NICHQ National Institute for Children's Health Quality

Insights

Start Producing Better Sickle Cell Disease Outcomes in Your Community Today

Precious, a child born with sickle cell disease, spent days crying because she was suffering and no one knew why. Later, when Precious was diagnosed, her family would learn her tissues were deprived of oxygen, causing frequent pain episodes that required medication for relief.

Fatima Oyeku was left in hospital emergency rooms, waiting in excruciating pain, while staff questioned her need for pain medicine, because Fatima, like most individuals with sickle cell diseases, exhibited no physical signs of pain.

In Lake County Indiana, where the closest treatment center is a 3-hour drive, children suffer with limited access to the care their disease requires. Lake County is not an exception but rather an example of the challenges patients face in underserved areas.

Approximately 100,000 Americans live with sickle cell disease (SCD), and each day they must overcome barriers to a happy, healthy life. While once considered a pediatric condition, most people living with SCD now survive into adulthood; however, they face a lifelong battle with pain, infection and health problems that can potentially affect every organ in the body. For the past three years, NICHQ has led the Sickle Cell Disease Treatment Demonstration Program

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(SCDTDP), a national effort focused on three goals that can improve the lives of those living with sickle cell disease (SCD):

- Improve access to care by increasing the number of providers treating patients with SCD
- Increase the number of providers prescribing hydroxurea (HU), an FDA-approved therapy
- Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD

NICHQ's recently released congressional report details the findings of the SCDTDP and provides recommendations for future interventions. Packaged below are some successful strategies and examples from communities about how they accomplished each goal and improved care for patients with SCD.

Improve access to care:

Eliminating geographic barriers is possible and yields impressive results. Within the program's three-year period, patients receiving care for SCD through the initiative increased to nearly 11,000 patients, which resulted in a nearly 30% increase in those receiving care. The following strategies demonstrate successful efforts:

- **Use of satellite clinics and telementoring programs to connect patients and local providers to SCD staff and resources at larger medical systems.** For example, while Omaha, NE is home to the SCD Center for Excellence, patients in other parts of the state have limited benefit because of the long distance to specialty providers. In response, Nebraska set up a telementoring clinic between the Center and geographically distant providers.
- **Opening comprehensive care centers in high-need locations.** The MLK Jr. Outpatient Center for Adults opened in Los Angeles, CA, a high-need location, which serves more than 1,000 potential patients.
- **Leveraging community health workers and local SCD community-based organizations to provide patient outreach and follow-up care.** Community health workers and organizations are the bridge between SCD patients and quality care. Their importance was evidenced in the Northeast region, where community health workers connected adult SCD patients with a medical home that managed their disease progression and symptoms.

Increase the number of providers prescribing HU:

By leveraging the same strategies that improved access to care, states and communities can also dramatically increase HU use. Additional strategies to pursue include:

- **Increased provider education about the importance of HU:** Educational methods included publications and presentations in various forums, such as conferences, webinar series, and focused events.
- **Educational materials for patients, such as brochures:** These efforts are already creating a significant impact. For example, the Pacific region saw an overall 26 percent

increase of patients on HU after the release of the patient tools including brochures and roadmaps.

Increase the number of patients with SCD that are receiving care from providers knowledgeable about treating SCD:

Addressing gaps in provider knowledge can help ensure that SCD patients receive the right care at the right time. Knowledgeable providers help states and communities better support patients with more accessible and effective care options. Educational solutions include:

- **Maintaining regular regional and statewide inperson events:** carving out time for interactions between providers and SCD experts (clinical and nonclinical) can better facilitate learning and accountability. All regions provided different annual or bi-annual opportunities for in-person events, including learning sessions and trainings.
- **Providing regional telementoring programs:** All participating regions identified remote gathering sites and developed learning curriculafor providers based on the NHLBI guidelines for the treatment of SCD. Many also created websites that including information on webinars, updates , and upcoming events.
- **Capitalize on CME credit modules**: Providing CME credits at webinars and events can be a helpful resource for increasing provider engagement.

These results and strategies are a promise to SCD patients, a promise that their lives can improve, regardless of where they live and the barriers they face. Be sure to download the Compendium of Tools and Materials to find out more specifics about the promising practices and strategies used by participants in the demonstration program.