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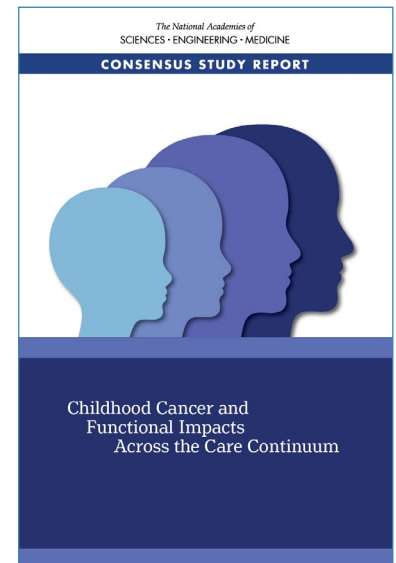
Childhood Cancer and Functional Impacts Across the Care Continuum

Since the late 1960s, the survival rate for children and adolescents diagnosed with cancer has steadily improved, with a corresponding decline in the cancer-specific death rate. While these improvements are encouraging, children who undergo cancer treatment often experience acute, chronic, and late adverse effects resulting from toxicities associated with treatment. In some cases, impairments resulting from cancer and its treatment are severe enough to qualify a child for monetary benefits through the U.S. Social Security Administration (SSA) Social Security Disability Insurance or Supplemental Security Income program. During fiscal year 2019, 2,725 children were awarded disability benefits for cancer claims.

To examine the current landscape of childhood cancer and disability, SSA asked the National Academies of Sciences, Engineering, and Medicine to convene an expert committee that would provide current information regarding the diagnosis, treatment, and prognosis of selected childhood cancers, including different types of malignant solid tumors, and the effect of those cancers and their treatment on children's health and functional capacity. The committee was also asked to address selected treatments currently being studied in clinical trials and to identify any non-financial limitations on the availability of treatments. The resulting report, *Childhood Cancer and Functional Impacts Across the Care Continuum*, presents the committee's findings and conclusions.

TIMEFRAMES OF INTEREST

High-quality cancer care spans a continuum from diagnosis through survivorship care or end-of-life care. The committee identified three timeframes of interest with respect to childhood cancers and SSA's disability determination processes. The first period covers the time from a child's cancer diagnosis through active treatment and an anticipated period of recovery from the acute effects of treatment, during which the child is unlikely to be able to participate in school or other activities. The second period covers the time following treatment and recovery from any acute effects of treatment, during which the child may continue to experience chronic effects of treatment and/or develop secondary late effects while still under the age of 18. The third period covers adulthood (age 18 and older), during which individuals may continue to experience chronic



effects or develop late effects of the treatment for their childhood cancer. The committee identified the period of transition from adolescence to young adulthood as particularly important because of the unique issues it presents with respect to cancer treatment, functional impacts, and disability adjudication.

SELECTION OF CANCER TYPES

The committee was asked to “provide an overview of the current status of the diagnosis, treatment, and prognosis of select childhood cancers, including different types of malignant solid tumors.” The committee’s selection of cancers for discussion in this report includes not only cancer types that would be captured within SSA’s “malignant solid tumor” category of child cancer listings (which appears to include all types of malignant solid tumors that are not otherwise specified in the listings), but also other types of solid tumors, including those of the central nervous system and hematologic malignancies that are specified in the cancer listings. The full list of conditions considered by the committee is shown in Box 1.

THE COMMITTEE’S OVERALL CONCLUSIONS

Based on its review of the relevant evidence, the committee formulated seven overall conclusions in six areas: (1) functional impacts of cancer and its treatment, (2) adverse effects of treatment, (3) occurrence and persistence of functional impairments, (4) transition from adolescence to adulthood, (5) participation in clinical trials, and (6) availability of pediatric cancer care providers and services. Below is an overview of the committee’s conclusions. For the full text of each conclusion, see the Overall Conclusions insert.

Functional Impacts of Cancer and Its Treatment

- During recent decades, the incidence of childhood cancers has increased at a modest rate, and the survival rates for many cancer types have improved. The result has been a growing number of survivors of childhood cancer who, starting from the time of diagnosis, are adversely affected by cumulative physical, cognitive, and psychosocial functional deficits, whose severity may increase over time, as a result of the cancer and its treatment.

Adverse Effects of Treatment

- Treatment of childhood cancers generally includes individual or combined use of different modalities (e.g., surgery, radiation, chemotherapy), each of which can precipitate a range of acute, chronic, and late-occurring impairments.

BOX 1. CONDITIONS ADDRESSED IN THE REPORT

Hematologic Malignancies and Histiocytoses

- Leukemias
- Lymphomas
- Histiocytoses

Central Nervous System (CNS) Tumors

- Glial tumors
- CNS germ cell tumors
- Choroid plexus tumors
- Embryonal tumors
- Ependymal tumors
- Pineal tumors
- Craniopharyngiomas

Non-CNS Solid Tumors

- Bone tumors
- Soft-tissue sarcomas
- Neuroblastomas
- Kidney tumors
- Liver tumors
- Germ cell tumors
- Retinoblastomas
- Other tumors: melanoma, thyroid cancers, colorectal carcinoma, adrenal cortical carcinoma

Occurrence and Persistence of Functional Impairments

- Functional deficits resulting from cancer and its treatment can improve over time, but many may persist or worsen, or even have onset at a later time, resulting in long-term functional impairments whose effects include restrictions on participation in the educational, vocational, and avocational arenas.
- Many survivors of childhood cancer do not achieve an age-equivalent degree of independence in one or more of several domains, which may include mobility; endurance; activities of daily living; and cognitive, social, or communicative skills.

Transition from Adolescence to Adulthood

- The transition from adolescence to adulthood is particularly challenging for adolescents diagnosed with cancer, as well as for survivors of childhood cancer.

Participation in Clinical Trials

- Clinical trials advance the standard of care for patients with childhood cancers and are critical to improving survival while also reducing toxicity, late effects, and subsequent neoplasms. Because of the small numbers of pediatric patients with cancer, trials would not generate meaningful results without a high rate of trial participation, which is generally considered to be the standard of care for childhood cancers.

Availability of Pediatric Cancer Care Providers and Services

- The availability of and access to pediatric cancer treatments, clinical trials, follow-up care, and rehabilitation and psychological services can be limited by geography and other factors, such as the availability of experts in pediatric cancer and survivorship care, as well as specialized technology.

CONCLUDING REMARKS

Despite improved survival in recent decades for many childhood cancers, the toxicities associated with cancer treatments remain high. As a result, a large proportion of survivors of childhood cancer are at significantly increased risk for serious, potentially disabling, and life-threatening acute, chronic, and late adverse effects of cancer and its therapy. Chronic health problems related to cancer treatment are common among survivors, increase in prevalence with the passage of time since diagnosis, and encompass a range of medical and psychosocial disorders and associated functional limitations.

Committee on Childhood Cancers and Disability

Paul A. Volberding (*Chair*)
University of California, San Francisco

Jason R. Fangusaro
Children's Healthcare of Atlanta and Emory University School of Medicine

Julia Glade Bender
Memorial Sloan Kettering Cancer Center

Andrea Hayes-Jordan
North Carolina Children's Hospital and University of North Carolina Health Care

Brandon Hayes-Lattin
Oregon Health & Science University

Tara Henderson
The University of Chicago

Pamela S. Hinds
Children's National Health System

Barbara L. Jones
The University of Texas at Austin

Jennifer I. Koop
Medical College of Wisconsin

Valerae O. Lewis
The University of Texas MD Anderson Cancer Center

Scott L. Pomeroy
Harvard Medical School and Boston Children's Hospital

David W. Pruitt
Cincinnati Children's Hospital Medical Center

Leslie L. Robison
St. Jude Children's Research Hospital

Nancy J. Tarbell
Harvard Medical School and Massachusetts General Hospital

Emily S. Tonorezos
National Cancer Institute

Brigitte Widemann
National Cancer Institute

Study Sponsors

U.S. Social Security Administration

Study Staff

Carol Mason Spicer
Study Director

Laura Aiuppa
Senior Program Officer

Tom Cartaxo
Associate Program Officer

Claire Saunders
Senior Program Assistant (*until April 2020*)

Torrie Brown
Senior Program Assistant (*from April 2020*)

Sharyl Nass
Senior Director, Board on Health Care Services

To read the full report, please visit
[nationalacademies.org/childhoodcancer](https://www.nationalacademies.org/childhoodcancer)

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