



Childhood Cancer Survivorship and Long-Term Outcomes

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Keywords

- Childhood cancer • Cancer survivorship • Survivorship care plan
- Cancer long-term follow-up • Health outcomes • Late effects

Key points

- The survival rate for childhood cancer continues to increase, leading to an ever-growing population of childhood cancer survivors.
- Childhood cancer survivors are at risk for long-term late effects related to their cancer diagnosis and treatment and should receive long-term follow-up care.
- Each childhood cancer survivor should receive an individualized, evidence-based survivorship care plan based on their cancer diagnosis and treatment.

INTRODUCTION

Childhood cancer is a life-changing experience for the patients, families, and medical personnel involved in the care and treatment of the patient. Today, there are an estimated 15,780 children and adolescents (from birth to 19 years of age) diagnosed with cancer annually in the United States [1], with approximately 1 in 285 children being diagnosed with cancer before they reach the age of 20 [1]. The overall 5-year survival rate between 1975 to 1979 was approximately 62% for all childhood cancers [2]. With advancements in diagnostic modalities and risk-based treatments, those diagnosed are more likely to survive their cancer diagnoses. In 2014, the overall 5-year survival rate after being diagnosed with cancer was approaching 85% [2,3], with acute lymphocytic leukemia (ALL) and Hodgkin lymphoma having survival rates greater than 90% and 97%, respectively [2,3]. Childhood cancer survivors represent a unique and growing population that has complicated medical and psychosocial needs. In 2010, there were an estimated 379,112 survivors of childhood cancer [3],

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with approximately a quarter of these surviving more than 30 years since diagnosis [4]. This translates to 1 in 530 young adults (between 20 and 39 years of age) being a childhood cancer survivor [3], and 1 in 1000 total individuals being a childhood cancer survivor [2].

Although the survival rates of childhood cancer continue to increase, the use of cancer treatments at young ages can create complications that may not be seen until adulthood. These complications, typically referred to as “late effects” or “long-term effects,” are related to physical, psychological, or psychosocial outcomes that develop or continue 5 years from cancer diagnosis. Research related to these outcomes began many decades ago but strengthened with the establishment of the Childhood Cancer Survivorship Study (CCSS) in 1994. The CCSS was established with funding from the National Cancer Institute and is composed of 31 participating institutions with a cohort of 35,923 childhood cancer survivors (and more than 5000 siblings of survivors) from 1970 to 1999 [5].

CHRONIC MEDICAL PROBLEMS

Chief among the “late effects” are chronic medical problems that develop after being diagnosed and treated for cancer. The use of the Common Terminology Criteria for Adverse Events (version 4.0; National Cancer Institute) allows researchers to score both acute and chronic conditions in patients and survivors of cancer [6]. This system grades conditions on a scale from grade 1 to grade 5, as listed in Table 1. Research has shown that approximately two-thirds of childhood cancer survivors experience at least 1 chronic medical problem, with one-third having a medical problem considered severe, disabling, life-threatening, or fatal [7]. Additionally, the incidence of severe, disabling, life-threatening, or fatal health conditions was greater among cancer survivors (53.6%) compared with siblings (19.8%) by age 50 years [8]. After adjustment for age, sex, and race or ethnic group, a study by Oeffinger and colleagues [9] showed that survivors were 3.3 times as likely to have a chronic health condition of any grade compared with their siblings and 8.2 times as likely to have a health condition of grade 3 or 4 compared with their siblings. Groups with highest risk of having a health condition of grade 3 or 4 were survivors of bone tumors, central nervous system (CNS) tumors, and Hodgkin lymphoma. These studies reveal that the burden of morbidity carried by childhood cancer

Table 1
Grading symptom severity for Common Terminology Criteria for Adverse Events, version 4.0

Grade	Severity
1	Mild; asymptomatic or mild symptoms
2	Moderate
3	Severe or medically significant but not immediately life-threatening
4	Life-threatening or disability
5	Death

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