

Primary Care of the Childhood Cancer Survivor



Anna Volerman, MD

KEYWORDS

- Childhood cancer survivor • Primary care • Treatment summary • Care plan

KEY POINTS

- As advanced therapies are developed, childhood cancer survivorship is increasing; however, these individuals face increased morbidity and mortality.
- Primary care providers play a fundamental role in the care of childhood cancer survivors and must monitor for late effects or recurrence and provide tailored preventive care.
- The individualized treatment summary and care plan provide crucial information for the long-term follow-up care of childhood cancer survivors.

CASE

A 25-year-old woman presents to your clinic to establish care. She has no acute concerns today. In reviewing her past medical history, she reports that she was diagnosed with leukemia at age 5. After receiving chemotherapy and radiation, she was told she was cured at age 10. She no longer sees an oncologist and was told to follow up regularly with a doctor. She asks if any testing is needed because of her cancer history.

INTRODUCTION

Childhood cancer affects 1 out of every 285 children younger than age 20 in the United States, with most common malignancies including leukemia, central nervous system (CNS) tumors, and lymphoma.¹ Because of advances in treatment, survival has steadily increased since the 1970s. Today more than 80% of children diagnosed with cancer are alive 5 years after diagnosis, thus considered cured.¹ With increasing survival rates, there are currently more than 375,000 survivors of childhood cancer in the United States with 70% of them age 20 or older.^{1,2}

As survival rates increase, childhood cancer survivors encounter short- and long-term effects of their cancer and treatments. They face an increased risk for

Department of Medicine and Pediatrics, University of Chicago, 5841 South Maryland Avenue, MC 3051, Chicago, IL 60637, USA

E-mail address: avolerman@uchicago.edu

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long-term morbidity and mortality in their adult years, compared with their siblings who serve as control subjects.³⁻⁵ A multicenter, longitudinal cohort study of children in the United States diagnosed with cancer between 1970 and 1986 demonstrated that 75% of childhood cancer survivors develop a chronic health condition by age 40.⁵ This condition is severe or life threatening in more than 40% of survivors.

Because of increased rates of morbidity and mortality from late effects, childhood cancer survivors require long-term follow-up care with a medical provider. With less than 20% of childhood cancer survivors receiving care at a cancer center or with an oncologist as adults, primary care providers play a vital role in the long-term care of childhood cancer survivors and thus need to have an understanding of survivorship care.⁶

HISTORY

In the primary care clinic, a patient's report of a history of childhood cancer should initiate the collection of specific information needed to appropriately manage the patient in the short and long term. Because of advances in cancer care for children, there is considerable variation in treatment; thus, details related to the patient's diagnosis, treatment, and complications are crucial for determining long-term follow-up care.

A treatment summary and survivorship plan should be developed by an oncologist at the end of a patient's cancer treatment. The treatment summary details the cancer diagnosis and treatment, including cancer type, location, and stage; chemotherapy names and cumulative doses; radiation types and cumulative doses; and surgical procedures. Individualized care plans also provide recommendations for the type and frequency of office visits, laboratory tests, and imaging, and surveillance areas and potential late effects. **Table 1** provides key information in the treatment summary and care plan.

Survivorship guidelines have been developed by the Children's Oncology Group, with abbreviated and comprehensive versions of care plan templates available at <http://www.survivorshipguidelines.org>.⁷ If the patient does not have a treatment summary or survivor plan, a treatment summary or available medical records should be requested to guide decision-making about long-term care.

MANAGEMENT GOALS

The primary care provider focuses on three aspects of care for childhood cancer survivors: (1) recurrence and subsequent malignancies, (2) late effects of treatment, and (3) preventive care. There are many models of care for survivors of pediatric cancers in academic and community settings. It is important for primary care providers to understand their role in coordination with the oncologist.

The management of childhood cancer survivors is informed by longitudinal studies that have followed survivors throughout adulthood. In North America, the primary group examining outcomes for this population is the Childhood Cancer Survivor Study.⁸ The study population includes an original cohort of more than 14,000 childhood cancer survivors who were diagnosed between 1970 and 1986 and treated at multiple centers in North America, along with approximately 4000 siblings as control subjects. Because of the advances made in therapy, the cohort is being expanded to include an additional 14,000 survivors diagnosed between 1987 and 1999 who are also being followed over time. Based on the data available with this cohort, more than 150 studies looking at specific late effects have been published.

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