SICKLE CELL DISEASE TREATMENT DEMONSTRATION PROGRAM

CONGRESSIONAL REPORT
Executive Summary

OCTOBER 2014

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NICHQ
National Institute for Children's Health Quality

EXECUTIVE SUMMARY

"When you live with a chronic illness your life revolves around your health. Therefore interacting with the medical staff be it nurses or doctors is an important part of my wellbeing… It is amazing to be able to walk in the emergency room and know what the protocol is because you were a part of implementing it and to know that there are people out there that care and want us to be treated fairly and not suffer in pain… I can also speak my mind and share my ideas and I am being heard. Thank you so much for opening your heart and listening to us. We don't get a lot of people like [TDP team] that don't mind doing the hard work it takes to see changes being made for people who need help advocating for themselves and just want to be heard and listened to."

-SCDTDP patient partner

Sickle cell disease is a chronic condition disproportionately affecting our country's most vulnerable populations, many of whom experience fragmented, poor quality and often inhumane care.[1,2] Improving the quality of care and overall health of individuals living with sickle cell disease is a critical challenge that requires a multifaceted approach. Multiple stakeholders including patients, family members, primary care providers, specialists, community-based organizations, public health agencies and payers need to work collaboratively to ensure individuals with sickle cell disease have access to a holistic system of care that ultimately leads to optimal health.

From September 2010 to September 2014, NICHQ (the National Institute for Children's Health Quality) served as the National Coordinating Center for the federally-supported Sickle Cell Disease Treatment Demonstration Program (SCDTDP). This report documents the work that NICHQ and its partners, Boston Medical Center, the Sickle Cell Disease Association of America and Family Voices, led during that time. The SCDTDP is administered by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA). In its role as the National Coordinating Center, NICHQ sought to improve the quality of care that individuals with sickle cell disease receive across the lifespan at nine SCDTDP demonstration sites within the United States.

NICHQ and its partners launched this work by convening a panel of leading experts with experience in the clinical science and best practices of treating sickle cell disease, along with current grantee networks and representatives from previous rounds of the program. This panel worked to determine the highest-leverage, evidence-based changes that would result in improving care for this population. The recommendations that came out of this meeting guided the work of the SCDTDP grantees as did ongoing support from project faculty and the Oversight Steering Committee, a collection of individuals who brought unique knowledge, skills, and connections to the project.

Over the four-year project, nine different SCDTDP grantees across the country worked together in the Hemoglobinopathy Learning Collaborative, coming together both virtually and in person to compare data, share results, discuss challenges and solutions, and refine their skills in the methods of improvement science. Since the goals of the Sickle Cell Disease Newborn Screening Program (SCDNBSP)—another HRSA program addressing care for individuals with sick-

le cell disease—were closely aligned with those of the SCDTDP, grantees from the SCDNBSP joined grantees from the SCDTDP in the Hemoglobinopathy Learning Collaborative. Grantees from both programs worked to improve care in many of the same areas, collaborated extensively, used many of the same methods, and collected data on many of the same quality measures. Outcomes from the SCDNBSP sites have been included in this report to Congress where relevant.

Participating grantees used quality improvement methodology to improve care along five core dimensions:

1. Ensuring timely, effective, and respectful care in the emergency department

Excruciating pain crises are a common experience for those with sickle cell disease, and treatment for these pain crises in the emergency department is all too often slow, ineffective, and insensitive. Timely, appropriate and respectful pain management in the emergency department can relieve pain, reduce hospitalizations, and reduce the development of chronic pain symptoms. *Substantial progress was made toward decreasing the time that patients with sickle cell disease must wait to have their pain assessed (69 percent improvement) and decreasing the time between triage and the receipt of first dose of pain medication (29 percent decrease).*

2. Ensuring that care is coordinated across primary and specialty providers and services

Care for individuals with sickle cell disease is often fragmented and uncoordinated, leading to missed appointments, poor medication adherence, and inconsistent provision of recommended components of care such as screenings and immunizations. Well-coordinated care in the context of a medical home, including support for chronic illness self-management, can lead to fewer and less severe complications of sickle cell disease. *The coordination of primary and specialty care was improved in many areas, including the percentage of patients who were evaluated by a hematologist within the past year (increase of 135 percent) and the percentage of patients whose care plans were reviewed during their visit (increase of 170 percent).*

3. Improving the follow-up care and counseling for families whose newborns have screened positive for sickle cell disease and trait, and offering screening and counseling to immigrant and adult populations

Early identification and proper follow up care and counseling is important for individuals with sickle cell disease and sickle cell trait, but newborn screening systems vary greatly state to state and infants with a positive screen can be lost to follow up. Strong screening and follow-up systems have many long-term benefits, including reduced mortality of children with sickle cell disease (from the use of preventative medication) and the ability of those with sickle cell disease and trait to make informed reproductive choices (from genetic counseling). *Grantee networks worked with providers, genetic counselors, families, and state departments of public health to ensure that families received notification of positive screens and that follow up care was provided. They also reached out to immigrant populations and provided free testing and counseling at a variety of community events.*

4. Improving the support and education that young adults receive as they transition from pediatric to adult care

Many individuals with sickle cell disease do not experience a smooth transition from pediatric to adult care. They may not have adequate knowledge or enough practice managing their medications and appointments, and it may be difficult for them to find appropriate adult providers and health care coverage. As a result, mortality rates can be elevated for young adults making this transition. A successful transition program can prepare young adults for this challenging time and help them avoid unnecessary complications of the disease. *Grantee networks developed and tested many tools and resources to use with transitioning young adults. Some grantees saw improvement in process-level measures such as the percentage of adolescents given a transition readiness tool, but overall the program did not see improvement in the outcome measure, the percentage of patients with a written transition plan.*

5. Optimizing the use of hydroxyurea, the only therapy for sickle cell disease approved by the Food and Drug Administration

For eligible patients, hydroxyurea can have a tremendous impact on their quality of life by reducing complications of sickle cell disease. However, use of hydroxyurea varies a great deal by provider and by institution, and poor understanding of the drug and its side effects limits its use. *Several grantee networks worked on practice guidelines and educational materials about hydroxyurea.*

Grantees also developed and tested many tools and resources to use with patients with sickle cell disease and sickle cell trait and their families, and conducted an array of educational and community events both for and with these individuals and their families. Finally, the program has led grantees to create and strengthen networks of clinical care sites, federally qualified health centers, and community-based organizations.

RECOMMENDATIONS

Ten years ago, the Sickle Cell Treatment Act provided funding for projects to demonstrate ways to improve care and outcomes for individuals affected by sickle cell disease. For the past four years, NICHQ and its partners supported these grantees using collaborative learning and quality improvement. This approach entailed regularly collecting data and sharing results and best practices among the grantees, which provided extensive opportunities for learning. This experience forms the basis for our recommendations. The accomplishments of the grantees over the past four years demonstrate the impact that can be realized when patients and families, providers, community-based organizations, and public health and government agencies work collaboratively to improve care for individuals with sickle cell disease. These recommendations were also informed by the challenges that we and the sites encountered, as well as the limits to what we and sites were able to accomplish. Our recommendations address several different levels of action: (1) Recommendations for clinical delivery and public health programs (2) Recommendations for the design or re-design of the Sickle Cell Disease Treatment Demonstration Program and (3) Recommendations for broad health policy.

The system of care for individuals with sickle cell disease should include the main tenets of the patient-centered medical home, and the overall goal of the SCDTDP should be to move beyond simply demonstrating how to improve care for these individuals to spreading these improvements so that all patients with sickle cell disease have access to a system of high quality care. All of the recommendations included in this report are directed towards achieving the aim of the Sickle Cell Treatment Act, which is to improve the health care and outcomes for individuals with sickle cell disease.

1. Recommendations for Clinical Delivery and Public Health Programs:

a. Address deficiencies in emergency department care of individuals with sickle cell disease experiencing acute pain crises by establishing pain protocols, providing and making widely available pain management plans and using more easily administered medications.

b. Continue to increase access to medical homes and enhance care management and care coordination through the use of care management plans jointly developed by primary care providers, specialists, hospitalists and other inpatient providers with patients and families.

i. Expand the evidence base related to the use of care plans and other care coordination tools in sickle cell disease.

c. Implement systems (e.g., electronic health record templates, order sets, tracking and feedback mechanisms) to increase rates of appropriate screening and preventative interventions (e.g., penicillin prophylaxis, immunizations, hydroxyurea, transcranial Doppler screening).

d. Ensure education regarding use of hydroxyurea extends beyond a discussion of benefits and risks to include discussion of patient preferences and strategies for self-management support.

e. Ensure that health care systems address psychosocial needs of individuals with sickle cell disease and their families as well as medical needs.

f. Ensure all facilities providing care for individuals with sickle cell disease incorporate the six core elements of transition where appropriate, including having a transition policy, developing a process for tracking and monitoring transition-age youth, assessing and using transition readiness assessments, planning for transition, transferring care and completing transfers.

g. Assess current practice patterns for screening of immigrants (including African, Caribbean, Hispanic and Middle Eastern immigrants) for sickle cell disease. Develop and/or refine screening processes and link identified individuals to systems of care based on this assessment.

h. Involve patients and families in the design and implementation of quality improvement activities.

i. Involve community-based organizations as partners in programs to improve care for individuals with sickle cell disease across the lifespan.

j. Implement data systems that enable management of the entire sickle cell disease population served through a clinical system or in a geographic area and track key processes and outcomes, including the use of effective therapies (e.g., hydroxyurea), emergency department visits, hospitalizations, and readmissions.

k. Use systematic approaches to quality improvement, based on data, family engagement, and evidence.

2. Recommendations for the Design or Re-design of the SCDTDP:

a. We endorse the focus of the new SCDTDP on increasing access to care, increasing the number of providers capable of caring for individuals with sickle cell disease and increasing the use of hydroxyurea, as well as adopting a regional model to spread improvements in care across broader sections of the country.

b. Resources of the SCDTDP should be aligned with prevalence of sickle cell disease, perhaps initially allocating resources to those regions with higher numbers of affected individuals with a future plan to expand resources to ensure all patients irrespective of geographic location have access to high quality care.

c. Until all patients with sickle cell disease have access to high quality care, consider implementation of telehealth strategies to ensure patients have some access to services even if they are not close to a sickle cell program or center.

d. Involve patients and families in program development and program activities to ensure that efforts are responsive to their ongoing needs.

e. Financial and technical support for data collection should be commensurate with programmatic needs; the current resources are grossly insufficient to collect and report on the necessary data elements.

f. The Health Resources and Services Administration should align funding cycles of the National Coordinating Center and program grantees to ensure similar start and end dates.

g. The Health Resources and Services Administration should require the National Coordinating Center and program grantees to adopt a shared measurement strategy and data collection system.

h. Improvement science should remain an integral component of the SCDTDP.

i. Interagency coordination and cooperation could amplify the impact and optimize the resources of the SCDTDP. This can occur across the bureaus of the Health Resources and Services Administration, e.g., through engagement with the Bureau of Primary Health Care, as well as across other agencies within the

Department of Health and Human Services and beyond. These other agencies include the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services (including its Center for Medicare and Medicaid Innovation), the Agency for Healthcare Research and Quality, the National Institutes of Health, the Office of Minority Health and others.

j. The work of the SCDTDP and the SCDNBSP should be aligned. Collaboration between grantees and the coordinating centers will maximize resources and impact while limiting duplication.

3. Recommendations for Health Policy:

The health care needs of this population should be addressed through broadly implemented health policies rather than relatively small demonstration programs. Specific policy options might include:

a. New payment models that ensure that all patients with sickle cell disease have consistent insurance access to high quality care that is linked to a quality performance reporting and improvement system (e.g., categorical eligibility for Medicare for patients with sickle cell disease, analogous to individuals with end-stage renal disease, regardless of age).

b. Adjusting Medicaid payment policies and enhancing reimbursement rates to include care coordination services for this population, as was recently implemented for Medicare.

c. The Center for Medicare and Medicaid Services should develop risk-based capitation strategies for sickle cell disease.

d. Consider specific reporting on readmissions for sickle cell disease in hospitals; this might be paired with financial incentives with appropriate adjustment for severity of illness and other indicators of risk.

e. Adopt recently developed performance measures for sickle cell disease into insurance programs (Medicaid, Children's Health Insurance Program, Medicare) across the lifespan. Incorporate these measures, or a subset of them, in the Bureau of Primary Health Care quality performance measures.

f. Specific workforce training programs for health care professionals interested in caring for individuals with sickle cell disease. Provide enhanced compensation and potential loan forgiveness programs for hematologist/oncologists committing to at least a minimum number of patients with sickle cell disease or proportion of their practice devoted to patients with sickle cell disease.

g. Incorporate sickle cell disease-specific requirements in federal regulations for meaningful use.

h. More broadly, assure that all federally supported health care programs (e.g., federally qualified health centers, Department of Defense and Veteran's Administration programs) apply the clinical recommendations noted above.

The current Sickle Cell Disease Treatment Demonstration Program has made great strides in improving the quality of care for individuals with sickle cell disease. Grantees were able to apply improvement science methods to make improvements in several processes of care that positively affect patients. These improvements include more timely and compassionate care in emergency departments, increased access to providers, and more reliable provision of recommended screenings and therapies. The encouraging results and work described in this report have provided a number of important lessons:

1. Targeted strategies implemented using a disciplined change approach can lead to significant improvements in the quality and timeliness of treatment in the emergency department and enhance patient experience of care.

2. Use of patient navigators, community health workers, community-based organizations and patient self-management tools can improve access, coordination and integration of services for patients with sickle cell disease.

3. An early and comprehensive approach to transition, combined with self-management support can help mitigate the many challenges that individuals with sickle cell disease face during this vulnerable time.

4. Multilevel interventions targeted at the patient, family, provider and system can increase hydroxyurea use.

5. Opportunity still exists to improve follow up care after screening to ensure patients are enrolled in comprehensive care. Further work is needed to identify the appropriate processes for screening immigrant populations for sickle cell disease.

6. A shared and coordinated measurement strategy across grantee networks can enhance the program's ability to measure improvements in key process and outcomes related to sickle cell care. Coupling the measurement with a systematic approach to improvement results in better care and will ultimately lead to better outcomes.

The current Sickle Cell Disease Treatment Demonstration Program has demonstrated that better care for individuals with sickle cell disease is possible. This report has synthesized what can and should be done to improve care and provided recommendations for how these improvements can be implemented. The recommendations regarding modifications to the Sickle Cell Disease Treatment Demonstration Program provide an opportunity for how this program can enable even greater learning and a have greater impact on the populations directly touched by grantee programs. Yet what are most needed are mechanisms to move these lessons into widespread practice and to address barriers (such as an insufficient provider workforce) beyond the scope of the currently designed program.

REFERENCES

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