

Insights

Enhanced Support During and After Transition from Pediatric to Adult Care Needed for People Living with Sickle Cell Disease

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Sickle Cell Disease (SCD) is the most common inherited red blood cell disorder in the United States. According to the [Centers for Disease Control and Prevention \(CDC\)](https://www.cdc.gov/sickle-cell-disease/), SCD affects about

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100,000 people in the U.S. More than 90% of people diagnosed with SCD are non-Hispanic Black or African American, and an estimated 3%–9% are Hispanic or Latino.

People living with SCD experience acute pain crises, dangerous infections, and other serious health problems that can damage every organ in the body. Improved therapies and screening programs have led to higher survival rates among people living with SCD. Yet, the complications of the condition still significantly increase the risk of [premature mortality](#), requiring providers who are knowledgeable and understanding during every stage of care. Unfortunately, there is a [national shortage of hematologists](#) who are adequately trained and interested in taking care of people living with SCD.

Mikeia Green, a fourth-year medical student at UC Davis living with SCD, has successfully transitioned from pediatric to adult healthcare. This time period is especially important as research has shown [increased mortality corresponding with the age of transition to adult centers of care](#). As an aspiring medical professional living with this inherited blood disorder, Green understands the impact of the physician shortage and hopes to one day use her experience and knowledge as both a patient and medical provider to advocate for other SCD patients.

NICHQ talked to Green about strategies that providers can use to improve the experience of care for young people living with SCD and enhance the process of transition from pediatric to adult care. The transition process involves the medical, psychosocial, and educational/vocational needs of adolescents and makes transitioning to work, community, and higher education much easier. Strategies for health professionals include educating pediatric patients early about the process of transitioning to adult care, streamlining systems for sharing medical records, and considering bias when making pain management recommendations. Read on for more about each strategy.

1. Educate Pediatric Patients Early

Adolescents living with SCD should be encouraged to begin asking questions of their care providers in preparation for the transition. The age to start this process will vary based on the individual and organizational policies. [The Got Transition® curriculum](#), a nationally recognized health care transition resource center, recommends ages 14-16. Clinics and community-based organizations (CBOs) should work with them to put together a plan that outlines pain management, obtain copies of medical records, understand how their care may change, and if they're leaving home (e.g., for school or work), help them establish a network of local providers who are equipped to manage the care needs of someone living with SCD.

Despite having the support of a local sickle cell disease organization and having an assigned social worker from her children's hospital to help with this process, Green still experienced challenges and noticed differences in the quality of care she received after leaving her pediatric care team.

"When I transitioned, it was a shock that people [physicians] did not seem to be as kind or as patient with the care I was receiving," Green said.

Young adults may no longer have parents and caregivers attend every appointment. However, they may still need support. [Evidence suggests](#) working with an advocate, such as a community health worker, is useful for improving health care and health outcomes for a variety of chronic conditions. In addition to providing informal counseling and social support, community health workers are equipped to advocate for individual and community needs and help ensure that people receive the needed medical and social services for which they are entitled.

2. Streamline Systems for Sharing Medical Records

Upon transitioning to the adult health system, people living with SCD often have long, documented medical histories. Ensuring that there is seamless sharing of patient medical records, including treatment and medication history, past hospitalizations, and other necessary information among all providers who may see the person is essential to provide exemplary care.

Using a cloud-based electronic health records (EHR) solution that assists in day-to-day healthcare interactions, includes patient medical records and history, and has a built out patient portal designed to enhance patient engagement and facilitate remote care is ideal.

Learn more about EHR use and other resources for providers and care professionals, in a [Compendium of Tools and Resources](#) created in conjunction with a comprehensive report to Congress detailing outcomes from the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program (SCDTDRCP).

3. Consider Your Biases When Making Pain Management Recommendations

The use of opioids for acute SCD pain management of crises has been effective. However, research suggests a variety of factors lead to [bias in prescribing the necessary medication](#). Due to a lack of standardization, care varies and can be misguided based on distrust of reported pain levels. Clinicians also [overestimate the prevalence of addiction](#) among patients with SCD. Contrary to this belief, most patients with SCD take less than 50 daily oral morphine milligram equivalent (OME). [The median OME dose was 6.1 in patients with SCD](#), with 71% of patients using less than 10 OME daily. [Estimates](#) show that 55-87% of patients use only 0-5 OME daily. While there is no OME level without risk, taking less than 5-10 OME daily does not greatly increase the risk of accidental overdose if taken as prescribed.

As a child living with SCD, Green said she felt more sympathy and patience from providers. However, after transitioning to adult care, she was surprised by how she was treated and didn't know about adult care policies. For example, Green was required to take a urine drug analysis and sign a pain contract.

"I was not prepared to have to sign an opioid pain contract," Green said. "I had no idea what that was or that I would only be getting opioids from one provider. I got way less pills per month than I did as a kid. Nobody ever questioned my opioid use as child, I would get an abundant supply of opioids and refills and that's something that stopped as soon as I became an adult."

Being more conscious of medication usage due to the reduction of her prescription was a challenge that Green said “really affected” her care and was a consistent area of worry and concern after transitioning to adult care- would she be able to control her pain adequately. Green was also required to receive a referral from a primary care physician to see a hematologist, which was another challenging experience.

In 2019, NICHQ interviewed patients, caregivers, and providers while [developing and implementing a comprehensive dissemination strategy to share the results from a Mid-South Clinical Data Research Network study](#) funded by the Patient-Centered Outcomes Research Institute (PCORI). Our findings showed that systemic and individual bias and racism contributed to poor patient/provider relationships, which in turn undermined solutions to appointment attendance problems. In 2020, the National Academies of Sciences, Engineering and Medicine produced: [Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action](#). Chapter 2 is dedicated to “Societal and Structural Contributors to Disease Impact” and discusses the historical impact of racism and implicit bias in and outside of the health care system. It’s important that providers acknowledge their implicit biases and work to set them aside and approach patients from a more informed perspective.

Download a collection of tools and resources that can be used to help facilitate conversations and guide your efforts in [improving relationships between providers and people living with SCD](#).