Why Childhood Cancer Survivors Are at Higher Risk of Colorectal Cancer—and What Their Doctors Can Do About It

Childhood cancer survivors were diagnosed with subsequent colorectal cancer at younger ages than expected and had high mortality rates.

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Childhood cancer survivors can carry many burdens into their adult life, including an increased risk of developing colorectal cancer.

“We know that patients who received abdominal radiation or pelvic radiation, or certain types of chemotherapy, to treat their childhood cancer are at a higher risk of getting colorectal cancer,” says University of Colorado Cancer Center member Ajay Major, MD, MBA. “Being exposed to radiation therapy and chemotherapy at a young age can damage other DNA in your body, putting you at higher risk for second cancers later in life.”

It’s an issue that Major frequently sees in his patients — particularly those who were treated for the blood cancer Hodgkin lymphoma as children — but like many cancer doctors, he wasn’t certain of the exact risk of colorectal cancer for childhood cancer survivors or how early and often they should be screened.

Looking at the data

“There are some guidelines about what we should be doing in terms of other cancer screenings in patients who survive childhood cancers, but one of the areas where there’s not a lot of good quality data is colorectal cancer,” says Major, who treats patients at the UCHealth Blood Disorders and Cell Therapies Center and is an assistant professor of hematology in the CU Anschutz School of Medicine. “We know that childhood cancer survivors are at increased risk of colon cancer, but we don’t know what strategies need to happen moving forward to help them.”

For a study published in August in the Journal of the National Cancer Institute (JNCI), Major led a group of researchers in analyzing data from the Childhood Cancer Survivor Study, a retrospective cohort study of more than 25,000 long-term childhood cancer survivors at 31 institutions, to learn more about their rates of colorectal cancer.

“What we found, which was surprising to us, is that of the childhood cancer survivors who develop colon cancer later in life, 50% of them are diagnosed before the age of 40, and almost 20% before the age of 30,” he says. “They are presenting at a much younger age than we would normally expect.

“The other alarming statistic we found is that if childhood cancer survivors get diagnosed with subsequent colorectal cancer, their likelihood of dying is three times higher than other childhood cancer survivors who don’t have colorectal cancer, and two times higher than non-childhood cancer survivors who have colorectal cancer.”

Screenings and other recommendations

Current guidelines call for childhood cancer survivors to begin screening for colorectal cancer at age 35 — 10 years earlier than the general population — but Major says the data show that doctors need to be more diligent to make sure patients are actually getting screened when they are supposed to.

“One takeaway from this research is that we should be aggressive about making sure that childhood cancer survivors are meeting the standard screening guidelines for survivors,” he says. “Unfortunately, only 30% to 40% of high-risk childhood cancer survivors actually get those guideline-based colorectal screenings. We really need to work on that.”

Major says the study also spotlights the need for childhood cancer survivors to maintain access to their medical records, whether it’s papers they keep in a safe place or a digital health passport that follows them throughout their life.

“Many of them survived their cancer, they go off to college, get a job, and then sometime in their 20s, they get a primary care doc who says, ‘What do you mean, you were treated for leukemia when you were 3 years old?’” he says.

“If you were treated in a different health care system 20 years ago, the only way I’d be able to find out what kind of chemotherapy you got is to request paper records, which might be tricky,” Major says. “If we had an electronic passport, so that a primary care doc can say, ‘Oh, you’re 32; I need to get you a colonoscopy,’ that would really simplify things. That’s what we’re working toward.”

More research, better relationships

The JNCI article makes mention of two promising clinical trials, happening at other institutes, aimed at prevention and earlier diagnosis of colorectal cancer in childhood cancer survivors — the ASPIRES study, which focuses on utilizing electronic screening reminders to increase screening adherence, and I-SCRY, an international study aimed at better understanding the risk and contributing factors for colorectal cancer. Equally important as the research, Major says, is for oncologists and primary care doctors to develop long-term relationships with childhood cancer

survivors.

“It’s important that they have an established relationship with a primary care doctor and are being vigilant for symptoms,” he says. “Nearly half the patients in the study were diagnosed because they had symptoms first, before they got a colonoscopy. New gastrointestinal symptoms or bloody or black stools are all reasons for childhood cancer survivors to talk to their primary care docs about colorectal cancer screening.

“We also need to develop more multidisciplinary survivorship clinics so that we can capture these patients when they interact with the health care system and get them into the appropriate resources that they need.”

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