, building on the experiences of our AYA cancer team over the last 9 years and focusing on actionable areas for clinicians. While many of these topics are relevant across all age groups, we find that they are specifically pertinent to enhancing cancer outcomes among AYAs. Beyond these select considerations, **Table 1** provides providers with an overview of cross-cutting care considerations in AYA cancer care.

Fertility

Addressing fertility for young patients is paramount. While there is not a precise overlap between the standard AYA age range and reproductive age, there is expert and guideline consensus that anyone of childbearing age should be educated about the potential effects of cancer and cancer treatment on future fertility.^{13,14} The influence of cancer treatment on future fertility is difficult to study and precisely quantify, but chemotherapy—particularly regimens containing alkylators—increases the risk of ovarian dysfunction and diminishes sperm production. Pelvic radiation and certain gynecologic and urologic surgeries can also affect fertility potential. While some AYAs recover reproductive organ function, other patients may permanently lose the ability to have biological children after cancer treatment. This outcome is a cause for significant emotional distress for many AYAs, and it is frequently mentioned as a top concern for young people facing cancer. The essential takeaways for providers are 2-fold. First,

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Table 1. Key Domains in AYA Cancer Care Guidelines

| APPROACHES TO AYA CARE | |
|----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Raising Awareness | Highlight AYAs as a developmentally unique population and increase awareness of AYA-specific needs and cancer risks (eg, through provider training and education). |
| Multidisciplinary Care | Build multidisciplinary teams including medical and psychosocial providers (eg, medical subspecialists, social workers, psychologists, nurses, physical therapists, sexual health and fertility specialists) who are knowledgeable in AYA developmental needs. |
| Risk Assessment | Assess AYA risk in various capacities such as genetic/familial risk assessment, risk of nonadherence (eg, based on unmet needs, treatment adverse effects), psychological distress screening during both treatment and survivorship, and assessment of patient awareness of behaviors that may increase cancer risk. |
| Innovative Models of Care | Bolster collaboration between pediatric and adult oncologists and allied health professionals; this may be accomplished by identifying an oncology provider AYA <i>Champion</i> . Develop tailored treatment plans that are specific to AYA patient factors and disease type and that are informed by patient preferences. |
| Equity | Focus on inequities related to age and other demographic factors (eg, lack of AYA-specific infrastructure, higher risk of financial toxicity, childcare needs, health insurance). Increase AYAs' awareness of and access to potential supports (eg, financial supports, LGBTQ+ advocacy organizations) to mitigate inequities. |
| ELEMENTS OF AYA CARE | |
| Psychosocial and Developmental Support | Acknowledge disproportionate impacts of cancer treatment on psychosocial outcomes for AYAs. Address these effects by providing appropriate psychosocial support (eg, routine, age-appropriate psychosocial screening and referral, educational and vocational support) for both patients and families with a focus on promoting patients' health-related self-efficacy. |
| Clinical Trials | Increase participation of AYAs in clinical trials by improving provider awareness of AYA-appropriate clinical trials, expanding age eligibility for trials whenever appropriate, and referring AYAs to centers with trial access. |
| Reproductive and Sexual Health | Increase access to fertility preservation by discussing fertility considerations with AYAs as soon as possible to improve timely referral to reproductive endocrinology and infertility specialists. Educate AYAs about contraception and safe sexual practice options based on cancer and treatment type before, during, and after treatment. Assess sexual health and function as part of standard cancer care assessment. |
| Palliative and End-of-Life Care | Refer AYAs to multidisciplinary palliative care teams early and without requiring advanced or terminal diagnoses. Involve AYA support systems in treatment decision-making. Tailor age-appropriate end-of-life discussions to each patient, and identify home-based or out-of-hospital support (eg, hospice or community-based palliative care). |
| Survivorship | Provide survivorship care that is as comprehensive as initial cancer care; this includes monitoring and surveillance that considers patient risk, development of survivorship plans, and ongoing access to other physical and mental health care resources. |
| OTHER CONSIDERATIONS | |
| Access to Care | Improve access to care via insurance and financial navigation support and to health care professionals with AYA expertise (eg, via referral to NCI-designated center, AYA-specific training for staff). |
| Connection to Local Resources | Develop relationships and referral pathways (eg, peer connection programs, primary care providers, cancer care-informed mental health providers) with local and community resources to supplement AYA cancer support. |
| Treatment Adherence | Strengthen AYA treatment adherence through patient education on treatment options and effects, medication guidance (including medication details and risk), adaptation of protocol based on patient lifestyle, referral to social work to address barriers (eg, transportation, insurance, or childcare services), and access to symptom management and palliative care. |
| Future Research | Further AYA cancer research on prevention and screening, reproductive health, psychosocial support, novel treatments, therapeutic guidelines, and barriers to effective care delivery (eg, treatment adherence) among other areas. |

AYA, adolescent and young adult; LGBTQ+, lesbian, gay, bisexual, transgender, questioning, and other; NCI, National Cancer Institute.

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there are a range of options available for fertility preservation. Second, a conversation about those options can be tremendously reassuring in the long term regardless of the path the patient chooses to take.

A comprehensive review of fertility preservation options is beyond the scope of this article. However, practical guidelines have been published that can be referenced when these cases arise. In 2023, Hoffman et al published an excellent “Viewpoint” in *JAMA Oncology* that offered strategies for fertility preservation in an easily digestible format.¹⁵ Briefly, these experts recommended early introduction of fertility discussions and prompt referral to fertility specialists for interested patients. Importantly, many of these treatments can be completed quickly—some within 24 hours (eg, sperm banking, leuprolide ovarian suppression) and others within a few days to 2 weeks. Some options are typically excluded from insurance coverage and carry substantial financial barriers, but many cancer programs and nonprofit organizations offer resources to help defray out-of-pocket costs. Clear communication and care coordination are essential, and it is worth revisiting fertility considerations and family planning options at transitional time points before, during, and after cancer treatment, since questions, concerns, or the degree of psychosocial distress may evolve as the patient progresses through treatment and survivorship. Although a patient may not use fertility preservation therapies at diagnosis, this does not mean that many treatments (eg, sperm banking, egg cryopreservation) would not remain options later in survivorship.

Spaces that promote interconnectedness and that give AYAs the opportunity to engage or be present with other AYA cancer patients are beneficial whenever possible.³²

Clinical Trial Participation

Clinical trial participation, which offers patients access to newer and potentially more effective treatments, is lower among AYAs than among both older and younger patients; some estimates suggest that just 2% to 5% of eligible AYAs participate in clinical trials.¹⁶⁻¹⁹ Limited clinical trial participation likely is a significant driver of the lack of overall improvement in outcomes for AYAs as compared with members of other age groups. Clinical trial participation among AYAs is hampered by eligibility criteria that are based on numerical age rather than biological or metabolic mechanisms and by limited physician awareness of AYA trials owing, in part, to a lack of a comprehensive AYA clinical trials registry. Adolescent patients also face barriers relating to slower drug development times and the additional clinician

effort required to enroll minors onto clinical trials.^{20,21} Efforts are ongoing to improve AYA clinical trial participation; these include increasing access to trials through community-based cooperative groups such as the NCI Oncology Community Research Program (NCORP), developing intergroup trials focusing on AYA cancers that leverage pediatric and adult oncology infrastructure, and expanding health insurance coverage as through the Affordable Care Act.¹⁶ Providers can help increase participation of AYAs in clinical trials by expanding their own awareness of AYA-appropriate clinical trials, being an institutional advocate for activation of clinical trials for AYAs, establishing relationships with colleagues at cancer centers where AYA trials may be more available, and referring patients to centers with trial access when possible.

Treatment Planning and Adjustment

Consideration of long-term side effects and toxicities of therapies is particularly important for young patients. For the oncology provider, side effects and toxicities of therapy carry several important implications. First, these potential concerns merit in-depth discussion with AYAs. However, patients may not process the potential long-term complications of therapy at the outset of treatment for a life-threatening malignancy. Returning to these discussions after treatment and encouraging enhanced surveillance for late effects in the survivorship phase is key to managing potential comorbidities should they arise. Second, spending extra time in the treatment planning phase to weigh the absolute risk of recurrence or death from cancer with the risks of long-term treatment-related harms is warranted. Often, these discussions are best led by providers who regularly provide care for and are well versed in the nuances of the specific AYA cancer in question and are ideally supported by high quality evidence. De-escalation of therapies can be considered in some cases. For instance, decreasing the use of radiation to treat Hodgkin lymphoma has led to a reduction in long-term harm while maintaining excellent survival outcomes. We encourage oncologists who do not routinely care for AYAs to contact AYA-experienced colleagues or to participate in AYA tumor boards for advice when developing a treatment plan to ensure the provision of the best possible care.

Survivorship

Comprehensive and timely survivorship care is critical for AYAs, since late effects may develop for decades following treatment. Despite this, many AYAs may not receive survivorship care focused on enhancing QOL, health span, and lifespan. Comprehensive survivorship care resources are limited at many cancer programs, and this population often faces financial and informational barriers in accessing this care. An essential first step is ensuring AYA survivors are connected to a primary care provider (PCP), which may involve social work or financial services to facilitate access. Clinicians can also provide counseling about the importance of ongoing survivorship care during active treatment, enhance communication between patients and their PCP by creating a survivorship care plan, and connect AYAs to national resources for AYA cancer survivors (Table 2). Additionally, survivorship care guidelines, such as those developed by the NCCN and the Children’s Oncology Group, offer guidance to providers in navigating comprehensive care provision (Table 2).

Table 2. Practical Tips and Resources to Address Select Domains of Recommended AYA Care Delivery

| AYA CARE DOMAIN | PRACTICAL TIPS | RESOURCES |
|----------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Psychosocial Support | <ul style="list-style-type: none"> Assess psychosocial needs (eg, health-related social needs/ social risk factors) systematically and at multiple time points using an existing AYA-specific tool. Identify referral pathways to address reported needs including in-house services (if applicable) and resources available in the community. Build a list of local community organizations and other external supports to inform outside referrals. When possible, schedule AYA patients on the same day to promote organic interaction of this population. Connect patients with national AYA resources. Regardless of what resources you have available at your center, you can connect AYAs to existing resources that can help to validate the AYA experience and provide connection points to support groups, financial assistance, and other supports. | <p>AYA needs assessment tools:</p> <ul style="list-style-type: none"> AYA Needs Assessment & Service Bridge (Figure 1) AYA Psycho-Oncology Screening Tool <p>Social needs screening resources:</p> <ul style="list-style-type: none"> SIREN Evidence & Resource Library Social Needs Referrals in Primary Care: An Implementation Toolkit <p>National AYA resources:</p> <ul style="list-style-type: none"> Stupid Cancer hosts a resource guide of national AYA resources and programs. |
| Fertility Counseling and Preservation | <ul style="list-style-type: none"> Implement a system to ensure that patients receive accurate counseling about potential risks to fertility at the time of diagnosis. Revisit the topic throughout the treatment trajectory. Identify a point person in your clinic to become educated on fertility preservation options available to cancer patients. Research and document local fertility resources, and establish a relationship with a local fertility clinic to create timely referral pathways. | <p>National guidelines for AYA fertility preservation:</p> <ul style="list-style-type: none"> NCCN Guidelines ASCO Clinical Practice Guideline Update <p>ASRM offers many resources and trainings for medical professionals.</p> <p>The Livestrong Fertility Discount Program can help connect patients with clinics around the country that offer discounted services.</p> <p>The Fertility Risk Calculator can help counsel patients on the reproductive risk of their treatment.</p> |
| Survivorship Planning and Care | <ul style="list-style-type: none"> Generate a survivorship care plan for each patient and share this with the patient's other health care providers. Support patients in finding a PCP, and educate the patient about the importance of having a PCP. Consider using shortcuts or smart phrases to pull AYA survivorship care guidelines into electronic health records more efficiently. Reconnect patients with national resources at the end of treatment, as they are often particularly relevant in survivorship (see Resources for Psychosocial support, above). | <p>COG Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers</p> <p>NCCN Survivorship Guidelines</p> <p>ASCO Survivorship Care Planning Tools</p> |
| Clinical Trial Participation | <ul style="list-style-type: none"> Consider clinical trial options for AYAs whenever possible. Promote patient awareness of ClinicalTrials.gov so that they can explore these options as desired. Identify a champion for AYA clinical trial participation; this would be someone who keeps an eye out for AYA clinical trials and advocates for institutional activation. Build networks with other centers that may facilitate clinical trial access. | <p>Search available clinical trials around the world: https://clinicaltrials.gov/</p> |

(Table 2 continued on page 33.)

Health Insurance

Insurance is a frustrating and common challenge when caring for young patients with cancer. Of course, this problem is not limited to AYAs; however, when looking at the US as a whole, young adults are the most frequently uninsured patient population.²² This factor can lead to delays in diagnosis and limited access to appropriate specialists

or supportive care services, and it is ultimately associated with worse cancer survival.²³ In addition, a lack of experience in navigating health care services means that AYAs often do not know how to advocate for themselves or manage insurance applications or claims appeals, and they may get stuck with inappropriately high-cost care without the right supports to navigate their options. Thus, it is worth

(Continued from page 32.)

| Table 2. Practical Tips and Resources to Address Select Domains of Recommended AYA Care Delivery | | |
|--------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Palliative and End-of-Life Care | <ul style="list-style-type: none">■ Offer palliative care services early per NCCN guidelines.■ Consider palliative care for AYA patients to be support for decision-making along the cancer trajectory. Ask AYAs to identify the individuals who are part of their decision-making team, and engage those individuals in palliative care conversations.■ Be mindful of concurrent care policies. State laws vary on which patients can receive hospice care while concurrently receiving cancer-directed therapy, and cut-offs sometimes fall in the AYA age range. Identify a champion who is aware of concurrent care rules and guidelines in your state.■ In the absence of palliative care providers, equip other team members with information from national resources. | <p>Voicing My Choices is a planning guide for AYAs to communicate to family, friends, and caregivers how they want to be comforted, supported, treated, and remembered. This may be most appropriate for teens and AYAs in their early-20s.</p> <p>Inheritance of Hope offers resources for parenting with cancer.</p> <p>The Conversation Project and Ariadne Labs developed What Matters to Me, a workbook for people with serious illness.</p> <p>CAPC offers provider trainings and other resources.</p> |
| Sexual Health | <ul style="list-style-type: none">■ During treatment, routinely inform patients of key safe sexual health practices such as importance of contraception and protections (eg, condoms, dental dams) against infection and bleeding due to heightened risks.■ Ask AYAs about sexual practice and function, and offer nonjudgmental space for questions.■ Identify potential referrals for sexual function concerns.■ Provide additional sexual health information via brochures, online resources, or smart phrases in after-visit summaries. Consider patient privacy, and obtain consent to have conversations or offer information about sexual health. | <p>UNC-AYA Cancer Program Sexual Health and Cancer Information and Resources page</p> <p>Managing Cancer Care Fertility & Sexual Side Effects</p> <p>ACCC also offers resources to support AYAs, including Addressing the Unmet Need of Sexual Health in Oncology Patients and The In-Betweeners: A Focus on Young Adults with Cancer</p> |
| General Resources | | <p>The Cactus Cancer Society offers “The Full Picture of AYA Cancer,” a series of continuing education courses that educates providers on AYA-specific considerations.</p> |

ASCO, American Society of Clinical Oncology; ASRM, American Society for Reproductive Medicine; AYA, adolescent and young adult; CAPC, Center to Advance Palliative Care; COG, Children's Oncology Group; PCP, primary care provider; SIREN, Social Interventions Research & Evaluation Network; UNC-AYA, University of North Carolina at Chapel Hill Lineberger Adolescent and Young Adult.

anticipating these challenges, asking about financial barriers and insurance access, and engaging AYAs with financial services and social work early in their disease course to try to prevent these issues. On a policy level, we encourage clinicians and oncology advocacy groups to continue to push for expanded insurance access and coverage for patients generally but especially for young people who are particularly vulnerable to gaps in insurance.

Comprehensive Considerations

A number of comprehensive guidelines on AYA cancer care have been published over the past 15 years spanning medical care, psycho-social care, advocacy and research efforts, and beyond.^{19-21,24-28} Although these guidelines vary in content and depth, there are overlapping domains that warrant the attention of any providers working with AYA patients. These key areas of overlap are summarized in Table 1. Additionally, a scoping review of these guidelines is currently underway; our team anticipates that it will be published over the next year.

Practical Considerations for Working with AYAs

AYA Care Delivery

We recognize that while guidelines for optimal AYA cancer care are increasingly available, adherence to these guidelines may be suboptimal in part because of a lack of concrete steps and resources for meeting these guidelines. In Table 2, we offer practical tips for addressing select domains of AYA care including both clinical and program development tips. On page 29 of this article, you will find a handout highlighting additional tips for direct patient interaction.

AYA Program Implementation

Across the country, we are seeing dedicated AYA cancer programs emerge. Importantly, you do not need to have a formalized AYA program or AYA-specific staff to integrate some of the tips above into your practice. However, there are resources available to guide these efforts if your center is interested in building out specialized care for

(Continued on page 36.)

Figure 1. AYA Needs Assessment & Service Bridge



You are being asked to complete this questionnaire as part of your care.
Please take a few minutes to answer the following questions to help us better address your needs.

| INFORMATION | I want more information about this concern | I have enough information about this concern | Not applicable |
|-----------------------------------------------------------------------------------|-------------------------------------------------------|----------------------------------------------|--------------------------|
| 1. My cancer diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. The short-term side effects of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. The long-term side effects of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. What will happen when treatments finishes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. My disease status | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. My test results | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. What to do if I have side effects from my treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. How my genetics may or may not have impacted my diagnosis and treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| CANCER CARE TEAM | I want my cancer care team to do a better job of this | My cancer care team is doing this already | Not applicable |
| 9. Respecting me as an individual, not just a cancer patient | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Offering to talk to me in private, without my family or friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Explaining what they were doing in a way I can understand | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Encouraging me to ask questions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Engaging me in decision-making about my treatment and respecting my decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Asking me about my treatment concerns | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| PHYSICAL HEALTH | I want more help with this concern | I have enough help with this concern | Not applicable |
| 15. Managing pain | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Managing my medications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Managing physical side effects of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Managing feeling tired/fatigued | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Managing loss of walking ability | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| EMOTIONAL HEALTH | I want more help with this concern | I have enough help with this concern | Not applicable |
| 20. Feeling anxious or scared | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. Feeling depressed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. Having what I need to cope with my diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. Worrying about my cancer spreading | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. Worrying about my cancer returning or getting another type of cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. Worrying about how my family is coping | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. Coping with changes in my dating or romantic life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. Coping with changes in my relationships with my family members | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. Coping with changes in my relationships with friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. Feeling a loss of independence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. Coping with changes in my physical ability | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. Coping with changes in my appearance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. Coping with not being able to do the same things as other people my age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. Managing the emotional side effects of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. Being able to make plans or think about the future | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Figure 1. AYA Needs Assessment & Service Bridge



(Continued from page 34.)

| SEXUAL & REPRODUCTIVE HEALTH | I want more information about this concern | I have enough information about this concern | Not applicable |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|----------------------------------------------|--------------------------|
| 35. My risk of infertility and my fertility preservation options | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. Treating infertility and other for having children in the future (i.e., sperm/egg freezing, artificial insemination, in vitro fertilization, surrogacy, adoption, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. Sexuality and intimacy during cancer treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 38. Sexual side effects of my treatment (eg, sexual dysfunction) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 39. The effects of treatment on long-term hormone changes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| HEALTH BEHAVIORS & WELLNESS | I want more information about this concern | I have enough information about this concern | Not applicable |
| 40. Nutrition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 41. Exercise or physical activity | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 42. Getting enough or better-quality sleep | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 43. Smoking or vaping during cancer treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 44. Drug or alcohol use during cancer treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 45. Spiritual support or resources | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 46. Alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| WORK & EDUCATION | I want more help with this concern | I have enough help with this concern | Not applicable |
| 47. Managing my school life while going through cancer treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 48. Managing my work life while going through cancer treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| PEER SUPPORT & PROGRAMMING | I want more help with this concern | I have enough help with this concern | Not applicable |
| 49. Being able to spend time with people my own age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 50. Being able to talk to people my own age who have been through a similar cancer treatment experience | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 51. Participating in social activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| FINANCES & EVERYDAY NEEDS | I want more help with this concern | I have enough help with this concern | Not applicable |
| 52. Paying my bills | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 53. Scholarship or loan repayment options | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 54. My health insurance (eg, access/eligibility, coverage, cost) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 55. Getting to and from my cancer care appointments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 56. Having children during my cancer care appointments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 57. Having stable housing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 58. Having access to food | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please indicate anything else you want help with, below:

(Continued from page 33.)

AYAs. Hospitals and health systems can seek support from [Teen Cancer America](#), a nonprofit foundation that provides seed funding and consultation services to hospitals around the country seeking to develop AYA cancer programs.²⁹ Additional resources are available that describe barriers to implementation of AYA programs, strategies to address these obstacles,³⁰ and practical lessons learned in program development.³¹

UNC Lineberger's Adolescent and Young Adult Cancer Program: Ongoing Efforts

Our program has grown over the past decade, and we have worked to find ways to better understand and support AYA patients and survivors. Below, we offer a few examples of program and research initiatives that our team has undertaken with the invaluable collaboration of partners and patients.

Survivorship Clinic Development

In recent years, we launched a transition and survivorship clinic to meet the diverse needs of AYA cancer survivors as they complete active therapy. This clinic was created in partnership with AYA survivors on our Young Adult Advisory Board to recognize the complex, multifaceted nature of AYA survivorship. Based on feedback from these patient advocate partners concerning potential medical trauma associated with the cancer center, our clinic was strategically located outside the cancer center to ensure that patients do not need to return to their treatment site. Survivorship care visits are jointly conducted with our AYA clinical social worker and an AYA medical provider (MD or NP) to ensure comprehensive needs assessment. Survivors are offered health education and referrals for services such as cancer rehabilitation, mental health care, or additional health screening and provided with a detailed survivorship care plan and AYA support resources.

AYA-Specific Spaces

Guidance on AYA care emphasizes a need for environments that are designed specifically with this population in mind.^{20,28} Spaces that promote interconnectedness and that give AYAs the opportunity to engage or be present with other AYA cancer patients are beneficial whenever possible.³² Over the years, patients have told us how isolated they feel as they sit in infusion spaces surrounded by significantly older adults. In partnership with the Be Loud! Sophie Foundation, First Citizens Bank, and Teen Cancer America, our Be Loud! Center for Young Adult Care opened in November 2023. This infusion space is designed specifically for young adult patients. As with our survivorship clinic, the conceptualization and creation of this space closely involved guidance from our Young Adult Advisory Board. The efforts of the board, the AYA team, and our partners resulted in the infusion center pictured on page 28. It incorporates design elements of nature, 2 (rather than 1) chairs for support people, moveable screens, and a café seating area where patients and caregivers can connect. Our team is excited about this space and the opportunities it offers for peer support, centralized programming, AYA-trained staff, and research. However, we also strongly believe that having a dedicated space is not a prerequisite to improving care for this population.

Similar goals can be achieved by using the tips shared above such as scheduling AYAs on the same clinic days to offer opportunities for organic connection.

Research Agenda

While we believe access to a space such as this will improve the overall patient treatment experience, we are testing this hypothesis in a current study. Our infusion space study aims to understand the impacts of the new infusion space on patient experience. We employed surveys and ethnographic interviews administered before treatment to gather patients' perspectives on their experiences in general adult infusion spaces prior to their use of the AYA-specific space. As the space becomes fully operational, we will conduct follow-up surveys and ethnographic interviews to allow for a comparison of patient experiences in these different spaces. Our hope is that this research will inform both future adaptations to the Be Loud! Center for Young Adult Care and the work of other health care settings who plan to implement similar changes to their built environments.

Within our institution, the monthly UNC AYA Research Working Group brings together research and clinical personnel across the UNC campus and beyond to share and receive feedback on works in progress and collaborate on prospective projects.

In addition to efforts focused specifically on our infusion space, our research agenda includes a formalized understanding of our program reach and impact more broadly. An ongoing UNC AYA Program Pilot Study uses electronic health record data linked with those from the North Carolina Cancer Registry to better characterize AYA patients in our cancer program, understand which patients engage with our team, describe the services that we are providing to AYAs, and evaluate the impact of the AYA Cancer Program on AYA-specific cancer outcomes. Ideally, the findings from this study will support other health care settings in developing their own AYA program by demonstrating the effectiveness of investment in this model of care.

As discussed above, the unique developmental position of AYAs means that the survival horizon of this population is lengthy. Most AYAs with cancer will be cured of their disease and survive well into adulthood. Thus, mitigating long-term effects of cancer care for this population is crucial. The UNC Childhood, Adolescent and Young Adult Cancer Cohort (UNC-CAYACC [NCT05096923]) is a first-


of-its-kind study that tracks patients from diagnosis through survivorship with a focus on describing the pro-aging effects of cancer and its treatments. The study aims to associate measures of aging and QOL with cancer, treatment, and psychosocial factors. We are hopeful that these and other research efforts will directly impact young people's cancer outcomes and QOL.

Transdisciplinary Collaboration

Much of our program's impact is driven by AYA-focused collaborations across teams and institutions. An early goal of the program was to engage in transdisciplinary education across the state; this goal was reached by the North Carolina AYA Oncology Symposium. This annual full-day symposium is a collaborative effort that also involves the Mountain Area Health Education Center and AYA programs at UNC Lineberger Cancer Center, Duke Cancer Institute, and Atrium Health Wake Forest Baptist. Increasingly, AYA champions in research and clinical care at other North Carolina cancer programs have contributed as presenters and symposium planners. Symposium agendas thus far have focused on sharing best practices in a variety of clinical care areas across the treatment trajectory and on exploring research and advocacy efforts in AYA oncology locally and nationwide. Within our institution, the monthly UNC AYA Research Working Group brings together research and clinical personnel across the UNC campus and beyond to share and receive feedback on works in progress and collaborate on prospective projects.

Our program has also formed various clinical initiatives. These include AYA disease group summits that bring together pediatric and adult providers to establish institutional best practices and enhance clinical trial enrollment. In addition, a clinical collaborative introduces palliative care and psychosocial services to high-need YA sarcoma patients at diagnosis. Our team also participates in a monthly AYA Molecular and Medical Tumor Board led by partners at Bon Secours Mercy Hospital in Greenville, South Carolina, which brings together AYA experts from community and academic centers across the southeast to promote high-quality, AYA-focused cancer care. These initiatives, among others, open avenues for engagement in AYA efforts that extend beyond the bounds of a formal AYA program.

Final Thoughts

We have been fortunate at UNC to have the institutional and community support to build a robust AYA oncology program. We recognize that the majority of AYAs receive cancer care in settings that may currently lack the buy-in or resources for a dedicated AYA team. The models of care that have been effective here may not be replicable, and they may not best serve the needs of different institutions and patient populations. However, we have learned from our partners and patients that any cancer program can improve care for this population through incremental adjustments and a commitment to exploring the unique needs of AYAs. The information we have provided here is a brief survey of a complex and ever-growing body of evidence that points to the importance of unique approaches to care for this population. We hope that the summaries, resources, and practice recommendations shared here can be helpful to other cancer centers as they refine their own unique approaches to the provision of high-quality, tailored AYA cancer care. 

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