Insights

A Roadmap for Improving Sickle Cell Care in Underserved Areas

If you have sickle cell disease (SCD) and live in Indianapolis, you'll likely face little problem accessing care and support from trained specialists. But travel outside Indiana's capital city and many communities lack supports to help those with SCD manage their disease.

"Lake County has the greatest need for pediatric SCD care, but despite its large population of children with SCD, there are no pediatric hematologists there," says Emily Meier, MD, MSHS, Pediatric Hematologist and Director of Sickle Cell Research at the Indiana Hemophilia and Thrombosis Center (IHTC), and partner on the NICHQ-led Sickle Cell Disease Treatment Demonstration Program (SCDTDP).

Because of Lake County's proximity to Chicago, many families would often travel out of state for pediatric care. However, that's no longer an option for the 52.6 percent of Lake County residents on Medicaid; Illinois recently stopped accepting Indiana Medicaid payments.

This severely limits access to care for pediatric SCD care. The closest pediatric hematology practice is in South Bend, which is about a 90-minute drive from Lake County. The two treatment centers in Indianapolis are 3 hours away. This prevents children from being screened properly and accessing standardized forms of care.

Another growing challenge across the state is a lack of providers serving adults with SCD. As treatment advances have improved outcomes for children with SCD, there is a growing need for adult care providers that didn't exist a generation ago – largely because of improved survival of children with SCD. Because SCD requires specialized treatments and affects a small portion of the population, many providers do not feel equipped to provide the necessary support to patients. Without healthcare providers who understand the unique needs and treatment options for adults with SCD, says Brandon Hardesty, MD, IHTC Adult Hematologist, most care for adult patients with SCD is delivered episodically in emergency rooms and clinics.

Improving Access and Education

The Indiana SCDTDP team is addressing these two intertwined needs simultaneously by increasing pediatric access and empowering providers to support adult patients.

For the former, the primary strategies have been strengthening and forging partnerships to

create outreach clinics and provide SCD education to families. This has led to the creation of the Sickle Screening Assessment Follow-up and Education (SAFE) Program. After screening coordinated by the Indiana Department of Health and the newborn screening lab, Sickle SAFE provides home visits, assessments, specialized family education, follow-up from birth to age 5, and education for preschools and schools.

For the latter, new educational opportunities and resources are being created for healthcare providers. In some instances, this has meant being proactive in engaging the medical community. For example, in April 2016, Meier led a dinner and training session for providers in Lake County on behalf of IHTC where credits for continuing medical education were available. In other cases, direct requests for SCD education have brought the SCDTDP team to underserved areas.

“A pediatric hematologist and a director of the family medicine residency program in Fort Wayne in Allen County observed that they were following patients through pediatrics, but that there were no further services for adults,” says Hardesty. “Because we previously worked with them to manage local hemophilia patients, they reached out to the IHTC to lead some SCD training for family medicine physicians.”

What’s more, Meier, Hardesty and the rest of the SCDTDP team are connecting Indiana providers with SCD experts through a telementoring program. Sickle Treatment and Outcomes Research in the Midwest (STORM) TeleECHO program allows physicians and practitioners from Indiana, Michigan, Ohio, Illinois, Wisconsin and Michigan to collaborate on strategies for addressing SCD and educate each other on evidence-based approaches.

“These local, county, state and regional collaboration may go a long way toward improving SCD care throughout Indiana,” says NICHQ’s SCDTDP project lead Sabrina Selk. “As providers create new partnerships and work together on implementing strategies to better serve their communities, they can close the gaps many patients face in finding quality care.”