NICHQ National Institute for Children's Health Quality

**NICHQ Insights**

# Continuing Sickle Cell Disease Care During the COVID-19 Pandemic

Right now, close to 100,000 people in the United States, many of whom are children, spend days experiencing acute pain, dealing with costly and uncomfortable hospitalizations, and fighting off infections – all common side effects associated with sickle cell disease (SCD). Thanks to innovative advancements in care and treatment, most people living with SCD now survive into adulthood, but each day must overcome barriers to a healthy life.

> Sickle cell disease is a group of inherited red blood cell disorders in which the red blood cells become inflexible and sticky and are C-shaped, similar to the farm tool commonly called a "sickle." SCD is an inherited disease that most commonly affects people of African descent as well as people from South America, South Asia, Southern Europe and the Middle East. In the United States, the vast majority of those with SCD are African Americans. Learn more about SCD **here**.

The COVID-19 pandemic has created barriers that greatly impacted the health and well-being of all children and families across the country, but those living with SCD and other chronic conditions face even greater risks. Individuals with SCD have a weakened immune system and are more prone to heart and lung co-morbidities, increasing the likelihood of complications from COVID-19.

COVID-19 has also negatively impacted the ability of those living with SCD to get regular or emergency care for symptoms and treatment of the disease. Spring 2020 was especially concerning, as the systems of care that children, parents and adult patients depended on for acute care, such as hospitals, clinics and emergency department care were affected or changed to serve the surge of patients with COVID-19 complications. Even when patients were able to access care, the risk of exposure to COVID-19 and fear of getting infected may have prevented or deterred many from getting the care they needed.

As the pandemic progressed, daily routines and medical care for those with SCD continued to be altered. Sickle cell providers and advocates have remained nimble to ensure that access to comprehensive and consistent care is maintained for children and families with SCD throughout the pandemic and beyond. That's why NICHQ connected with providers from the southeast regional collaborative Education and Mentoring to Bring Access to Care (EMBRACE) Network to

gain insight on the strategies being implemented to help patients with SCD and families get the care they need. EMBRACE is now sharing lessons they learned this far to ensure that SCD patients continue to receive the best care and guidance during the crisis.

The EMBRACE Network is supported through the Sickle Cell Disease Treatment Demonstration Regional Collaborative Program, funded by the US Health Resources and Services Administration (HRSA); NICHQ serves as the National Coordinating Center for the project.

**Making patient safety a priority**

The health and safety of children and adults with SCD has always been the priority for providers. The pandemic has created an even greater need to help families and patients manage acute health episodes to avoid emergency room visits that may increase exposure to COVID-19.

Information about COVID-19 and its effect on those living with SCD has been constantly evolving, so it's crucial for SCD providers to work together to provide consistent messaging and share information and resources from trusted sources. EMBRACE worked with the Sickle Cell Disease Association of America (SCDAA) for information to share across the southeast region, which issued immediate guidance for patients and providers. This guidance, which remained consistent with guidelines from the Centers for Disease Control and Prevention (CDC), steered patients and families with SCD to quarantine at home and then shelter in place, along with forgoing non-emergency in-person visits such as routine check-ins or screening tests.

> COVID-19 guidance provided by the SCDAA for providers and SCD patients and caregivers was gathered from a variety of SCDTDRCP grantees, including experts from the EMBRACE team.

Above all, patients are advised to communicate with their provider before going to an emergency department or hospital if they were experiencing an acute episode. To reduce the need for emergency services, it has been more crucial than ever for providers to stress the importance of following a routine health maintenance plan for those with SCD, including taking all recommended disease modifying medications.

**Ensure access to both routine and acute care through telemedicine**

"Systems of medical care swiftly transitioned from in-person to telemedicine approaches," says Dr. Strouse, a Co-Principal Investigator for the EMBRACE network and Director of the adult SCD program at Duke University Hospital in Durham, N.C. "In the early days of the pandemic, this allowed providers to connect with patients and families with immediacy to share guidance about staying safe from exposure to coronavirus."

The rapid change to telemedicine in Spring 2020 meant that thousands of providers were able to meet the needs for routine touch points to monitor health and wellness as well as some acute care needs. With this ability to continue communication, family caregivers and patients could maintain contact with their SCD specialist who could triage their condition and closely monitor patient care needs. This was key in reducing urgent care use – important given the that visits to health care facilities would risk increased exposure.

“While there is still care that needs to happen in the physical clinic setting between patient and providers, telemedicine could become a part of routine care and monitoring,” says Dr. Osunkwo, Co-PI for the EMBRACE Network and the Director of the Sickle Cell Disease Enterprise at Atrium Health’s Levine Cancer Institute in Charlotte, N.C. “My no-show rate has drastically reduced, and I can now connect with patients more efficiently and co-manage them better through video visits."

**Creating new approaches to accessing to care**

The pandemic further pushed the need to develop innovative ways to create access to care in order to support patient health and wellness during and beyond the pandemic. The EMBRACE leadership team is leading research efforts in conjunction with their peers in the four other HRSA SCDTDRCP Regional Coordinating Centers (RCC) to study the impact of telemedicine on SCD care access and quality. Results are anticipated within the coming year, but in the meantime, the teams have made important observations:

- **Importance of reimbursement for telemedicine:** Public and private insurance waivers to reimburse telemedicine visits have been critical to the continuation of care and monitoring of treatment during the pandemic. This funding also allows critical lab screenings to be completed closer to a family’s home with follow-up telemedicine visits. Children and adults taking disease modifying therapies like hydroxyurea can continue to have their treatment carefully monitored and changed as needed to manage their health.
- **Identifying new pathways to effective care:** “We hope to find aspects of care that can be achieved effectively with more convenience to patients and families at less cost to both them and the system overall,” says Dr. Kanter, a co-principal investigator for EMBRACE, lifespan hematologist and Director of the University of Alabama Medical Center’s Adult Sickle Cell Clinic.

For now, though, the EMBRACE providers advise individuals with SCD to follow the guidance recommended by providers and the advocacy community and to reach out to them with any questions and concerns- they are there for them! While the future is uncertain, there have been strides made during this pandemic that may help improve access to care, especially for patients in remote geographic locations, distant from their specialty providers. As more is learned about long-term management of COVID-19, there will continue to be new ways to explore how best to keep children and families with SCD healthy and safe.

Looking for more information on ensuring a smooth transition to telemedicine? In this article, we're sharing seven strategies on conducting services virtually.