Follow-up of Childhood Cancer Survivors: The Role of the Primary Care Physician

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A 16-year-old boy with a history of leukemia at age 12 years complains of right hip pain of several months' duration. A 34-year-old woman who had Hodgkin lymphoma at age 14 years comes in for a routine physical. A 24-year-old woman who was treated for osteosarcoma of the left distal femur as a teenager presents with new-onset dyspnea. How would these patients' history of childhood cancer guide your approach?

Progress in the treatment of childhood cancer over the past several decades represents one of the greatest success stories in modern medicine (Figure). Cure rates now approach 80%.1 The population of long-term survivors of childhood cancer has steadily increased to more than 270,000 in the United States.2 However, their cure has come with a cost: most childhood cancer survivors experience health problems related to their chemotherapy, radiotherapy, or surgery.

In this article we provide an overview of the physical and psychological disorders that survivors of childhood cancer may encounter. On page 443, we present 3 cases that illustrate specific challenges often faced by survivors, and we outline monitoring strategies that can help you minimize the long-term adverse effects of cancer treatments.

LONG-TERM PHYSICAL SEQUELAE OF CANCER THERAPIES

Among children treated from the 1970s through the 1990s, a chronic disease will develop in about 75% by 40 years of age; a serious health problem will develop in over 40%; and many will have multiple conditions.3,4 (Examples of late effects of radiation therapy and chemotherapy are listed in the Table.) The risk of morbidity increases with age; many sequelae of cancer therapy do not become apparent until 10 or 20 years after treatment. Almost 1 in 2 long-term survivors will have significantly diminished health status.5 In addition, the risk of premature death secondary to another cancer or heart or lung disease is significantly increased.6 However, the risk of morbidity, diminished health status, and premature mortality can be reduced by longitudinal health care that incorporates targeted strategies for prevention, early detection, counseling, and education.
PSYCHOLOGICAL IMPACT OF CHILDHOOD CANCER AND ITS TREATMENT

Similar to the medical sequelae, the psychological impact of cancer during childhood depends in part on a number of disease-, treatment-, and demographic-related factors. Survivors of disease or therapy that involved the CNS are at the greatest risk for psychosocial morbidity, including learning disabilities, social and behavioral adjustment difficulties, and limited capacity for independent living in adulthood. Long-term survivors of bone tumors, sarcomas, and Hodgkin lymphoma show higher levels of cancer-related anxiety and fears than do other groups, possibly because these illnesses are usually diagnosed during adolescence and young adulthood—at a developmental stage of heightened awareness and sensitivity.

Although the prevalence of clinical psychiatric disease in survivors is similar to that in the general population, survivors are twice as likely to have symptoms of moderate depression, anxiety, or somatization. A small but significant subgroup of survivors experience distress many years following
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treatment completion, with 25% to 30% estimated to be at increased risk for long-term adjustment problems. Lower socioeconomic status, female sex, and lower educational attainment predict adaptation difficulties among long-term survivors—much as these factors do in the general population.

Subclinical distress experienced by long-term survivors includes symptoms of post-traumatic stress disorder (PTSD) and fear of cancer relapse. Parents of survivors also are at elevated risk for PTSD.

However, along with these potential psychological problems, survivors may enjoy positive psychological outcomes secondary to the cancer experience. For example, they may have an increased sense of mastery and resilience and a greater appreciation of life.

RISK-BASED, SURVIVOR-FOCUSED HEALTH CARE
The increased risks for premature mortality, serious morbidity, and diminished health status that childhood cancer survivors face do not plateau with aging. Many of the late sequelae will not become apparent until 20 or 30 years after the cancer was treated. However, the incidence and severity of many of these risks can be modified through prevention or early detection.

Systematic, individualized, lifelong follow-up: the ideal. The Institute of Medicine strongly recommends lifetime follow-up care for all pediatric cancer survivors. Optimally, care should be longitudinal, proactive, and anticipatory. It should take a systematic approach to screening, surveillance, and prevention, incorporating risks associated with the previous cancer, cancer therapy, genetic predispositions, lifestyle behaviors, and comorbid health conditions. Preventive strategies should include a healthy diet with adequate calcium intake, avoidance or cessation of tobacco use, and the recommended level of physical activity.

The Children's Oncology Group (COG) strongly encourages the staff at all treating institutions to prepare a cancer treatment summary for all pediatric cancer survivors. This summary should include 3 key components:

- The type of cancer, date of diagnosis, and date of completion of therapy.
- Description of the therapy, including radiation (field and dose), chemotherapy (with cumulative doses of key agents, such as anthracyclines), and surgical procedures.
- A listing of the primary long-term or late effects associated with the therapy and the corresponding screening recommendations.

Most children treated in the past decade are transitioned from their oncologist to a specialized long-term follow-up (LTFU) program at the treating institution. The staff for these programs develops a cancer treatment summary, provides targeted education and counseling for the child and the parents, and monitors for late effects. Ideally, the LTFU program's staff communicates with the survivor's primary care physician and sends him or her a copy of the treatment summary.

The "shared care" model. We advocate shared care between cancer centers and primary care practitioners. The way in which care is shared between these 2 parties depends on the patient's degree of risk. Survivors at high risk for late effects (eg, brain tumor and Hodgkin lymphoma survivors and those who received a bone marrow transplant) should be followed regularly by the cancer center while their non-cancerrelated health care needs are seen to by the primary care physician. Monitoring for physical and psychosocial late effects in survivors at moderate risk (eg, acute lymphoblastic leukemia and non-Hodgkin lymphoma survivors) can be provided by either the primary care practitioner or the cancer center, depending on patient and physician preferences and available resources. Survivors at low risk for late effects (eg, those treated with surgery alone or with low-risk chemotherapy) likely need little monitoring as long as they do not experience significant psychological distress, and they can be followed like persons in the general population who are at standard risk for future disease.

THE KEY ROLE OF PRIMARY CARE PRACTITIONERS
In the real world, shared care in accordance with these principles is not what generally occurs. Although the number of specialized LTFU programs based at a cancer center or a children's hospital has increased throughout North America, most adolescent and young adult survivors—for a variety
of reasons (eg, changes in insurance plans, moves, going off to college)—are not followed on a regular basis through such a program. Nor are most formally transitioned to a primary care clinician along with the appropriate information. Even when a transition has occurred, survivors often are seen by a primary care physician who did not know them at the time they were treated for their cancer—again because of insurance plan changes or mobility. However, a well-informed primary care practitioner who is alert to the special needs of such patients can play a critically important role in the delivery of timely and often lifesaving health care.

Recognizing that most childhood cancer survivors are followed by health care providers who are not familiar with their specific history and risks, the COG has developed (and continues to update) evidence-based screening recommendations for children, adolescents, and young adults who have received treatment for cancer. The COG recommendations are available at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org), along with more than 50 patient education modules. Work is also under way to create a Web-based, algorithm-driven program that a primary care clinician might use to print out an individualized screening plan for a survivor.

**References:**


**Links:**

[1] [http://www.physicianspractice.com/authors/tara-henderson-md-mph](http://www.physicianspractice.com/authors/tara-henderson-md-mph)
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