Meeting the Special Needs of Adult Survivors of Childhood Cancer

Most people diagnosed with pediatric cancer are living longer than ever, but many face unique challenges as adults.

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Pediatric cancer is usually survivable. But as survivors grow into adulthood, many will face unique challenges, from physical and psychosocial issues to navigating the world of adult health care.

The American Cancer Society (ACA) projects that nearly 10,000 children from birth through age 14 in the United States will be diagnosed with cancer this year. Leukemia, brain and central nervous system tumors, and lymphoma are the most common pediatric cancers. It's estimated there are more than half a million survivors of childhood cancer in the U.S. today.

Today, about 85% of children with cancer survive five years or more beyond their diagnosis, the ACA says – a vast improvement from 50 years ago, when the five-year survival rate was 58%. A 2020 study projected that children diagnosed with cancer in the 1990s who had reached the five-year survival milestone would live, on average, another 57.1 years.

As more survivors of pediatric cancer reach adulthood, middle age, and beyond, more attention has turned to helping these survivors cope with special chronic health conditions – known as late or long-term effects – related to their cancer, their treatment, or both. Some may even be diagnosed with another form of cancer. Also, many survivors face various psychosocial challenges in adulthood.

University of Colorado Anschutz Cancer Center member Linda Overholser, MD, MPH, a primary care physician, specializes in supporting cancer survivors, including those who have experienced pediatric cancer. She says that with a growing number of patients living longer after a cancer diagnosis, there is an urgent need for health counseling, more cancer screenings, and preventive health measures for cancer survivors, along with effective communication between primary care and oncology providers.

An associate professor in the CU Anschutz Division of General Internal Medicine, Overholser is medical director of the division's Thriving After Cancer Treatment is Complete (TACTIC) clinic at UCHealth University of Colorado Hospital (UCH). She also represents the cancer center on the National Comprehensive Cancer Network's Survivorship Guidelines Panel, which develops evidence-based recommendations for the care of cancer survivors.

We turned to Overholser to better understand the unique challenges facing survivors of pediatric cancer.

What are some physical health conditions that you see in pediatric cancer survivors who have reached adulthood?

At our survivorship clinic, our patients on average are in their late 20s, and they have completed cancer treatment at least two years earlier. But they may have or may be at risk for comorbid medical conditions that come on at earlier ages than their peers.

We often see patients with medical conditions that result from cancer treatment. There are long-term effects that start during treatment and can sometimes persist well into survivorship. And there are late effects that can first develop years or even decades later.

Secondary cancers – also called subsequent cancers – are a significant group of late effects. Sometimes people can even develop third or fourth cancers, and they can develop at younger ages than is usual for these cancers.

I don't want anyone to think that just because they got treated for cancer as a child that they're guaranteed to get a second late cancer. A lot depends on what treatment they received. Radiation therapy, for example, is one of the risk factors for the development of subsequent cancers. A classic example is women who received chest radiation for their cancer. They can be at significantly increased risk for breast cancer, so they require surveillance and monitoring at a much younger age than an individual who didn't get treatment for cancer as a child or adolescent.

Also, there are guidelines in place to monitor pediatric cancer survivors for earlier-onset colorectal cancer, breast cancer, skin cancer and thyroid cancers, which can occur as a late effect of radiation treatment as a child.

What about conditions other than cancer?

Heart disease is particularly relevant for this population. Sometimes, certain cancer treatments can place individuals at risk for cardiomyopathy – weakening of the heart muscle – or premature coronary vascular disease, valvular heart disease, or even strokes.

Cranial radiation treatment can affect the pituitary gland or the thyroid gland, causing some endocrine-related late and long-term effects.

Sometimes, pediatric cancer survivors come to our clinic who have been treated for growth hormone deficiency because of their cancer treatment and go on to develop hypogonadism or low pituitary function. There is evidence to show that certain subsets of individuals who received cranial radiation can be at increased risk of metabolic syndrome, obesity, diabetes, and high blood pressure.

Other examples of late or long-term effects from treatments include hearing loss or long-term neuropathy, affecting nerves in the hands and feet.

It’s important for providers to identify risk factors and monitor them more closely than you would in someone who didn’t have cancer as a child.

Other than physical health, what are some other key challenges that pediatric cancer survivors face?

Psychosocial challenges are such a big piece of this. I can’t emphasize that enough. When I first started in medicine, I don’t think I appreciated this aspect of cancer care. The tendency was to say, “Oh, you’ve completed your cancer treatment, so congratulations. Everything’s good now; go on and live your life.” But psychosocial issues can remain or evolve after cancer treatment is completed, and are so often underappreciated.

A lot of your identity is formed when you’re growing up and you’re deciding, “Who am I? What’s my personality? What are the things I’m into? What makes me me?” Sometimes, a pediatric cancer survivor has had to miss a lot of school because of their cancer treatments. And if you’re trying to navigate that as you’re dealing with cancer treatment, it can be difficult. There may be anxiety, depression, and PTSD.

At the same time, you may be navigating romantic relationships, or have sexual health concerns,

or be making decisions about starting a family. And along with that can come concerns about fitting in with your peers or being able to do the same things as your friends and colleagues. Because of these concerns, we have a clinical health psychologist who works with us in our clinic to help provide an assessment and to provide a more interdisciplinary approach to survivorship.

If you're a cancer survivor and you're entering into young adulthood, you may be just starting your career. You're usually very mobile – moving around the region or the country for work, school, or other reasons – and more prone to what we call getting lost in follow-up in the medical system. These challenges can create practical barriers for individuals to receive the ongoing care that is recommended.

Is it difficult for pediatric cancer survivors to make the transition to adult health care?

Typically, they first get treated at a children's hospital in a pediatric setting, which usually means they had parents or other caregivers to help them navigate the system and help make decisions. As they get older and enter adulthood, they transition out of a system they may have grown accustomed to, and they have to develop the skills to deal with the adult care system. There can be a lot of confusion and uncertainty.

In some instances, individuals may even develop PTSD, and there may be things about the medical system that can be triggering for individuals as adults. They may hear a provider talk about screening tests or blood work or something we noticed on an x-ray. That can be triggering, because when they had experiences like that before, it was life threatening.

And there's a financial piece to this. When they were children, when they got treated, it was probably going to be through their parents' insurance, if they had coverage. Now, once they age out of their parents' insurance, they have to make that transition as well. Now they're thinking, "What am I going to do for my health insurance? What if I have a high deductible plan? How am I going to pay for the evaluations that I may need?" If we're now recommending more intense or more frequent monitoring, that's a very practical concern, because it can come with additional cost concerns as well.

Tell me about your TACTIC clinic and how it serves pediatric cancer survivors.

We're a monthly clinic within the Internal Medicine Clinic at the UCHealth Anschutz Outpatient Pavilion. We started in 2008 as a transition clinic for adult survivors of childhood cancer.

Children's Hospital Colorado has a mechanism – the HOPE Survivorship Program – for following young patients who they've treated successfully for cancer and are now in the survivorship phase. The strategic thinking behind our clinic was how to support their transition to the adult care setting. Many of the referrals we have received have graduated from the HOPE program.

The clinic consists of a one-time consultative visit with a team, including myself as a general internist, a pediatric oncologist, and a clinical health psychologist. We also have an oncology nurse educator and coordinator.

We discuss their histories, what kind of treatment they've had, any comorbid conditions, any symptoms they're experiencing, significant family history and any psychosocial concerns. And then we think about what kind of care they're going to need moving forward and provide specific recommendations for long-term follow-up. For example, "We recommend that you have a yearly neck exam to check for thyroid issues," or, "You're eligible for early colon cancer screening." We confirm with individuals that they have a preferred source of ongoing primary care with whom they can implement ongoing screenings and surveillance.

It's a great group of people to work with and a great group of patients to be involved with. I'm blessed that I've had the opportunity to be involved with TACTIC.

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