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SETTING THE STANDARDS FOR LIFE AFTER CANCER

Expanding Medical Field Faces Challenges of Improving Quality of Life, Outcomes for Childhood and Adolescent Cancer Survivors

Many pediatric and adolescent cancers today have a 75 percent to 80 percent cure rate. But a sobering reality is that some of the long-term side effects of pediatric cancer treatment can be almost as debilitating as the cancer itself. » Aggressive treatments can have far-reaching and sometimes lifelong adverse impacts on young patients, which troubled Lillian R. Meacham, M.D., in 1991 when she began to study the late effects of cancer therapy. » Today, Dr. Meacham is the Kathelen V. Amos Children's Chair for Cancer Survivorship and Medical Director of the Cancer Survivor program at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta. Established in 2001 with Dr. Meacham as its sole physician, the program today boasts a staff of nine who work to help improve the quality of life for nearly 1,000 childhood and adolescent cancer survivors.

Centered on Solutions

The Aflac Cancer Center's cancer survivor team neither diagnoses nor treats cancer. Instead, it works with oncologists to diagnose late effects as early as possible. If survivors show adverse health conditions, the cancer survivor team facilitates getting those late effects of cancer therapy addressed by appropriate specialists.

"Cancer survivor healthcare is a new and growing field of medicine," said Ann C. Mertens, Ph.D., a childhood cancer epidemiologist who leads the cancer survivor program's research efforts. "People diagnosed with cancer are living longer, regardless of the age they were at diagnosis or their disease type. Consequently, treatment programs have evolved in the last five to 10 years to include a longer-term scope of research. We realized that we needed to start looking at the entire life span of the pediatric cancer survivor to fully understand the late effects of cancer therapy including infertility, cardiovascular disease and second malignancies.

"Our cancer therapeutic modalities, which resulted in leaps in cancer cure rates, were so aggressive that the process became, 'cure, but at what physical cost to the patient?' "

The team developed what it believes to be a vital tool to assist pediatricians and their young cancer survivors: the Survivor Healthcare Plan (SHP). Once children have been off cancer therapy for two years, they are referred to the Aflac Cancer Center survivor program, where their post-therapy health plans are created to guide them for the rest of their lives. The information culled from that tracking effort is recorded in the patient's SHP.

A three-part, individualized dossier, the SHP includes a summary of the survivor's cancer type and treatment history, a late effect risk profile and a recommended surveillance plan. To develop the risk profile and surveillance plan, the SHP follows "gold standard" Long-Term Follow-Up Guidelines from the Children's Oncology Group.

"Different cancers and different treatment modalities put the survivor at risk for different problems," Dr. Mertens said. "Depending on the scenario, there are late effects that a survivor, his family and his physicians need to know about. But it is also important for them to know what not to worry about." The risk profile helps clarify the survivor's situation.

The Far-Reaching Effects of Cancer Treatment on Young Patients

According to researchers at Children's, one in approximately 640 young adults in the United States today is a survivor of pediatric cancer. Two-thirds to three-quarters of those survivors suffer from some type of significant adverse health outcome.

A recent study published in the *New England Journal of Medicine* suggests that almost 75 percent of adult survivors of pediatric cancer have significant chronic health conditions such as osteoporosis, growth failure, delayed puberty, infertility, musculoskeletal problems and cognitive and psychosocial dysfunction. Forty percent have severe, disabling or life-threatening health conditions such as a second malignancy, congestive heart failure, pulmonary fibrosis and complications to the hepatic, renal and gastrointestinal organ systems.

Drs. Meacham and Mertens say their goals for the Cancer Survivor program are early detection and early treatment. While some late effects, such as hypothyroidism, can be eliminated through medical intervention, others can only be managed. But management can be very effective when late effects are detected early enough.

"If you have a learning disability as a result of cancer treatment, we cannot make it go away," Dr. Meacham said. "But our neuropsychologist can use testing to determine the educational methods that will optimize the survivor's learning experience. Then our neuropsychologist works with educators in that survivor's school to actually deliver that learning experience. By keeping late effects from progressing we can improve patients' quality of life and hopefully, in the big picture, even decrease healthcare costs through early intervention."

An Important Tool for Long-Term Follow-up Care

A family goes on vacation and their daughter, a pediatric cancer survivor, becomes ill. The parents contact a local pediatrician but, upon learning the girl is a cancer survivor, he refuses care because her cancer history makes the case "too complicated."

Lillian R. Meacham, M.D., Medical Director of the Cancer Survivor program at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta, said this frustrating and scary occurrence could have been made easier with a Survivor Healthcare Plan (SHP).

The SHP consists of three parts:

1] A treatment summary with the entire history of the survivor's cancer type, cancer treatment protocol and response. The summary also contains a current medical problem list and an up-to-date list of current medications.

2] A personalized risk profile based on that patient's type of cancer and specific cancer treatment modalities.

3] Recommended surveillance for each late effect for which the patient is at risk.

The risk profile and surveillance plan is based on nationally reviewed and approved "gold standard" recommendations for the long-term follow up of survivors of pediatric, adolescent and young adult cancers developed through the Children's Oncology Group (COG). These evidence-based guidelines list elements of the patient's history, physical examinations and laboratory and radiologic tests recommended, as well as the frequency by which those tests should be done to aid in the detection of specific late effects. The Aflac Cancer Center is a part of the COG network.

Dr. Meacham said her program is working to create an Internet-accessible network of the state's cancer survivors and their SHPs.

"Unfortunately, the abstraction of the medical record is labor-intensive and can take a skilled nurse one-to-two hours, depending on the complexity of the case," Dr. Meacham said. "Imagine how much easier diagnosis and treatment of any medical problem would be if survivors or their treating physicians could link into the network and get the most up-to-date SHP instantly. They could almost immediately put the presenting medical condition into perspective and get on with the business of determining appropriate treatment."

Both Drs. Meacham and Mertens believe early detection, treatment and long-term management of late effects can have positive results beyond the medical realm.

"If you change the definition of 'side effect,' perhaps we also are able to prevent some of the economic side effects of cancer treatment," Dr. Meacham said. "We cannot prevent neurocognitive problems associated with aggressive treatment of childhood and adolescent cancers. But maybe we can prevent joblessness and its economic implications by recommending and advocating for optimal learning environments, working to keep the survivor in school and

helping them acquire training for the best career possible."

Dr. Mertens agreed. "Our body of research showed us a significant number of pediatric and adolescent cancer survivors were going into special education programs. However, once they were in those programs their graduation rates were as high as the rest of the population and many survivors eventually went on to college. So, just a little acknowledgment up front that a child needs special attention can make all the difference."

Every Survivor Enrolled, Every Physician Aware

An SHP becomes increasingly important as patients get older, Meacham said. "It gets harder, for a variety of reasons, to track survivors as they age," she explained. "However, even with a lapse in care, an SHP provides a history and protocol for physicians and families at a glance. The SHP includes the recommendations to maintain optimal health in the survivor. Some refer to the SHP as "the roadmap to survivorship."

As cancer-survivor medicine is a new field of medicine, many oncologists, pediatricians and family practitioners are unaware of the field's significant progress. Drs. Meacham and Mertens are committed to increasing awareness of cancer-survivor medicine and its discoveries, and connecting Georgia's pediatric and adolescent cancer survivors with the resources they need to live quality lives.

"Our first goal is to get every survivor treated in the Aflac Cancer Center program into our survivorship program," Dr. Meacham said. "Our second goal, accomplished last year, was to develop the Georgia Pediatric Alliance for Cancer Survivors, or GPACS."

GPACS is funded by the Georgia Cancer Coalition, an independent non-profit organization whose goals are to reduce the burden of cancer in Georgia. One of the group's goals is to make sure that every pediatric cancer survivor in the state has an SHP.

The goal of the collaborative effort, she said, is to eventually ensure that all pediatric cancer survivors receive the recommended survivor care and ultimately reduce the severity of late effects of every childhood and adolescent cancer survivor in Georgia.

Tracking—and Changing—Outcomes

Drs. Mertens and Meacham are passionate about the Aflac Cancer Center survivor program and the impact it already has had on cancer treatment protocols. What they and other cancer survivor teams across the country gain in research and clinical experience is fed back into clinical trials to help develop cancer treatment strategies that optimize cure and minimize late effects.

"The data collected in long-term follow-up programs like ours cycles back into COG [Children's Ongology Group] cooperative efforts and clinical trials," Dr. Mertens said. "What we are doing affects people who are only now being diagnosed, so clinician scientists can modify protocols to keep their likelihood of survival high but keep their quality of life high as well. It is a nice circle."

Lillian R. Meacham, M.D., is the Kathelen V. Amos Children's Chair for Cancer Survivorship and Medical Director of the Cancer Survivor program at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta and Professor of Pediatrics at Emory University School of Medicine.

Ann C. Mertens, Ph.D., is Director of Clinical Research at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta and Professor of Pediatrics at Emory University School of Medicine.

Looking for Answers?

There is a growing body of information online for patients, families and treating physicians about the late effects of pediatric and adolescent cancer therapy.

www.childrensoncologygroup.org
A resource for pediatricians, this Web site offers physicians an array of resources including long-term follow-up guidelines, a directory of services for late effects diagnosis and treatment and more.

www.survivorshipguidelines.org
For physicians, this Web site offers the Children's Oncology Group's Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers.

www.curesearch.org
The Children's Oncology Group's Web site for parents, siblings, teachers and others affected by childhood cancer. This site includes information about different types of cancer and their treatments, educational resources and more.

www.canceradvocacy.org
The National Coalition for Cancer Survivorship is a survivor-led Web site that offers resources and acts as an advocate for cancer survivors and their families.

www.georgiacancer.org
The Georgia Cancer Coalition Web site offers information about clinical trials, treatment, access, research and education initiatives in the field of cancer research.

www.choa.org/cancersurvivorship
The Children's Healthcare of Atlanta Cancer Survivorship Web page offers educational information about long-term follow up after cancer diagnosis and treatment.

www.georgiacancer.org/pdfs/Cancer-Surv-Prog-Child-Tee.pdf
This page offers a directory of cancer survivorship programs and resources nationwide. Information includes the type of treatment, mission and contact information for each center listed.

www.nccn.org/patients/patient_gls.asp
The National Comprehensive Cancer Network/American Cancer Society (NCCN/ACS) Treatment Guidelines for Patients help people with cancer make informed decisions. Through a partnership with the American Cancer Society, the NCCN translates NCCN Clinical Practice Guidelines in Oncology™ for all of the major cancers and supportive care issues into easy-to-understand patient versions, available in both English and Spanish.