

Gaps in transition from pediatric to adult care for sickle cell disease associated with more hospital visits

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Credit: National Institutes of Health

Individuals living with sickle cell disease (SCD) who experience a delay

of more than six months in transitioning from pediatric to adult care are twice as likely to be hospitalized compared to those who transition in less than two months, according to a study published in [Blood Advances](#).

SCD is the most common inherited red blood cell disorder in the United States, affecting an estimated 100,000 people. According to the Centers for Disease Control and Prevention, SCD affects one out of every 365 Black or African American births and one out of every 16,300 Hispanic American births. Current guidelines recommend that patients with SCD transfer from [pediatric care](#) to adult care within six months.

"There are a lot of barriers to transition. Patients may not be comfortable with their new providers and not know where to go, but a lot of those challenges are addressable," said Kristen Howell, MPH, Ph.D., assistant professor at Texas A&M University. "These data show that if we can decrease that transfer gap, we'll hopefully see improved health care and outcomes."

Researchers examined 356 young adult patients with SCD who ended pediatric care between 2012 and 2018 at St. Jude Children's Research Hospital in Memphis and transferred to an adult SCD program at a partner institute. Approximately 88% of those studied transferred to adult health care within six months, with a median transfer time of 1.4 months. Those who transferred within six months had more outpatient pediatric and adult care visits compared to those who did not.

Young adults with transfer gaps of six months or longer were 1.89 times more likely to have had an inpatient hospital visit at two years of follow-up compared to those who transitioned in fewer than two months and had fewer outpatient visits in adult care. At eight years of follow-up, those who took more than six months to transition to adult care were

2.01 times more likely to have an inpatient visit.

"If these [young adults](#) are frequently visiting the hospital for acute reasons, it's a pretty clear indicator that they are not doing well," said Dr. Howell. "Having continuity of care can make a big difference, and that should be a goal for hospital systems."

Dr. Howell noted that while barriers to transition may vary, and could include gaps in [insurance coverage](#), gaps in how young adults understand their condition and medications, discomfort moving from a familiar facility to a new one, and potential institutional and practitioner bias. Per evidence-based guidelines, the researchers recommend beginning the process as early as age 12 and using care coordinators, or transition champions, to make the transition a smooth one.

There were a few limitations to the study, including the use of a small sample size of data from a single health care system. The researchers also excluded individuals who failed to transfer to adult care, and conclusions could not be drawn about the health care use of these patients. Further, St. Jude Children's Research Hospital has a well-established transition program that may not be generalizable to other programs.

The researchers hope to expand their study to additional institutions to see if there are similar findings with a different population. Jane Hankins, MD, MS, director of the St. Jude Global Hematology Program, is leading efforts to evaluate St. Jude's SCD transition program to identify which parts may be transferable to other institutions hoping to establish or improve their own transition programs.

More information: Kristen Howell et al, Gaps during Pediatric to Adult Care Transfer Escalate Acute Resource Utilization in Sickle Cell Disease, *Blood Advances* (2024). [DOI:](#)

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