

Cancer-related follow-up care underutilized by young adult survivors of childhood cancer

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Treatments for childhood cancers have been increasingly successful, with a greater than 80 percent 5-year survival rate. However, there are numerous, lifelong risks that appear in years following treatment. Thus,

life-long surveillance is needed to prevent and reduce the severity of treatment-related late effects. Unfortunately, as survivors age, and their risk for late effects increases, engagement in survivorship care decreases.

A research team, led by Joel Milam, Ph.D., professor of epidemiology and biostatistics at the UCI Program in Public Health, is examining gaps and disparities in lifelong follow-up among survivors, including taking a closer look at long term follow-up care plans, specifically for underserved populations. The study shows that age and [ethnic background](#) is associated with inadequate follow-up care among young adult childhood [cancer](#) survivors.

Key findings showed that Hispanic (vs. non-Hispanic, White) and older survivors were significantly less likely to receive a recent follow-up care visit. The study's findings are published in *JNCI Cancer Spectrum*.

"Long-term follow up care is essential for managing the health of young cancer survivors and with growing numbers of cancer survivors, greater efforts are needed to increase healthcare engagement as survivors age, and to minimize ethnic disparities in access," Milam said. "We recommend stronger tactics for reaching survivors including patient and provider education, written treatment summaries and standardized plans for transitioning survivors from the pediatric to adult care settings."

To conduct their study, the research team formed a study cohort they coined Project Forward and invited over 2,000 childhood cancer survivors to participate who were sourced from a Los Angeles County cancer registry. They enrolled 1,166 participants in their cohort who had been diagnosed with any cancer at stage 2 or greater (except for brain and melanoma, which included stage 1 or greater) between 1996 and 2010 and were now in their mid-20s or mid-40s.

Self-report surveys were received from a range of socio-demographic backgrounds, about a variety of information, including age, race/ethnicity, [insurance coverage](#), indicators of healthcare engagement, ability to manage one's health, family influence and mental health.

"We found that if our participants had insurance, a receipt of a written treatment summary and discussions with their physician about long-term care needs, they were at greater odds of utilizing long-term follow-up care," Milam added. "Unfortunately, we also saw that older Hispanics and other ethnic groups were associated with lower odds of recent care putting them at risk for future [health](#) complications."

Another healthcare gap that the researchers highlighted was that more than half of the survivors had never received a written cancer treatment summary. Only 12% of the respondents reported that they received all the long-term care components that were assessed, indicating a need for improvements in delivering the full spectrum of survivorship care.

The research team is planning to continue their research and investigation of sociocultural factors (e.g. culturally-based beliefs about disease, language, understanding of insurance, neighborhood resources) and are already underway to address disparities and to develop more tailored support.

More information: Joel Milam et al, Project Forward: A Population-Based Cohort Among Young Adult Survivors of Childhood Cancers, *JNCI Cancer Spectrum* (2021). [DOI: 10.1093/jncics/pkab068](https://doi.org/10.1093/jncics/pkab068)

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