Practice Notes

Leveraging Community Health Worker Program to Improve Healthcare Access for Sickle Cell Disease in Georgia

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ABSTRACT

A five-year project, Access to Care was developed and implemented by the Sickle Cell Foundation of Georgia (SCFG) leveraging community resources and partnerships to increase access and improve the quality of healthcare and healthcare coordination in an adult sickle cell disease (SCD) population in underserved and rural areas of Georgia. The project is comprised of three phases: (Phase 1) the Community Health Worker Program - to improve the health outcomes of individuals living with SCD through healthcare coordination; (Phase 2) the CME-accredited Provider Training Program - to increase the knowledge of non-specialty providers in Georgia to increase provider capacity and confidence to provide care and treatment for individuals with sickle cell disease; and (3) Sickle Cell Clinic Days – specialty care provided by a hematologist in minimally resourced and underserved areas including Augusta, Columbus, Macon and Savannah and counties. Eight hundred and sixty-nine (869) individuals in 75 Georgia counties have received care coordination services with 113 placed in medical homes. Three hundred and sixty-eight (368) health care providers have participated in six face-to-face trainings and 30 have participated in two webinars. Partnerships include local sickle cell associations and support groups; local health departments; hospitals/Emergency Departments; local medical societies; local academic institutions; stakeholders; Georgia Department of Public Health; Global Blood Therapeutics; and Morehouse School of Medicine. With 8,427 residents living with SCD, Georgia has the nation's fourth largest SCD population in the nation with the second highest SCD incidence among black and/or African American births in the nation. Evaluation measures include process and output data monitoring, collection of observational data, i.e., participation and appointment tracking, and case management recording utilizing case management software; pre-and post-questionnaires to measure changes in knowledge, attitudes, skills covered in workshops and seminars.

Keywords: sickle cell, health care access, leveraging resources

INTRODUCTION

The quality of life of individuals living with a chronic condition is, in part, impacted by their access to appropriate health care. Access to care is also one component of preventing or delaying complications, improving function, delaying pain, and managing disease (https://www.healthypeople.gov/2020/). The Sickle Cell Foundation of Georgia's (SCFG) Access to Care Project is designed to increase access, quality, and the level of healthcare coordination for individuals living with sickle cell disease (SCD) in the state of Georgia; diversify and enrich Georgia's talent pool of primary care and family physicians with continuing medical education (CME)-accredited training on the treatment of SCD; and increase access to specialty (clinical) services for adult out-of-care individuals living with SCD in rural and underserved areas of Georgia.

Sickle cell disease (SCD) is a genetic blood disorder caused by a defect in protein structure – an aberration in the red cell oxygen transport molecule, hemoglobin, (Pauling, et. al., 1941) wherein the amino acid glutamate is replaced by valine. This amino acid substitution causes a distortion in the shape of red blood cells from the normal biconcave disk shape, producing rigid, sticky, sickle-shaped cells. These sickle cells obstruct small blood vessels and capillaries disrupting the flow of oxygen to body tissues. The obstruction in the flow of blood coupled with oxygen deprivation to tissues cause severe and debilitating pain, known a vaso-occlusive episode (commonly referred to as sickle cell or pain crises). The episodes are part of a genetic pleiotropic effect that may impact every organ in the body, causing multiple medical complications (Ilesanmi, 2013). SCD is a complex, chronic illness affecting approximately 100,000 Americans. In the United States (U.S.) the disorder is most prevalent among individuals of African descent, followed by individuals of Hispanic, Middle Eastern, and Indian descent.

Despite being the first identified molecular disorder (in 1910 and 1949), (Pauling, et. al., 1941) the progress in the

care, management, and survival of people with SCD has lagged significantly. Advances in SCD treatment have been limited compared with later discovered molecular disorders, such as cystic fibrosis (CF)where more treatments have been developed to benefit patient populations. Though both are devastating conditions with shortened life expectancies, between 2009 and 2013, there were nearly twice as many publications and slightly more clinical trials for CF than SCD. Between 2010 and 2013, five new drugs were developed for CF and none were developed for SCD (Strouse, et. al., 2013).

Before the 1970s, most children with SCD in the U.S. died before adolescence. Advances in treatment and the establishment of comprehensive, highly specialized pediatric centers decreased the mortality rate for children with SCD by 3 percent each year in a study from 1979 to 2005 (Lanzkron, 2013). The collective scientific and medical focus was on preventing children from dying. However, there was little foresight regarding what happens to these children when they become adults. The Lanzkron (2013) study found that mortality rates for adults with SCD increased by 1 percent during the same period with a life expectancy reduced by approximately 30 years. Currently, the only available cure is limited to bone marrow transplantation and the promise of gene therapies currently in clinical trials. Options available to only a very small segment of the SCD population. Of the 762 drugs approved by the U.S. Food and Drug Administration for orphan diseases (population <200,000) between 1983 and 2018, only two were for SCD (U.S. Food, 2019 & U.S. Food, 2019). Two additional drugs were introduced in 2019.

Medical complications and frequent hospitalizations often disrupt the lives of individuals living with SCD, interrupting schooling and compromising their ability to maintain steady employment. This leaves some segments of adults with SCD uninsured and underinsured making most SCD centers money-losing cost centers. As a result, the number of hematologists, core providers for individuals with SCD, who care for patients with nonmalignant conditions is distressingly low (Marshall, 2018). The lack of health care providers with comprehensive knowledge to care for individuals with SCD makes it difficult for individuals to receive the standard of care necessary to improve health outcomes and reduce mortality.

Georgia is the 9th most populous state in the U.S. (U.S. Census Bureau, 2020) with the fourth largest population of individuals with SCD (8,427) nation-wide (Hassel, 2010). Of the 159 counties in the state, 148 (93%) are designated as medically underserved and 108 counties (68%) are rural (population=<35,000) (Georgia State Office of Rural Health, 2011). The state has two comprehensive SCD centers for adults located in North (Metropolitan Atlanta) and East Central (Augusta) Georgia, with hematologists centralized in those areas. Non-specialty health care providers throughout the state reported reluctance to care for individuals with SCD because of lack of knowledge and negative perceptions of individuals with SCD; and would prefer to refer them to specialists (Georgia Health Policy Center, 2014). Consequently, individuals with sickle cell disease face a minimum two-hour drive for specialty care often creating a higher reliance on emergency departments at significantly higher costs and decreased quality of care.

Engaging non-hematologists as care providers for individuals with SCD is vital to addressing the provider deficit. Training by skilled SCD providers could greatly enhance the knowledge and confidence of primary care providers, especially if training is coupled with access to a hematologist. Leveraging available capacity within existing medical center infrastructure can be an effective mechanism for creating care programs for individuals with SCD at a lower cost. Federally Qualified Health Centers (FQHC) could be a key support because of their focus on disease prevention and long-term management of chronic conditions (Access to Care Summit proceedings, 2019).

Increasing access to care requires patient support. Individuals with SCD face several challenges, including navigating a maze of providers, scheduling appointments, and managing a large array of medication and medical regimes. Additionally, social determinants of health – inadequate housing, food insecurity, understanding of disease self-management, etc. can impact health seeking behaviors and undermine health outcomes. Community Health Workers (CHWs) are trusted, knowledgeable frontline health personnel who typically come from the communities they serve. CHWs bridge cultural and linguistic barriers, expand access to coverage and care, and improve health outcomes. As critical links between their communities and the health care system, CHWs reduce health disparities; boost health care quality, cultural competence and affordability; and empower individuals and communities for better health (American Public Health Association, 2009). In a study conducted by Overholser, et. al. (2014) utilizing CHWs to increase access to care by individuals with sickle cell disease, 62% of patients identified a primary care provider and attended a first appointment. CHWs help bridge to medical services to improve healthcare engagement, self-management, treatment plan adherence, and health outcomes (Hsu, 2016). Such patient assistance programs are associated with fewer missed appointments, which correlate with costly hospitalizations and readmissions.

METHODS

Phase I Community Health Workers

SCFG secured Health Resources and Services Administration (HRSA) Sickle Cell Disease Newborn Screening funding in 2015 for two years (2015-2016) through the Sickle Cell Disease Association of America (SCDAA) to start a CHW Program to improve the health outcomes of individuals living with SCD. During the first

year of funding (2015), SCFG developed a five-year plan presented to the Georgia State Legislature to increase access to care with incremental funding. The five-year plan proposed a public-private partnership between the state and community organizations to improve the quality of life and SCD care access in the state of Georgia. Registry and Surveillance System for Hemoglobinopathies (RuSH) data were used to target areas of the state with high rates of SCD and community potential partners were identified:

- Augusta – East Georgia
- Columbus – Midwest Georgia
- Macon – Central Georgia
- Savannah – Southeast Georgia

During this first two-year period of the project, CHWs were located in Metropolitan Atlanta and in Columbus in partnership with the local sickle cell association. SCFG engaged the local community partner to generate strategies that would be implemented in the Columbus area to improve health outcomes of individuals living with SCD. The local partner identified the needs of individuals in Columbus living with SCD, their health seeking behaviors, and available community resources. Included in the planning process was the identification of potential candidates to serve as a CHW for the Columbus area. The local partner provided office space for the CHW and collaborated with the CHW to identify individuals with SCD in need of care coordination services.

In 2017, SCFG expanded the deployment of CHWs to Augusta and Macon; and initiated planning for expansion to Savannah. SCFG partnered with the sickle cell support group in Macon to provide office space. In each of the cities, CHWs established partnerships with the local health departments, FQHCs, hospitals, clinics, and community organizations. Community partners served as a source of referrals for the CHW and a resource for primary care and other community services. CHWs provided appointment assistance, resource coordination, linkages to primary care, and follow-up. In Macon, the CHW partnered with the telemedicine hematology team to ensure individuals kept their appointments and were linked to a primary care provider.

In 2018, a CHW was hired to service Savannah and the surrounding area. SCFG worked closely with the local SCD association to establish a relationship with one of the FQHCs in Savannah. The partnership with the FQHC included office space for the CHW and clinical space for a visiting hematologist. Through efforts of the CHW, the FQHC serves as a medical home for un-insured and under-insured individuals with SCD in Savannah. The CHW quickly established a partnership with the Memorial Health Children's Hospital of Savannah and provides support to the hospital's transition program, established in 2019.

Phase II: Provider Training

In 2018, SCFG initiated provider training in areas of the state with no hematologist. A curriculum was developed to include caring for persons with SCD in non-specialty settings; overview of SCD; pain management; emerging trends; protocols for management in emergency settings; and care coordination using CHWs. The 2014 National Heart, Lung, and Blood Institute's "Evidence-Based Management of Sickle Cell Disease" (U.S. Department of Health and Human Services, 2014) is used as a basis for clinical instruction. The training is led by an expert hematologist and a family medicine physician with extensive experience with SCD treatment in family medicine and emergency department settings. In partnership with Morehouse School of Medicine, providers earn up to four CME credits for the four-hour course. Providers are encouraged to participate in the Extension for Community Health Care Outcomes (ECHO) sponsored by Atrium Health for additional training and to enroll in the U.S. Department of Health and Human Services, Office of Minority Health Sickle Cell Disease Training and Mentoring Program (STAMP) to gain access to consultations with sickle cell experts.

A toolkit (see Appendix for list of contents) was developed and is disseminated during the training to include the American Society of Hematology clinical pocket guides of evidence-based practices, emergency department protocols, and other physician-focused materials. Training participants have included family medicine providers, nurse practitioners, pediatricians, internists, nurses, OB/GYN providers, emergency department physicians, physician assistants, medical assistants, and medical students. SCFG collaborated with local stakeholders to plan, coordinate, and deliver training – community based organizations, health departments, academic institutions, hospitals, FQHCs, and local SCD organizations. Local partners identify facilities, assist with marketing; and in some instances, participate as presenters.

Phase III: Sickle Cell Clinic Days

In 2019, SCFG established Memoranda of Understanding (MOU) and Business Associates Agreements with community health centers, health departments, and FQHCs in Columbus, Macon, and Augusta to host "Sickle Cell Disease Clinic Days" at their facilities. SCFG Medical Director and Operations Manager collaborated with the Clinical Directors to establish protocols to be used at each facility – appointment setting; facility enrollment (at FQHCs); lab work; facility liaison; medical record sharing; forms; intake; prescriptions; etc.

The first clinic day was held at a FQHC in Savannah followed by clinic days at a FQHC and a community health center in Columbus. In Savannah, the CHW makes appointments and facilitates FQHC enrollment for labs, prescriptions, and primary care. The facility provides a nurse liaison to expedite any lab work needed. In Columbus, both facilities have patients with SCD and appointments are

managed by facility staff. New patients are also managed by facility staff. The hematologist makes monthly visits to the facilities seeing no more than 15 patients per visit.

RESULTS

Since inception, 869 individuals in 75 Georgia counties have received care coordination services with 113 placed in medical homes (primary care). The Social Functioning and Emotional Distress Scales of the Adult Sickle Cell Quality of Life Measurement System (ASCQ-Me short forms) were used to measure changes in the two constructs of individuals receiving CHW services in Metropolitan Atlanta, July through December 2019. Seventy-two percent (72.4%) of individuals receiving services reported improvement in social functioning (less difficult to engage in social functions, less difficult to get out and do things they enjoy). Respondents reported that after receiving CHW services, they:

- relied less on others to take care of them
- were slowed down less by their health
- found it less difficult for them to do the things they like
- were prevented from going out less often
- found it less difficult to do things with their friends

Sixty-eight percent (68.7%) reported improvement in emotional distress (worried less about getting sick and needing to go to the hospital). Respondents reported that after services, they experienced:

- reduced feelings of complete hopelessness because of their health
- reduced feeling of loneliness
- less depressed feelings about their health problems
- less worry about getting sick
- less worry about needing to go to the hospital

Three hundred and sixty-eight health care providers have participated in six face-to-face trainings and 30 have participated in two webinars.

- 91% reported increases in disease knowledge
- 87% reported increases in knowledge of disease management and treatment, and better understanding of patient experience
- 77% reported improved comfort levels treating individuals with SCD
- 89% reported a desire for a follow-up support mechanism

A total of 40 patients have been seen at the FQHCs and community health center in Savannah and Columbus. Patients have reported high levels of satisfaction with the services received and the number of patients is slowly increasing. A small number of patients from the southern part of the state travel an hour or more to their Sickle Cell Clinic Day appointment in Savannah. However, most identify not having to drive long distances to see a hematologist as the most significant advantage of the Sickle Cell Clinic Days.

DISCUSSION

This project builds on leveraging existing resources, thus taking the time to understand the local landscape is critical to the successful implementation of this kind of project. Local stakeholder input and ownership requires time and patience. Each location has its own politics, culture, and motivations for project involvement and each presents lessons learned to be applied to the next location. For example, the patient profile in Columbus differs greatly from the patient profile in Savannah. Columbus has no hematologists, adult or pediatric. Over the last year, a monthly pediatric SCD clinic has operated out of a local pediatrician's office. Adult patients in Columbus are diverse in age, income, and educational levels and have had to drive two hours to see a hematologist. In many instances, they have been in care though not as regularly because of the need to travel. Savannah has a very limited number of hematologists. Most of the Savannah Sickle Cell Clinic Days patients tend to be young adults – college students or recent graduates with limited income and no insurance. Many of the Savannah patients had not seen a hematologist in over a year and had been receiving care in emergency departments and urgent care centers. Some are emerging adults making their first adult appointment before leaving pediatric care. A small number are established adults from the more southern part of the state with no hematologists.

In Columbus we discovered variability in capacity and infrastructure of community health centers that we had not expected. During a clinic day, we found that one of the centers did not have a laboratory on site and used a third party. The lesson learned is to collect comprehensive capacity information from potential partners to determine the most efficient and practical way to provide hematology services in that location. It is also necessary to ascertain if the location is suitable for a one-day clinic.

The CHW program has served as the foundation for the overall project. Not only do they serve as liaisons between the individuals living with SCD and medical and community resources, because they are an established part of the community, they serve as liaisons between local stakeholders and other aspects of the project. They also play an important role in getting individuals to their appointments with both reminders and support, such as arranging transportation. Within the FQHCs and community health centers, relationships have been forged between the visiting hematologist and the SCFG Medical Director (family practice). Increasingly, FQHC providers are reaching out to the SCFG clinical staff for consultations on specific cases involving individuals with SCD they are caring for.

SCFG is a non-clinical community based organization and there was a learning curve in understanding how to actually provide clinical services in these very different communities

and how the CHWs function. We grossly overestimated the number of patients that the hematologist could see in a visit, underestimated the amount of time needed for new patients, and did not account for the time needed for both stakeholders and patients to get acclimated to the program. Because significant travel is involved for the hematologist, establishing predictable, monthly schedules for the cities saves on travel costs. A consideration to expand the reach of adult hematology services is to ramp up the utilization of telemedicine. This presents an additional learning curve for implementation and interface with our community partners. Investigating strategies and infrastructure requirements to offer virtual training and real time consultation to non-specialty providers can expand the number of providers that can be trained and ultimately grow the pool of providers who can deliver knowledgeable and appropriate care for SCD across the state.

IMPLICATIONS FOR PUBLIC HEALTH

This project is an example of finding ways to utilize existing resources in areas that are poorly resourced, looking beyond the deficits in underserved and under-resourced areas and finding ways to leverage and build on the resources that are in place. The SCFG Access to Care Project takes an innovative approach working with a diverse group of stakeholders to plan, implement, and evaluate the project. SCFG engaged with community organizations during both the planning and implementation stages of the project. Community stakeholder meetings included representatives of community organizations, health care providers, and individuals living with sickle cell disease. Stakeholders identified community needs, strengths, and resources and identified potential community partners. State and local level policy makers provided input on the areas of the state in need of services; developed state policies; and made resources available to implement project activities. The project collaborated with public, private, and faith-based community health centers to develop protocols and processes needed to provide hematology care to individuals with SCD in their areas and to increase access to primary and other sub-specialty care (behavioral health, OB/GYN). Physicians and consultants in private practice plan the delivery of medical services and collaborate with academic institutions to plan and deliver training for health care providers.

This project engaged partners across disciplines (including individuals living with SCD); encouraged and granted local ownership of project activities; and demonstrated flexibility in mid-course operations corrections. This strategy resulted in increased access to care in underserved areas of the state and can easily be replicated in other communities and disease sectors.

Acknowledgements

We thank Dr. James R. Eckman for his unwavering support in the planning and implementation of the provider training and for his continuous support and guidance. This work is supported by the Georgia Department of Public Health, Division of Health Promotion, Global Blood Therapeutics, Sickle Cell Disease Association of America/Health Resources and Services Administration, and United Way of Greater Atlanta.

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APPENDIX

Provider Training Toolkit Contents

Information

- Hydroxyurea and Transfusion Therapy for the Treatment of Sickle Cell Disease: A Pocket Guide for the Clinician, 2014, American Society of Hematology, www.hematology.org
- Management of Complications of Sickle Cell Disease: A Pocket Guide for the Clinician, 2014, American Society of Hematology, www.hematology.org
- Health Maintenance and Management of Chronic Complications of Sickle Cell Disease: A Pocket Guide for the Clinician, 2014, American Society of Hematology, www.hematology.org
- Red Blood Cell Transfusion: A Pocket Guide for the Clinician, 2016, American Society of Hematology, www.hematology.org
- Emergency Management of Sickle Cell Disease, National Heart, Lung and Blood Institute algorithm for the management of acute pain crises
- Hydroxyurea (patient brochure), Sickle Cell Disease Association of America/Sickle Cell Foundation of Georgia
- Living Well with Sickle Cell: Community Health Services for People with Sickle Cell, Georgia Community Connections, Sickle Cell Foundation of Georgia
- Sickle Cell Disease and Family Planning, Sickle Cell Foundation of Georgia

Additional Training Opportunities

- Fact Sheet and Enrollment Information – The Sickle Cell Disease (SCD) Training and Mentoring Program (STAMP): A Pilot Program for Primary Care Providers, U.S. Department of Health and Human Services, Office of Minority Health
- Fact Sheet and Schedule – Improve Sickle Cell Care and Outcomes with Project ECHO, Atrium Health, Levine Cancer Institute
- Training Description and Access Information – Reducing Complications of Therapeutic Blood Transfusion for Sickle Cell Disease, Georgia Health Policy Center, Georgia State University