

# Perspectives from a Community Oncologist



by Mark J. Mogul, MD

In this edition of *Oncology Issues*, Dr. Sender has written an excellent review of the issues faced by a historically underserved patient population—the young adult (ages 15 to 39) with cancer. He appropriately addresses many of the issues that differentiate this population from younger and older age patients with cancer. From the perspective of an oncologist practicing in a community cancer center, I would like to briefly discuss a few additional challenges concerning these cancer patients.

For example, the adolescent age range is one of the most difficult times to face life-threatening illness as it is a time of seeking independence. In addition to a cancer diagnosis, adolescents must also deal with all of the issues related to transitioning to adulthood. Social acceptance is of enormous importance in this age group as is a burgeoning sexuality—all of which can be greatly impacted by cancer and the therapy given to treat this disease.

Because social acceptability and physical appearance are often paramount, teenagers and young adults with can-

cer may not confide in adults about potentially embarrassing physical changes or symptoms. Complications of anti-cancer therapy, such as alopecia (loss of hair), hirsutism (excessive hairiness), weight gain, disfiguring surgeries, and more, add to an already difficult psychosocial time. School attendance for this age group is often mandatory, and yet many adolescents and young adults with cancer have to delay or stop their schooling altogether, which only complicates the situation.

These stressors are compounded by feelings of adolescent “invincibility,” all of which may lead to later diagnosis and consequently a poorer prognosis. Additionally, this age group tends to be highly transient, often moving between jobs or schools. These changes can complicate short- and long-term follow-up and preventative efforts.

Sadly, this age group has a very low participation in clinical trials—often less than 20 percent participation. Compare this number to the 90+ percent clinical trial participation we see with pediatric patients whose parents ensure study entry and strict compliance. Without close parental supervision—something adolescents and young adults are actively seeking to avoid—compliance with anti-cancer treatment regimens and follow-up care plans is a major concern.

## Who Should Treat Adolescents and Young Adults with Cancer?

Pediatric cancer programs are ideally suited to deal with this population in that there are social workers, child life therapists, and nurses experienced in the age-specific concerns of this group. These issues are enormously time consuming and personnel intensive. Thus, the low patient numbers and high staff-to-patient ratios of the pediatric cancer center are very advantageous. In fact, this area is perhaps the most significant difference between this population and other age groups. Medical oncology practices are likely to be unable to appropriately deal with issues stemming from the age-specific concerns of this group, so frequent consultation

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## Practical Suggestions to Enhance Early Detection of Cancer and Clinical Trial Participation in Older Adolescents and Young Adults

Archie Bleyer, MD, an early champion for the AYA population, developed this list in his superb review article on the topic.<sup>1</sup> Specifically, Bleyer suggested that clinicians and cancer patients:<sup>1</sup>

- Understand that transcending the adolescent and young adult passage requires the realizations that life is finite; that health is not an entitlement—it must be earned and maintained; and that disease strikes randomly, but regularly.
- Appreciate that cancer occurs in 1 in every 200 older adolescents and young adults and that everyone is at risk.
- Know that there are very few known causes of cancer during early adulthood and that “it just happens,” regardless of the health of the person.
- Be aware that young adults often deny symptoms, are too embarrassed to report them, or attribute them to psychosomatic manifestations.
- Know that in addition to performance or referral for conventional cancer screening tests as appropriate by age and gender beginning at age 20 years, on the occasion of a periodic health examination, the cancer-related check up should include examination for cancers of the thyroid, testicles, ovaries, lymph nodes, oral cavity, and skin, as well as health counseling about tobacco, sun exposure, diet and nutrition, risk factors, sexual practices, and environmental and occupational exposures.
- Ensure that beginning in their early 20s, women should be told about the benefits and limitations of breast self-examination and the importance of prompt reporting of any new breast symptoms to a health professional. For individuals who choose to perform breast self-examinations, a health professional should teach them how to do it and check their technique during a periodic health examination.
- Ensure that women undergo cervical cancer screening within 3 years after beginning to have vaginal intercourse, but no later than age 21 years. The Pap test performed in conjunction with the pelvic examination should be performed every year if it is a conventional test or every 2 years if it is a liquid-based test, until age 30 years, when after 3 normal test results the screening can be spaced out to every 2 to 3 years.
- Ensure that before beginning to have sexual intercourse, each female should be immunized against the human papillomavirus by receiving the new vaccine.
- Ensure that males have a testicular examination during every periodic health examination and should promptly report new scrotal symptoms or masses to a health professional.
- Understand that illness in older adolescents and young adults is easy to miss—even for skilled and experienced clinicians.
- Encourage and assist young adults to seek care at a comprehensive healthcare center.
- Realize that young adults are least likely to have adequate health insurance and that they should not allow themselves to “age out” of insurance.
- Convey that what is done at the time of the cancer diagnosis is important, and that the best outcome is determined by the initial evaluation and therapy. Optimal cancer management means doing it right from the start!
- Ensure that you offer young adults diagnosed with cancer information about clinical trials. If none are available on site, help them find centers that participate in clinical trials suitable for their age.
- Understand that the adolescent and young adult cancer patient enrolled on a clinical trial need understanding and support in order to best adhere to the trial’s requisites.
- Appreciate that individuals who become spouses or parents during the adolescent and young adult years are now responsible for the health of others.





and consideration of transfer to a pediatric and/or adolescent cancer program should be considered.

Where should patients between the ages of 15 to 39 be treated? In pediatric cancer centers that are better suited to address the psychosocial needs of this population but that are also filled with toddlers and often housed in Children's Hospitals? Or should this age group receive anti-cancer treatment in busy adult cancer programs filled with the elderly?

Interestingly, a study by Klein-Geltink and colleagues found that, in fact, most young adults are treated at adult practices.<sup>2</sup> This scenario is highly disadvantageous from a curative perspective considering most young adult cancers are curable with appropriate aggressive chemotherapy with growth factor support.

Adolescents can withstand the intensive therapy that much younger patients almost always receive. In other words, adolescents with cancer can tolerate dosing schedules that many oncologists (who treat mostly adults) would be uncomfortable prescribing, since most adult patients have significant co-morbidities that make these regimens intolerable if not life-threatening. Therefore, one could argue that for the typical pediatric diseases—ALL, AML, NHL, and hepatic and bone sarcomas—young adults should be on pediatric treatment trials; whereas young adults with more typical “adult” tumors—such as breast cancer, ovarian cancer, melanoma, and colon cancer—would be better served by adult oncology specialists.

To address this issue of specific age-appropriate therapies, a relatively recent—and exciting—development is the collaboration of large adult cooperative study groups, such as CALGB, SWOG, and ECOG, with the Children's Oncology Group (COG). As a result of this collaboration, many COG studies for the treatment of hematopoietic disorders include patients up to age 29; a number of sarcoma studies include patients up to age 50.

## Going Forward

Transition is another area of concern for adolescent and young adult cancer patients. These transitions include 1) pediatric and adolescent oncology patients transitioning from active therapy to long-term survivorship and then ultimately back to primary care physicians and 2) adolescent and young adult cancer patients transitioning from pediatric cancer programs to adult cancer programs. Since this hugely important area of enormous breadth and depth is beyond the scope of this article, I refer readers to what are widely considered the most comprehensive guidelines developed to date, *Establishing and Enhancing Services for Childhood Cancer Survivors: A Long-Term Follow-up Program Resource Guide*, available online at: <http://www.childrensoncologygroup.org/disc/le/pdf/LTFUResourceGuide.pdf>.

## The Adolescent and Young Adult Oncology Program Review Group

Funded by the Lance Armstrong Foundation in collaboration with the National Cancer Institute (NCI) this group's goal is to further study issues related to young adults with cancer. When putting this group together, five categories of recommendations were developed:<sup>3</sup>

1. Identify characteristics that distinguish the unique cancer burden in the older adolescent and young adult cancer patient.
2. Educate, train, and communicate findings to improve awareness, prevention, access, and quality cancer care to older adolescents and young adults.
3. Create tools to study the older adolescent and young adult cancer problem.
4. Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).
5. Strengthen and promote advocacy and support of the older adolescent and young adult cancer patient.

Much progress has been made in the last 10 years to address the specific medical and psychosocial needs of the adolescent and young adult with cancer. With continued interest, research, and collaboration between pediatric and medical oncologists, the survival rates and quality of life will surely continue to improve for this unique patient population. 📌

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## References

<sup>1</sup>Bleyer A. Young adult oncology: the patients and their survival challenges. *CA Cancer J Clin.* 2007;57:242-255.

<sup>2</sup>Klein-Geltink J, Shaw AK, Morrison HI, et al. Use of paediatric versus adult oncology treatment centres by adolescents 15-19 years old: the Canadian Childhood Cancer Surveillance and Control Program. *Eur J Cancer.* 2005;41:404-410.

<sup>3</sup>Adolescent and Young Adult Oncology Progress Review Group. *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer.* Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LiveStrong Young Adult Alliance; 2006.