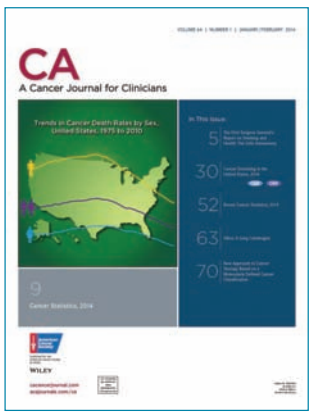
ACS Releases New Statistics Report on Cancers in Children and Adolescents

BY SARAH DIGIULIO

An estimated 15,780 new cases of cancer are predicted to occur in children and adolescents this year, along with 1,980 deaths from cancer in this age group.

A new report from the American Cancer Society estimates that among U.S. children and adolescents (age 19 and younger), 15,780 new cases of cancer will be diagnosed this year and 1,980 deaths from cancer will occur.



The article, now available online ahead of print in *CA: A Cancer Journal for Clinicians* (***DOI: 10.3322/caac.21219***), and also disseminated as a Special Section of the Society's "Cancer Facts & Figures 2014" (***cancer.org/statistics***), summarizes the most recent and comprehensive data on cancer incidence, mortality, and survival from the National Cancer Institute, the Centers for Disease Control and Prevention, and the North American Association of Central Cancer Registries.

"We've been frustrated with the aggregated numbers because they don't tell the full picture of where we're making progress and where we still have shortfalls," **Rebecca Kirch**, the ACS's Director of Quality of Life and Survivorship and Cancer Control and an editor of the report, explained in an interview.

"This report is intended as a roadmap to help prioritize where extra attention needs to be paid for cancers that haven't seen progress. It is essential to help us plan out and prioritize the research agenda and the advocacy agenda—so that we can develop better clinical outcomes, both in terms of cure rates and quality of life measures."

She noted that although ACS's annual report always includes data on childhood and adolescent cancer survivors, this is the first report in approximately a decade to include incidence and mortality rates broken down by cancer subtype, as well as information about these survivors' long-term and late effects from treatments.

"Progress in childhood cancer has been dramatic for some sites, but we cannot let that blind us from the fact that progress has been disappointingly slow for other sites, and that cancer remains the second leading cause of death in children," Otis W. Brawley, MD, the ACS's Chief Medical Officer, said in a news release.

"There is much work to be done to improve outcomes, to reduce side effects, and, we hope, to understand more about the molecular events that lead to childhood cancer in order to come up with ways to prevent or detect it early."

Report Details

Key statistics and findings from the report are the following:

- The annual incidence of cancer from birth to age 19 is 18.8 per 100,000 individuals;
- Approximately one in 285 children will be diagnosed with cancer before age 20;
- Today about one in 530 young adults between age 20 and 39 is a childhood cancer survivor;
- The most common cancers in children age 14 and younger are acute lymphocytic leukemia (26%), brain and central nervous system (CNS) cancers (21%), neuroblastoma (7%), and non-Hodgkin lymphoma (6%);
- The most common cancers in children age 15 to 19 are Hodgkin lymphoma (15%), thyroid carcinoma (11%), brain and CNS cancers (10%), and non-Hodgkin lymphoma (6%);
- Non-Hispanic white (white) and Hispanic children have the highest incidence rates for childhood and adolescent cancers;
- Although incidence rates are substantially lower for non-Hispanic African American children and adolescents than for whites and Hispanics, death rates are similar due to lower survival rates in African Americans;
- The overall incidence of pediatric cancer in the U.S. from 1975 to 2010 increased by an average of 0.6 percent per year, with incidence rates increasing specifically for four cancer types (acute lymphocytic leukemia, acute myeloid leukemia, non-Hodgkin lymphoma, and testicular germ cell tumors);
- Incidence rates decreased for Hodgkin lymphoma and remained stable for other cancers;

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ADH/ALH

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STUART J. SCHNITT, MD: "The similarities rather than the differences between ADH and ALH is one of the main take-home messages from the Mayo study. The time has come to find ways to better stratify risk and identify which women with atypical hyperplasia are at highest risk."

the findings regarding atypical hyperplasias," he said.

"We now recognize that both ADH and ALH are associated with a substantially increased risk of breast cancer, that both lesions appear to represent direct cancer precursors as well as markers of increased risk. I think the similarities rather than the differences between ADH and ALH is one of the main take-home messages from the Mayo study. The time has come to find ways to better stratify risk and identify which women with atypical hyperplasia are at highest risk."

And, although treatment and monitoring guidelines from the American Society of Clinical Oncology or the American Cancer Society would be helpful, the extant data are not sufficiently robust to permit consensus guideline recommendations, he said.

"Guidelines need to be evidence-based, and the available evidence from individual studies is based on very small numbers in some subgroups. Perhaps attempting to combine data from the Nurses' Health Study, the Vanderbilt Study, and the Mayo study would be a worthwhile undertaking and provide more statistical power than any of the studies alone."

"We showed that even though the two types of atypia look different histologically, they behave quite similarly in terms of later breast cancers in patients."

IOM Workshop Explores Challenges in Protecting Cancer Clinical Trial Participants

BY PEGGY EASTMAN

WASHINGTON—As cancer clinical trials have become larger and more complex and potentially sensitive patient genomic analyses more common, issues of protecting the privacy and rights of participants in those trials have become more challenging—issues that were explored at a scientific workshop here hosted by the National Cancer Policy Forum (NCPF) of the Institute of Medicine.

Federal regulations such as the Common Rule and the Health Insurance Portability and Accountability Act (HIPAA), which was recently modified, protect the privacy of individually identifiable health information. So do the rules of local institutional review boards (IRBs). But, in an era of massive computerized data collection and increased data sharing to advance scientific knowledge, thorny questions about privacy, rights, and informed consent have arisen. IOM workshop speakers examined many of those issues in detail, and the Institute expects to publish a written summary of their deliberations in about six months.

The current landscape for clinical trial investigators presents "a conundrum," said NCPF member Richard L. Schilsky, MD, Chief Medical Officer of the American Society of Clinical Oncology and former Chairman of Cancer and Leukemia Group B. Patients' clear right to privacy must be balanced against the vision of a continuous learning system in health care, embraced by both ASCO and the IOM, he noted, pointing out that "you can't do much learning" if new information observed in clinical trials cannot be disclosed.

"IRBs are extremely conservative, by and large. IRBs should become advocates for responsible research—not obstacles." He added, "I'm of the opinion that we spend a lot of time protecting people from things they don't want to be protected from."

INSTITUTE OF MEDICINE
National Cancer Policy Forum Workshop
Contemporary Issues in Human Subjects Protections

Need Reset

Another speaker, NCPF Vice Chair Patricia A. Ganz, MD, agreed on the need to balance patient protections with the need for a continuous learning environment in cancer clinical trials and cancer care: "Truly we do need a reset to improve the whole clinical research enterprise; I think we would want every patient potentially to be a research subject," said Ganz, Distinguished University Professor at the Fielding School of Public Health and Director of Cancer Prevention & Control at UCLA's Jonsson Comprehensive Cancer Center.

Ganz, who moderated a workshop session, chaired the IOM committee that last year published the sweeping 384-page "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis" report (*OT 10/10/13 issue*).

Today, protections for cancer patients are becoming more complicated in part because the line between clinical research and care is often blurred, said Angela Bradbury, MD, Co-chair of the IOM workshop planning committee and Assistant Professor in the Division of Hematology-Oncology at the University of Pennsylvania. "Research and clinical care are often intertwined in oncology," blurring

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> "The increase in biobanking and genomic analysis of patient samples has changed the landscape of clinical research, raising ethical questions about consent for future research and the protection of patient information."

CHILDHOOD & ADOLESCENT CANCERS

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- Overall five-year survival rates across all cancer sites increased from 63 percent between 1975 and 1979, to 83 percent between 2003 and 2009; and
- Death rates for all childhood and adolescent cancers combined steadily declined from 1975 to 2010 by an average of 2.1 percent per year (resulting in an overall decline in mortality of more than 50%).

The report includes additional information on risk factors, symptoms, treatment, and long-term and late effects for the most common cancers types in children and adolescents by site. Data in the report also show that some cancers still do remain deadly, such as diffuse intrinsic pontine glioma—for which the median survival time after diagnosis is less than one year, Kirch added. "There is no available treatment—nothing we can do."

Other Challenges

Other challenges detailed in the report are that only a small proportion of childhood cancers have known or preventable causes; and that early diagnosis of cancer in children is often difficult because of the similarity of symptoms to more common childhood diseases.

The clinical scene for children and adolescents with cancer looks very different than it does for adults—from diagnosis onward, Kirch said. "We don't have a lot of information yet about what's causing some of these cancers. And, we don't have screening tools for the types of cancers that kids get like we do for adults."

Another challenge: Even though advances in survival have been made for many types of cancers, many children treated for cancer still have high risks of long-term health issues associated with treatment (see *OT*'s coverage of unmet survivorship needs of childhood cancer survivors in the ***9/25/13 issue***).

In acute lymphocytic leukemia there has been progress in treatment and improvements in cure rates, but emerging literature shows that long-term side effects are still problematic for these patients, Kirch explained. "The toxicities of our treatment are a significant concern. We still need to make sure people's lives, across the life course, are pain- and symptom-free to the extent that is possible."

Remembering the 17%


Ann-Margaret Hedges

Asked to comment about the report for this article, **Leslie L. Robison, PhD,** Chair of the Department of Epidemiology and Cancer Control and Associate Director for Cancer Prevention and Control at St. Jude Children's Research Hospital, noted that the report highlights the improvements in survival rates for childhood and adolescent patients with cancer in the past four decades. "But, it is important to also focus on the work that remains to cure the other 17 percent of patients [the report notes the overall survival rate across all cancers for this patient population is 83%], and to understand the long-term consequences of treatment in the cured population who have 60 to 70 years of life ahead of them."

Another key take from the report, he added, is the need for prevention research: "This report emphasizes—after decades of research—how little we know about the causes of the cancers that occur in this young population."

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