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# The Survivorship Care Gap:

## After Childhood and AYA Cancers, How to Keep Survivors in Follow-Up Care

BY SARAH DIGIULIO

Experts call the prevalence of undiagnosed disease in survivors of childhood cancers "concerning"—and say the challenges of keeping survivors of childhood, adolescent, and young adult cancers in long-term follow-up care throughout their lives are likely to blame. More on the solutions most likely to improve patient outcomes… *Page 8*


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## The Survivorship Care Gap:

# After Childhood and AYA Cancers, How to Keep Survivors in Follow-Up Care

**BY SARAH DIGIULIO**

Even though treatment summaries and survivorship care plans facilitate the communication of survivors' needs back to the primary care doctors, those providers still may not be the most appropriate to care for those patients because the required care for survivors can be vastly different than for the general population.

This next part of our series on the shortfalls in cancer survivorship care explains why the challenges of providing long-term follow-up care to patients diagnosed as children or as young adults can leave these survivors with disproportionately high unmet medical, psychosocial, and practical needs.

The first step to improving survivorship care for these patients, the experts say, is keeping survivors of young cancers in consistent follow-up care.

A recent study assessing the long-term health outcomes of 1,713 survivors of childhood cancers found that 98 percent had at least one chronic health condition (hundreds having been diagnosed through clinical screens for the study), and that by age 40, 80 percent of the survivors in the study had a life-threatening, serious, or disabling chronic condition (***JAMA* 2013;309:2371-2381**) (*see box on next page*).

"We knew that we would see late effects, but, the extent that we saw them and the extent of undiagnosed disease was concerning," the study's lead author Melissa Hudson, MD, Director of the Cancer Survivorship Division and Co-Leader of the Cancer Prevention & Control Program at St. Jude Children's Research Hospital, said in an interview.

"Our findings show that the survivors weren't in follow-up care and weren't pursuing the types of risk-based evaluations that would help detect and monitor disease."

Other recent data comparing adolescent and young adult (AYA) cancer survivors with their peers without a history of cancer has shown that the cancer survivors reported higher prevalences of: smoking (26% of AYA survivors vs. 18% of those without a history of cancer), obesity (31% vs. 27%); chronic conditions, including cardiovascular disease (14% vs. 7%); asthma (15% vs. 8%); disability (36% vs. 18%); poor mental health (20% vs. 10%); and poor physical health (24% vs. 10%) (***Cancer* 2012;118:4884-4891**).

These findings show that AYA survivors commonly reported unhealthy behaviors and significant barriers to health care access, the study's lead author, Eric W. Tai, MD, MS, Medical Officer with the Centers for Disease Control and Prevention's Comprehensive Cancer Control Branch, noted in an email.

### The Provider Issue

It's expected that survivors of childhood cancers will develop chronic health conditions earlier than patients without a history of cancer, Hudson said, discussing the findings in the recent *JAMA* paper. "But, the findings from this study made us aware of the lack of community health care providers' knowledge of the need to do risk-based screening evaluation or consider cancer history in the context of general health of those patients," she said.

Most community-based general practitioners and internists do not know to look for the late effects of cancer treatments in childhood cancer survivors decades after diagnosis and treatment, explained Lisa Diller, MD, Chief Medical Officer at the Dana-Farber/Boston Children's Cancer Center and Medical Director of the David B. Perini, Jr. Quality of Life Clinic there.

And as adults, patients will likely have no memory of what cancer treatment they received at age one, two, or three, she added. "So this now adult is left holding the reins of a very distant medical history that may have a significant impact on their quality of life and medical health in the future. That's the gap."

### Addressing *that* Gap

Even though treatment summaries and survivorship care plans facilitate the communication of survivors' needs back to the primary care doctors, primary care providers still may not be the most appropriate to care for those patients because the required care for survivors can be vastly different than for the general population, Diller said.

Specialized clinics such as Dana-Farber's David B. Perini, Jr. Quality of Life Clinic for childhood cancer survivors offer care for patients' late effects related to cardiovascular health, psychological difficulties, secondary tumor risks, cognitive and developmental challenges, fertility, physical fitness, and nutrition. The clinic's specialty-care physicians have developed what Diller termed a subspecialty specific to their area of expertise in childhood cancer survivors—"They have experience seeing more than one childhood cancer survivor in a year or a lifetime."

Survivors of childhood cancers (i.e., those diagnosed at age 21 or younger) who have been off treatment for at least two years are generally encouraged to be seen at the clinic in addition to primary care. Patients do not need to have been treated for their cancer at Dana-Farber to visit the clinic—many new patients come when they get married, start a family, or relocate.

MELISSA HUDSON, MD: "What's unique about pediatric cancer survivors is that providers wouldn't have on the radar to think about some of the health issues we see in this population because they would typically be occurring in older patients. So, providers may not ask the correct questions or put the pieces together to realize those issues might be related to the patient's cancer treatment."

Patients are encouraged to be seen at the clinic two, five, and 10 years post-treatment, or on an as-needed basis, but the majority of patients come annually, she said. "The goals of the clinic are to make sure that the complexity of a childhood survivor's situation is addressed medically and emotionally."

Patients can continue coming to the Perini clinic into adulthood only so long as they have a primary care provider, too, Diller noted. But, the challenge still is figuring out which patients can be transferred back to primary adult care: Though the clinic has an internal medicine physician as a consultant, "we're still pediatricians mostly."

### A Transition Clinic

Children's Mercy Hospital's Survive & Thrive Program offers follow-up care to meet childhood cancer survivors' medical and psychosocial needs after they finish cancer treatment—but to help those patients transition out of the pediatric setting into adult care, Children's Mercy Hospitals and Clinic is working with the University of Kansas Medical Center (affiliated with

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### Continuing Series

Earlier articles in this series covered other key discussions on survivorship care:

- Delivery models and care plans (***9/10/12 issue***),
- The nurse's role on the care team (***10/10/12 Nursing Hem/Onc Spotlight***),
- The persistent psychological effects survivors face (***11/10/12 issue***), and
- The overlooked late effects of breast cancer survivors (***4/10/13 issue***).

The award-winning series is also posted in this Collection on the *OT* website: **http://bit.ly/OT-SurvivorshipSeries-SarahDiGiulio**.

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the Midwest Cancer Alliance) on opening its Transitions Clinic later this year,

Wendy McClellan, RN, Nurse Coordinator of the Survive & Thrive Program for childhood cancer survivors at Children's Mercy Hospitals and Clinics in Kansas City, explained in an interview. The program brings together pediatric, adult primary care, and oncology providers to think through what this model of survivorship care should look like: "It creates a unique opportunity for survivorship programs to reach out, build relationships, and be resources to those doctors," she said.

"We need to teach survivors to be advocates for their own health."

Once patients age out of pediatric care, they will get referred to an internal medicine physician working with the Transition Clinic who is knowledgeable about the Children's Oncology Group survivor guidelines and will be familiar with these patients' medical needs. Patients will also be referred to the Transition Clinic Nurse Navigator, who will coordinate the patient's care by facilitating appointments, providing patient and family education, and assisting the physicians to develop individualized survivorship care plans.

"This model works because of the relationships we have built," McClellan said. "Our survivors, especially those with complex needs, will benefit from receiving care at a center with access to a variety of specialists. We know not all of our survivors need the same level of care, so reaching out to the community providers and offering education is one way we are trying to increase provider knowledge."

In addition, McClellan and colleagues are developing a web-based education series for providers on caring for adolescent and adult survivors of childhood cancer for the clinic, which begins with a face-to-face conference and covers cardiac care, secondary malignancy risk, fertility concerns, endocrine issues, and psychosocial issues. The goal of the series is to encourage networking among primary care providers and facilitate the relationships and support they need to provide long-term care for these survivors, she said.

## Research Spotlight: Health Outcomes of Adults Treated for Childhood Cancer

New data published in *JAMA* reported that among adult survivors of childhood cancer, the prevalence of adverse health outcomes was high, and a systematic risk-based medical assessment identified a substantial number of previously undiagnosed problems typically more prevalent in an older population (***JAMA* 2013;309:2371-2381**).

The data were collected from the St. Jude Lifetime Cohort Study of 1,713 patients age 18 or older, who had been diagnosed and treated for cancer between 1962 and 2001 and had survived at least 10 years past diagnosis. Participants underwent baseline history and physical exams, as well as a clinical evaluation recommended by the Children's Oncology Group guidelines for risk-based screening and surveillance.

The data showed that:

- Impaired pulmonary, cardiac, endocrine, and nervous system function made up the most prevalent dysfunction in the patients;
- Among survivors exposed to pulmonary toxic cancer treatments, 65.2% had abnormal pulmonary function (35.7% of that dysfunction was identified during the study);
- Among survivors exposed to cardiotoxic therapies, 56.4% had cardiac abnormalities (46.5% of those abnormalities were identified during the study);
- 62% of survivors developed endocrine disorders;
- Among survivors exposed to platinum agents or ear irradiation, hearing loss was detected in 62.1% of the population;
- Among survivors exposed to eye radiation, glucocorticoids, or busulfan, cataracts were detected in 20.6% of the population;
- Neurocognitive impairment was found in 48% of the survivors exposed to central nervous system treatment; and
- The prevalence of hematopoietic, hepatic, skeletal, and urinary tract dysfunction was less than 20% among the survivors.

Among all survivors, 98.2% of the participants had a chronic health condition and 67.6% had a serious, disabling, or life-threatening chronic health condition. Overall, 45 years after cancer treatment, 95.5% of the survivors had a chronic condition; and 93.5%, 35 years after treatment.

### The Knowledge Gap

Starting the Transitions Clinic was a result of survey findings that McClellan and her colleagues collected from 272 young adult survivors of childhood cancers who had been treated at Children's Mercy or at the University of Kansas Cancer Center, she said (***Oncology Nursing Forum* 2013;40:254-262**). Fifty-two percent of the survivors wanted more information about what late effects to expect, and 47 percent wanted more information about how to deal with those effects and what types of tests they needed to screen for those effects.

"There's a knowledge gap in what providers know. Primary care providers need to know what the long-term and late effects of treatment are for these survivors," McClellan noted. The key takeaway from the research, McClellan said, was that we need to better understand how we can better prepare our survivors for their transitions between care.

"We need to keep doing what we're doing in the survivorship clinics. Survivors need their treatment summaries. They need to better understand what some of the late effects can be. We need to teach survivors to be advocates for their own health."

WENDY MCCLELLAN, RN: "We need to better understand how we can better prepare our survivors for their transitions between care."

### Continued Access to Care

And for survivors of pediatric and AYA cancers, understanding treatments they had and their risks for late effects is important because most will transition between providers more than once after they leave oncology care—as insurance changes or as they relocate, Hudson explained. "We really worry about cancer survivors in that critical age of young adulthood who have aged out of their parents' policies and are trying to find a job that's going to, hopefully, offer insurance or health benefits."

Research among long-term survivors of adolescent and young adult cancers has shown that even when insured at levels comparable to those of similarly aged adults without cancer, the cancer survivors

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Research among long-term survivors of AYA cancers has shown that even when insured at levels comparable to those of similarly aged adults without cancer, the cancer survivors report substantial access and cost-related barriers to accessing and utilizing health care.

## iPad Extra—Hear More!

Listen on the iPad edition of this issue to hear **Ruth Rechis, PhD**, Vice President of Programs at the LIVESTRONG Foundation, elaborate on the unique challenges she has faced in the 21 years since she was diagnosed with Hodgkin lymphoma at age 15.

OT Broadcast News

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# Closer Look: AYA-Specific Survivorship Challenges

Unique for the survivors of adolescent and young adult cancers are the psychosocial issues that stem from the timing of when these patients were diagnosed, said Bradley Zebrack, PhD, MSW, MPH, Associate Professor of Social Work and a member of the University of Michigan Comprehensive Cancer Center's Cancer Surveillance and Outcomes Research Team. "The experience of life disruption is going to be different within the AYA population."

Zebrack, a survivor of a young adult cancer himself, has co-authored numerous papers reporting findings from the Adolescent and Young Adult Health Outcomes and Patient Experience (HOPE) study (which collected data from 523 patients diagnosed with cancer between the ages of 15 and 39), as well as papers reporting findings from the Childhood Cancer Survivor Study.

Survivors of childhood cancers and adolescent and young adult cancer survivors will all face the burden of having to deal with a history of cancer for the rest of their lives, Zebrack, said. To some extent, the long-term health risks are similar for these groups of patients (survivors of childhood cancers and AYA survivors)—fertility concerns, risk of recurrence, cognitive dysfunction, and other late effects—although those risks also depend in large part on the cancer itself.

But, for AYA survivors, education gets disrupted, work opportunities may be affected, and they may be missing out on life experiences such as dating, high school prom, or graduations, he said. All of those disruptions have life-long implications: "AYAs are still developing the psychological and emotional capabilities just to deal with life in general, let alone cancer."

## Unmet Practical Needs

In addition to psychosocial and emotional needs—for AYA survivors, it's also the practical needs that often go unmet, according to new data from the LIVESTRONG Survey for People Affected by Cancer. Ruth Rechis, PhD, Vice President of Programs at the LIVESTRONG Foundation, presented the following findings at a recent workshop hosted by the National Cancer Policy Forum of the Institute of Medicine along with LIVESTRONG.

Of 1,338 individuals diagnosed with cancer between the ages of 15 and 39:

- 39% of the survivors (or the survivors families) had to go into debt or borrow money because of their cancer;
- 7% indicated they had filed for bankruptcy because of their cancer;
- 83% worried about having to pay their medical bills;
- 84% had made a change to their work since their diagnosis; and
- 24% had taken steps to preserve their fertility before their cancer treatment.

For their medical needs—such as vision, lung functioning, cardiac effects, and others—survivors can be referred to medical specialists, Rechis explained. "But there may not be a psychologist or a social worker in town who has experience working with cancer survivors. So, sometimes it can be the practical and emotional needs that can be harder to get care for."

## Interventions

Most effective for these patients are the interventions that help patients adjust to the "new normal" of life after a cancer diagnosis, Rechis said. "If we can get kids back in to school as soon as they are medically able, they are much more likely to be better reintegrated into both their social and their school world, even 10 years later."

One program, she noted, is the Leukemia and Lymphoma Society's "Staying Connected"—a free, community-based education program for patients and their families, school personnel, and health care professionals that discusses the challenges AYA cancer survivors may face through their education, strategies to meet AYA survivors' short- and long-term education needs, and support resources schools and families can use.

BRADLEY ZEBRACK, PHD, MSW, MPH: "The experience of life disruption is going to be different within the AYA population."

Based on newer observational studies, interventions that provide peer support, such as camps or adventure therapy programs, have also been shown to be helpful for promoting self-esteem and meeting the other emotional and psychosocial needs of these survivors, Zebrack said.

Participating in those programs gives the young adults the opportunity to share common concerns about typical day-to-day life issues—like dating, body image, relationship, and school—they may otherwise be missing out on because of having had cancer.

One program he noted, First Descents (**firstdescents.org**), offers outdoor excursions for young survivors (such as kayaking and rock climbing trips), which according to the mission statement, empower survivors "to climb, paddle, and surf beyond their diagnosis, defy their cancer, reclaim their lives, and connect with others doing the same."

The testimonials that come from patients who have participated are very positive, Zebrack said. But even though there is wide availability of support programs and resources with the aim of connecting cancer survivors to share common needs and concerns, not all patients know those resources are available. "We could be doing a much better job of informing patients about the availability of community-based support programs."

## iPad Extra—Watch More!

Download the iPad edition of this issue to watch this short documentary about four young adults diagnosed with cancer. They discuss how the experience affected their education, careers, personal lives, and more. Produced by LIVESTRONG and Alpheus Media.

OT Video News

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report substantial access and cost-related barriers to accessing and utilizing health care (***Cancer* 2012;118:5964-5972**).

A study of 979 patients who self-reported a cancer diagnosis between age 15 and 34 (who were at least five years past diagnosis) found that those survivors reported forgoing care due to cost at higher levels than the 67,216 patients with no history of cancer who also participated in the study.

The percentages of uninsured participants were similar in both the patients with a history of cancer and the healthy controls (21% vs. 23%, respectively). But, 76 percent of uninsured survivors, compared with 48 percent of the uninsured controls, reported avoiding medical care in the past year because of costs. And, 21 percent of the insured survivors reported forgoing medical care because of cost compared with 11 percent of the healthy controls.

"The AYA cancer survivor population needs to makes sure they're getting to the doctor regularly, talking about their cancer history, and getting screened at an early age before any problems emerge," explained Anne C. Kirchhoff, PhD, MPH, Assistant Professor of Pediatrics and Investigator in the Cancer Control and Population Sciences Research Program at Huntsman Cancer Institute. But this data shows that patients have problems accessing care due to cost barriers—both insured survivors with a history of cancer and uninsured survivors with a history of cancer—at higher rates than their peers

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without a cancer history, she said. “That’s very striking.”

### Will the ACA Make a Difference?

Changes already in effect and more coming later this year and into next because of the Affordable Care Act should help improve all survivors’ access to care, Kirchhoff said. The legislation makes it possible for individuals under the age of 26 to be covered by their parents’ insurance policies. Preventive services including mammograms, colonoscopies, Papanicolaou tests, and pelvic exams must be offered at no cost to patients enrolled in the new insurance plans (seeing in-network providers) and to Medicare patients.

The health care exchanges that roll out this fall should help connect previously uninsured individuals to plans where they can get coverage. And, starting in 2014, health insurance plans cannot refuse to cover or increase charges for an individual with a pre-existing condition, which has been effective for children under age 19 since 2010.

ANNE C. KIRCHHOFF, PHD, MPH: “This population needs to makes sure they’re getting to the doctor regularly, talking about their cancer history, and getting screened at an early age before any problems emerge.”

But, another recent study that Kirchhoff co-authored suggests that cancer survivors are undereducated in terms of how the new legislation could improve their care—which means that additional strategies to increase patient knowledge about the ACA are needed, according to the paper, published online ahead of print in the *Journal of Oncology Practice* (***doi: 10.1200/JOP.2013.000919***).

Fifty-three adult survivors of childhood cancer from the Utah Cancer Surveillance Epidemiology and End Results Registry were interviewed about their familiarity with the provisions of the new law. Though 28 participants (57%) were aware of the insurance mandate, only seven (14%) were aware that the ACA allows dependents to stay on their parents insurance until age 26, and only six (12%) were aware that the ACA protected individuals with pre-existing conditions.

“For a lot of survivors after they reach the five-year mark, it’s easy to lose touch or stop following up with a provider about their cancer—even though 10, 20, and 30 years down the road these individuals are still facing higher risks for chronic disease,” said the lead author, Echo Warner, MPH, a research analyst in the Cancer Control and Population Sciences Department at Huntsman Cancer Institute.

ECHO WARNER, MPH: The findings suggest that cancer survivors are undereducated in terms of how the new legislation could improve their care—which means that additional strategies to increase patient knowledge about the ACA are needed.

CHARLES A. SKLAR, MD: “As survivors’ risks for serious medical problems actually increase, they’re much less likely to be getting focused survivorship care.”

“Improving health insurance coverage for pediatric cancer survivors can give them better access to follow-up care consistently throughout their lives.”

And for survivors of childhood, adolescent, and young adult cancers, it is that lack of access to consistent follow-up care throughout their lifespan that can lead to the biggest gaps in their survivorship care.

It is the lack of access to consistent follow-up care throughout survivors’ lifespan that can lead to the biggest gaps in their survivorship care.

The trajectory of life after cancer is longer for survivors of young cancers than for survivors who were diagnosed later in life, explained Charles A. Sklar, MD, Director of the Long-Term Follow-Up Program at Memorial Sloan-Kettering Cancer Center. “As survivors’ risks for serious medical problems actually increase, they’re much less likely to be getting focused survivorship care.”

Survivors of young cancers can be more susceptible to the late effects of treatment because those treatments may have affected their cognitive development, sexual development, growth, or reproductive capacity, he said. “They have all those things ahead of them. And, they carry the burden of the long-term effects of their treatment for many more years—so in many ways, they have more issues long-term than many of the adult cancer survivors.”