

Identifying and Addressing the Needs of Adolescents and Young Adults With Cancer: Summary of an Institute of Medicine Workshop

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Key Words. Adolescent • Young adult • Cancer survivorship • Psychosocial aspects • Fertility preservation • Adverse effects

ABSTRACT

Cancer is the leading disease-related cause of death in adolescents and young adults (AYAs). This population faces many short- and long-term health and psychosocial consequences of cancer diagnosis and treatment, but many programs for cancer treatment, survivorship care, and psychosocial support do not focus on the specific needs of AYA cancer patients. Recognizing this health care disparity, the National Cancer Policy Forum of the Institute of Medicine convened a public workshop to examine the needs of AYA

patients with cancer. Workshop participants identified many gaps and challenges in the care of AYA cancer patients and discussed potential strategies to address these needs. Suggestions included ways to improve access to care for AYAs, to deliver cancer care that better meets the medical and psychosocial needs of AYAs, to develop educational programs for providers who care for AYA cancer survivors, and to enhance the evidence base for AYAs with cancer by facilitating participation in research. *The Oncologist* 2015;20:186–195

Implications for Practice: Each year nearly 70,000 adolescents and young adults (AYAs) between the ages of 15 and 39 are diagnosed with cancer, but there are numerous challenges in providing optimal care for this population. The Institute of Medicine's National Cancer Policy Forum convened a public workshop to examine the needs of this patient population. This article highlights potential action items to improve the care and outcomes for AYA patients with cancer.

INTRODUCTION

Cancer is the leading disease-related cause of death in adolescents and young adults (AYAs) [1]. Each year nearly 70,000 AYAs between the ages of 15 and 39 are diagnosed with cancer, approximately 6 times more than children under age 15. The prevalence of cancer histology varies by age [Fig. 1].

In 2006, the National Cancer Institute (NCI) convened a progress review group to address the research and cancer care needs of AYAs [2]. A plan outlining strategies for implementation of these recommendations was developed in 2007 [3]. Since then, progress has been made in bringing attention to the special needs of AYAs with cancer (e.g., the growth of the LIVESTRONG Young Adult Alliance, now a separate entity known as Critical Mass: The Young Adult Cancer Alliance, and research efforts such as the NCI AYA HOPE study

[4]). However, many challenges remain in providing optimal care for this population.

To facilitate discussion about gaps in care that AYA cancer patients confront and potential strategies and actions to improve the quality of their care, the National Cancer Policy Forum of the Institute of Medicine (IOM) convened a workshop titled *Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer* in July 2013 [5]. In September 2013, the NCI also held a workshop to review data and identify research gaps in AYA oncology. The two workshops were organized to be complementary; the NCI workshop had a primary focus on epidemiology (incidence, survival, mortality) of select AYA cancers, as well as evidence related to basic biology and clinical trial enrollment, whereas the IOM

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