

For Uninsured People With Cancer, Securing Care Can Be Like Spinning a Roulette Wheel

Researchers at the American Cancer Society estimate that about 30,000 uninsured people are diagnosed with cancer each year.

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Eighteen months after April Adcox learned she had skin cancer, she finally returned to Charleston's Medical University of South Carolina last May to seek treatment.

By then, the reddish area along her hairline had grown from a 2-inch circle to cover nearly her entire forehead. It oozed fluid and was painful.

"Honestly, I was just waiting on it to kill me, because I thought that's what was going to have to happen," said the 41-year-old mother of three, who lives in Easley, South Carolina.

Adcox had first met with physicians at the academic medical center in late 2020, after a biopsy diagnosed basal cell carcinoma. The operation to remove the cancer would require several physicians, she was told, including a neurosurgeon, because of how close it was to her brain.

But Adcox was uninsured. She had lost her automotive plant job in the early days of the pandemic, and at the time of her diagnosis was equally panicked about the complex surgery and the prospect of a hefty bill. Instead of proceeding with treatment, she attempted to camouflage the expanding cancerous area for more than a year with hats and long bangs.

If Adcox had developed breast or cervical cancer, she likely would have qualified for insurance coverage under a federal law that extends Medicaid eligibility to lower-income patients diagnosed with those two malignancies. For female patients with other types of cancer, as well as pretty much all male patients, the options are scant, especially in [South Carolina and the 11 other states](#) that haven't yet implemented Medicaid expansion, according to cancer physicians and health policy experts who study access to care.

In the face of potentially daunting bills, uninsured adults sometimes delay care, which can result in worse survival outcomes, [research shows](#). The odds of patients getting insurance to help cover the cost of treatment play out a bit like a game of roulette, depending upon where they live and what

type of cancer they have.

“It is very random — that’s, I think, the heartbreaking part about it,” said Dr. Evan Graboyes, a head and neck surgeon and one of Adcox’s physicians. “Whether you live or die from cancer shouldn’t really be related to what state you live in.”

The Affordable Care Act gave states the option to expand Medicaid eligibility and cover more people. Shortly after the law passed, [just 2.6% of adults ages 18 to 64](#) with a new cancer diagnosis lacked insurance in Medicaid expansion states versus 7.8% in nonexpansion states, according to a study published in JAMA Oncology in 2018. Researchers at the American Cancer Society, who conducted the analysis, estimate that about 30,000 uninsured people are diagnosed with cancer each year.

But in all states, lower-income uninsured patients with breast or cervical cancer may have another route for coverage, even if they don’t otherwise qualify for Medicaid. Adults with cancer detected through the [National Breast and Cervical Cancer Early Detection Program](#) can enroll in Medicaid for the duration of their cancer treatment, as a result of advocacy efforts and federal legislation that started more than three decades ago.

In 2019, 43,549 breast and cervical cancer patients were enrolled, according to a [Government Accountability Office report](#) published in 2020.

“If you’re lucky to be diagnosed with breast or cervical cancer, you’re good,” said Dr. Fumiko Chino, a radiation oncologist at Memorial Sloan Kettering Cancer Center in New York City, who studies cancer treatment access and affordability. “But otherwise, you may have some significant obstacles.”

The total amount billed to the insurer during the year following a cancer diagnosis can be steep. For instance, costs in 2016 averaged [\\$168,730 for lung cancer and \\$137,663 for colorectal cancer](#), according to a 2022 study that calculated insurance claims for several common malignancies diagnosed in privately insured patients.

Since uninsured adults can struggle to afford preventive care, their cancer may not be identified until it’s more advanced, making it costlier for the patient and the health system, said Robin Yabroff, an author of the study in JAMA Oncology and a scientific vice president at the American Cancer Society.

Patients who can’t get financial assistance through a safety-net facility sometimes rack up medical debt, use credit cards, or launch fundraising efforts through online sites, Yabroff said. “We hear stories of people who mortgage their homes to pay for cancer treatment.”

Cancer patients can purchase insurance through the ACA health insurance marketplace. But they often must wait until the regular enrollment period near the end of the year, and those health plans don’t become effective until the start of the next calendar year.

That's because the federal law was designed to encourage people to sign up when they are healthy, which helps control costs, said MaryBeth Musumeci, an associate teaching professor of health policy and management at George Washington University in Washington, D.C. If a new diagnosis were a qualifying event for new coverage, she said, "then it would incentivize people to stay uninsured while they were healthy and they didn't think they really were going to need coverage."

Meanwhile, the on-ramp to Medicaid coverage for lower-income patients with breast and cervical cancer is a story of successful advocacy, dating to a [1990 law](#) that created the national breast and cervical screening program. Mammography started to be [widely recommended in the 1980s](#), and advocacy groups pushed to reach more underserved individuals, said Katie McMahon, a policy principal at the American Cancer Society Cancer Action Network, the organization's advocacy arm.

But research showed that some uninsured adults struggled to get care for those cancers detected through the screening program, McMahon said. A 2000 law [allowed states to extend Medicaid](#) to them, and by 2008 all 50 states and the District of Columbia had done so, according to the 2020 GAO report.

For other cancer patients, one of the remaining avenues to coverage, according to Chino, is to qualify for disability through the Social Security Administration, after which they can apply for Medicaid. The federal agency has a [lengthy list of criteria](#) for cancer patients. It also has a [Compassionate Allowances program](#), which offers faster reviews for patients with certain serious medical conditions, including advanced or aggressive cancers.

Although the rules vary, many patients don't qualify until their disease has spread or the cancer requires at least a year of intense treatment, Chino said. That presents an inherent catch-22 for people who are uninsured but have curable types of cancer, she said.

"To qualify for Medicaid, I have to wait for my cancer to be incurable," she said, "which is very depressing."

For example, the Compassionate Allowances program doesn't list basal cell carcinoma, and it covers head and neck cancer only if it has spread elsewhere in the body or can't be removed surgically.

Adcox said that before her 12-hour operation last June, her financial assistance application with the Medical University of South Carolina was still pending. Someone from the hospital, she recalled, estimated the bill would be \$176,000 and asked how much Adcox could put down. She cobbled together \$700 with the help of loved ones.

But she did qualify for financial assistance and hasn't received any bills, except from an outside lab services provider. "It's over," Adcox said. She's since undergone radiation and will have more reconstructive surgeries. But she's cancer-free. "It didn't kill me. It didn't kill me."

Still, not everyone finds a safety net.

Brian Becker, of El Paso, Texas, was uninsured and not working when he learned he had chronic myelogenous leukemia in summer 2021, said Stephanie Gamboa, his ex-wife and the mother of their young daughter. His cancer physician required an upfront payment, she said, and it took several months to borrow enough money.

He started chemotherapy the following year, and over months lost weight and became weaker, returning to the emergency room with infections and worsening kidney function, Gamboa said. The last time their daughter saw her father, “he couldn’t get out of bed. He was literally skin and bones,” Gamboa said.

Becker started the process to request disability benefits. The text he sent Gamboa, which she shared with KHN, stated that review of his application began in June 2022 and was expected to take six months.

The denial letter, dated Feb. 4, 2023, arrived more than a month after [Becker’s death in December](#) at age 32. It read in part: “Based on a review of your medical conditions, you do not qualify for benefits on this claim.”

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