

Survivorship Issues in Adolescent and Young Adult Oncology

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KEYWORDS

- AYA cancer survivorship • Onco-fertility • Risk-based care • Resiliency
- Proactive care • Health promotion

KEY POINTS

- Adolescent and young adult (AYA) cancer survivors face challenges distinct from those in either younger or older age categories.
- Types of cancer seen in the AYA population overlap with pediatric as well as older adult cancers, although outcomes are not the same.
- Fertility and reproductive health issues are especially important and relevant topics for AYA individuals with cancer.
- It is important to understand and anticipate the psychosocial issues that affect AYA individuals with cancer.
- Primary care provider interaction with AYA cancer survivors provides an opportune moment for health promotion.

INTRODUCTION

Of the estimated 15.5 million individuals with a history of cancer alive in the United States as of 2016 estimates, approximately 644,000 are adolescents and young adults (AYAs) living with cancer.¹ With advances in cancer treatment over the last quarter century, there has been an increasing recognition that AYAs face unique challenges when it comes to a cancer diagnosis. Differences exist worldwide in defining the upper and lower age limits of AYAs in the context of oncology clinical care and research²; in the United States, the AYA population is generally defined as ages 15 to 39. Despite

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the slight disparity in these age ranges, AYA oncology has evolved into a distinct area of study for a variety of reasons. Although bridging the life phases of late childhood and early adulthood, care for AYA individuals often involves transitions in care settings because these patients may begin treatment in a pediatric setting, but continued treatment and/or follow-up often occurs in adult care settings. In addition, the developmental phases that define the young cancer survivor are often marked by important life events, such as graduations, new careers, marriages, and starting families. These factors can impact cancer care all the way from diagnosis through long-term survivorship. Issues around access to care, treatment regimens, and availability of clinical trials, fertility concerns, psychosocial issues, and health behaviors as risk factors for future morbidity must be considered even long after active cancer treatments are completed. Although cancer survivorship is being recognized as a phase of the cancer continuum requiring attention to specific health and psychosocial matters, this takes on special meaning for a population of individuals who are simultaneously navigating changes in education, employment, insurance, family planning, relationships, and physical and social development.

Epidemiology

Cancer survival rates for AYAs have improved over the last 40 years; however, this trend has not kept pace with similar improvements in survival for either younger or older age groups.³⁻⁵ This lag in survival has not always been the case, and up until the last quarter of the twentieth century, the AYA population had higher survival rates than their younger or older counterparts.⁴ Recognition of this disparity in survival rates is part of the reason that AYA oncology came to exist as a focus of study and clinical care. The differences between AYA survival and those who were diagnosed at a younger age may be explained in part by the fact that AYAs are less likely to get treated in pediatric cancer settings where treatment regimens may be more aggressive and clinical trials more likely available,⁶⁻⁸ although there may also be differences in tumor biology.

Cancer is a significant health issue for AYAs, because it remains the leading cause of disease-related death in this age group.⁹ From 2002 to 2006, the relative 5-year survival rate for AYA cancers was estimated to be 82.5%.⁴ This rate is similar to 5-year survival rates noted in the under 15 age group (82.0%) and better than the over 40 age group (65.9%). There is some recent evidence suggesting the survival trends for adolescents may be catching up to the pediatric cancer population.¹⁰ AYA patients with cancer are less likely to be enrolled in clinical trials.¹¹

The types of cancer seen in the AYA population as a group are distinct⁹ because they overlap on each end of the spectrum with cancers seen in both the pediatric and the adult populations, although treatment outcomes may differ.^{4,12} In this age group for asymptomatic individuals with no previous cancer history and with no increased risk based on hereditary predisposition or family history, the only cancer screening recommended in general practice would be cervical cancer screening in women,¹³ such that AYA cancers would not typically be picked up by screening, which is one difference from cancers diagnosed in older populations. Even within the AYA cohort, the prevalence of certain cancers changes based on age of diagnosis such that in younger AYAs (15–24 years) there is a higher prevalence of “pediatric” cancers (leukemia, lymphoma), whereas by the time an individual ages into the older AYA cohort (ages 25–39), breast and colon cancer become more prevalent.⁹

Access to Care

It is known from studies with the childhood cancer survivor population (which includes adolescents) that most individuals treated at pediatric cancer centers are generally

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