

Axing the Affordable Care Act Means Young Adults with Cancer Lose Coverage

Exclusion from parents' insurance may lead to life-threatening lapses in chemo and radiation, study shows.

November 5, 2020 By Suzanne Leigh

A new study led by UCSF Benioff Children's Hospitals and the Children's Hospital of Philadelphia (CHOP) has quantified the impact of repealing the 2010 Affordable Care Act (ACA), which enables 18- to 25-year-olds to remain on their parents insurance plans, including cancer patients who require long-term medical follow-up.

In the study, which publishes in [JCO Oncology Practice](#) on Oct. 22, 2020, researchers found that patients with a pediatric cancer who were protected under the ACA's dependent coverage provision were more likely to remain on private insurance for longer durations compared to their older peers who turned 19 before the Act.

The study builds on previous UCSF research showing that children who are covered by private health insurance have better outcomes than those who are not, the authors said, and heightens concern that upcoming U.S. Supreme Court rulings could lead to the ACA being dismantled.

"The dependent coverage provision is important for all young adults and critical for survivors of pediatric cancer who require intensive treatment and long-term follow-up for many years after remission," said first author [Lena Winestone](#), MD, of the UCSF Division of Allergy, Immunology and BMT, and the [UCSF Helen Diller Family Comprehensive Cancer Center](#).

"Many of the patients followed in the study were on active cancer treatment," Winestone said. "We know that even brief disruptions in insurance have been associated with harmful health consequences. Strict adherence to chemotherapy regimens, for example, is essential for those patients with acute lymphoblastic leukemia," which is the most common type of pediatric cancer.

Protections to Young Adult Patients with Cancer

The researchers accessed administrative claims from a database covering a large population of geographically diverse, commercially insured enrollees. From this data, they tracked adults who

were born in 1982 or later, had been diagnosed with pediatric cancer between 2000 and 2015, and had private insurance prior to diagnosis. Most patients had leukemia (acute lymphoblastic and acute myeloid), lymphoma (Hodgkin and non-Hodgkin), or tumors of the brain or spine.

The researchers contrasted insurance status in four age groups, starting with the youngest group of 2,829 patients who turned 19 within two years following the ACA. They matched them by cancer type, diagnosis date, demographics, and treatment characteristics to a cohort who were two years older and thus unprotected by the Act. They found the average time to end of coverage was 26 months, versus 22 months for the older group, a 15 percent reduction in the risk of insurance loss. The younger patients also were more likely to retain coverage for four years – 37 percent versus 31 percent.

The researchers compared this data with 8,978 patients, who were also matched to each other by cancer type, diagnosis date and clinical characteristics. These two groups were ages 23 to 25 and 26 to 28 at the time of the ACA. They found that the average time from diagnosis to disenrollment was 20 months for both groups, even less than the 22 months for the second youngest group. This difference may be attributed to general changes in insurance coverage over time or the lesser impact of the Act on the second youngest age group, according to Winestone.

The ACA also includes expansion of Medicaid, as well as a ban on excluding patients with pre-existing conditions. These provisions are particularly important given the greater difficulty of obtaining coverage and higher rates of being denied coverage among cancer survivors, the authors noted.

While the data did not identify patients' insurance status following disenrollment or provide information about cancer grade/stage or other biologic features – all of which were noted as limitations for the study – Winestone said the findings add insight into the impact of the ACA on young adult cancer survivors, of whom three-quarters develop a chronic medical condition and more than one-third suffer from severe or life-threatening conditions.

“Cancer survivors experience ongoing loss of income and financial burden related to their medical issues,” she said. “At a time when unemployment is rising to unprecedented levels, due to the economic fallout of the pandemic, the Affordable Care Act provides a mechanism for patients to maintain access to their parents' health insurance.”

The earlier research, of which Winestone was senior author, indicates that [coverage by private insurance may boost survival in pediatric cancer patients](#). According to the 2019 study, 71 percent of patients with private insurance who had been diagnosed with bone and soft-tissue sarcomas were alive five years after diagnosis, compared to 61 percent of pediatric cancer patients with public insurance.

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