STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

Larry Hogan, Governor - Boyd Rutherford, Lt. Governor - Dennis R. Schrader, Secretary

January 31, 2017

The Honorable Edward J. Kasemeyer
Chair
Senate Budget and Taxation Committee
3 West Miller Senate Office Building
Annapolis, MD 21401-1991

The Honorable Maggie McIntosh
Chair
House Appropriations Committee
121 House Office Building
Annapolis, MD 21401-1991

RE: 2016 Joint Chairmen's Report, Page 70, M00F03.02 – Sickle Cell Disease Study

Dear Chair Kasemeyer and Chair McIntosh:

Pursuant to page 70 of the Joint Chairmen's Report of 2016, the Department of Health and Mental Hygiene respectfully submits this report on Sickle Cell Disease. Specifically, it was requested that the Department of Health and Mental Hygiene review adult sickle cell disease infusion center models, and complete an analysis of the feasibility of establishing additional sickle cell infusion centers for adults in the State.

I hope this information is useful. If you have any questions regarding this report, please contact Webster Ye, Director of the Office of Governmental Affairs, at (410) 767-6480.

Sincerely,

Dennis R. Schrader
Secretary

Enclosure

cc: Howard Haft, Deputy Secretary, Public Health Services
David Lashar, Chief of Staff
Donna Gugel, Director, Prevention and Health Promotion Administration
Webster Ye, Director, Office of Governmental Affairs

Maryland Department of Health and Mental Hygiene
Prevention and Health Promotion Administration
Office for Genetics and People with Special Health Care Needs

Sickle Cell Disease Study

As required by the 2016 Joint Chairmen's Report, Page 70, M00F03.02

Larry Hogan
Governor

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Secretary

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Introduction

Sickle cell disease (SCD) is a genetic blood disorder where oxygen-carrying red blood cells become distorted into the shape of a sickle. This altered shape can result in a range of complications for patients, including pain crises, which may prompt emergency department (ED) visits, some of which result in hospital admissions. SCD infusion centers are designed to provide rapid and specialized care for SCD pain crises and function as alternatives to EDs. SCD-focused care delivered through infusion centers may reduce patient ED utilization and result in lower rates of hospitalization for adults with SCD pain crises. The purpose of this study is to review adult SCD infusion center models, and to provide a comparative analysis between the comprehensive care model and the multidisciplinary specialty clinic model in order to determine the feasibility of establishing additional adult SCD infusion centers in Maryland.

Background

Sickle Cell Disease

SCD is the most common inherited blood disorder in the United States.[1] According to the Centers for Disease Control and Prevention (CDC), approximately 100,000 Americans are affected by SCD, and SCD occurs in approximately 1 out of every 365 African-American births.[2] SCD primarily affects people of African, Hispanic, Southern European, Middle Eastern, and Asian Indian descent.[3]

SCD results from changes in hemoglobin, a protein found in red blood cells which allows those cells to carry oxygen throughout the body. With SCD, abnormal hemoglobin in red blood cells can cause the cells to distort into a crescent or sickle shape. This shape decreases the flexibility of the red blood cells, which renders them fragile and prone to destruction within the circulatory system; this in turn results in reduced numbers of red blood cells (anemia). The sickled red blood cells may also adhere to the inner lining of blood vessels and cause changes to the mechanical dynamics of blood flow, causing blockages in very small and microscopic blood vessels. These blockages can prevent adequate blood flow to bones and certain body organs. This phenomenon is termed vasoocclusion, and it can lead to multiple complications. Pain from vasoocclusion is a prominent feature of SCD and is a common reason for ED visits among people with SCD.[4] Acute chest syndrome is a serious and potentially fatal complication that results from vasoocclusion of microscopic blood vessels in the lungs and resultant lung damage. Other complications of SCD include risk of stroke, increased risk of certain infections, chronic kidney disease, poor growth, and other complications impacting multiple organ systems.

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[1] U.S. National Library of Medicine, "sickle cell disease," 13 December 2016, National Institutes of Health, 20 December 2016 <https://ghr.nlm.nih.gov/condition/sickle-cell-disease#statistics>.
[2] "Sickle Cell Disease (SCD)," 31 August 2016, U.S. Centers for Disease Control and Prevention, 5 December 2016 <http://www.cdc.gov/NCBDDD/sicklecell/data.html>.
[3] *Id* fn 3.
[4] Tanabe, P., Artz, N., Courtney, M., Martinovich, Z., Weiss, K., Zvirbulis, E., and Hafner, J., "Adult Emergency Department Patients with Sickle Cell pain crisis: a learning collaborative model to improve analgesic management," Academic Emergency Medicine, 17(4) (2010): 399-407, Wiley Online Library, 9 December 2016, <http://onlinelibrary.wiley.com/doi/10.1111/j.1553-2712.2010.00693.x/full>.

Management of patients with SCD is multifaceted and includes preventive care (e.g., prophylactic penicillin for infants and young children to reduce the risk of certain bacterial infections and routine screening for vascular complications), management of acute complications (e.g., pain crises and acute chest syndrome), and management of chronic complications that may involve multiple organ systems (e.g., chronic kidney disease). In 2014, evidence-based clinical guidance for management of SCD was released from an expert panel convened by the National Heart, Blood, and Lung Institute.[5] Key findings from the panel include evidence-based recommendations on the long-term daily use of hydroxyurea (a drug used to reduce or prevent SCD complications) and on the use of blood transfusions for individuals with SCD. The panel noted that vasoocclusive crises "are a particularly complex management concern," and gave recommendations for care during these crises including rapid initiation of intravenous opioids for severe pain according to an individualized, patient-specific protocol, or an institutional SCD-specific protocol.

Health Care Challenges for Individuals with SCD

Individuals with SCD may experience challenges accessing quality care due to factors such as transportation needs, lack of health care providers with experience caring for patients with SCD, and racial bias that may be encountered within the health care system. SCD patients may also be subjected to negative stereotypes, such as suspicion of pain medicine-seeking behavior when presenting for pain crises. Research indicates that health care providers may tend to overestimate the prevalence of addiction among SCD patients, which ranges from 0% to 11%.[6] In addition to acute care needs, many adults with SCD suffer from chronic illness, including chronic pain and other conditions arising from SCD complications.

Historically, SCD has primarily been a disorder of children; however, with advances in technology and clinical care, 95% of children with SCD now live into adulthood.[7] Enhanced survival has led to new challenges related to the transition of SCD patients from pediatric care to adult care, which may impact the clinical course of their disease.[8] A 2010 study that followed SCD patients in the Dallas Newborn Cohort discovered that young adults have a high risk of mortality during the transition between pediatric and adult medical care, especially in the context

[5] Yawn B.P., Buchanan G.R., Afenyi-Annan A.N., Ballas S.K., Hassell K.L., James A.H., Jordan L., Lanzkron S.M., Lottenberg R., Savage W.J., Tanabe P.J., Ware R.E., Murad M.H., Goldsmith J.C., Ortiz E., Fulwood R., Horton A., and John-Sowah J., "Management of Sickle Cell Disease, Summary of the 2014 Evidence-Based Report by Expert Panel Members," JAMA, 312(10) (2014):1033-1048, doi:10.1001/jama.2014.10517, NCBI, 9 December 2016, <https://www.ncbi.nlm.nih.gov/pubmed/25203083>.

[6] *Id* fn 4.

[7] Koch, K.L., Karafin, M.S., Simpson, P., and Field, J.J., "Intensive management of high-utilizing adults with sickle cell disease lowers admissions," American Journal of Hematology, 90(3) (2015): 215-219, Wiley Online Library, 9 December 2016, <http://onlinelibrary.wiley.com/doi/10.1002/ajh.23912/abstract>.

[8] Hemker, B.G., Brousseau, D.C., Yan, K., Hoffmann, R.G. and Panepinto, J.A., "When children with sickle-cell disease become adults: Lack of outpatient care leads to increased use of the emergency department," American Journal of Hematology, 86(10) (2011): 863–865, doi:10.1002/ajh.22106, Wiley Online Library, 9 December 2016, <http://onlinelibrary.wiley.com/doi/10.1002/ajh.22106/full>.

of acute medical events, and concluded that access to specialized care is essential for this vulnerable population during transition.[9]

Individuals with SCD frequently seek care for acute SCD-related pain through EDs, where they may encounter long wait times and may receive sub-optimal pain management. Some ED visits will result in hospital admissions. The number of ED visits by SCD patients has increased 28% since 2006, and in 2013 88% of SCD ED visits were for patients 18 years and older.[10] Factors that may contribute to ED utilization and reliance among young adults with ongoing health care needs include loss of a medical home, loss of insurance coverage, decreased access to ambulatory/outpatient care providers, and worsening disease with age.[11] In addition, according to 2010 data, the 30-day hospital readmission rate for SCD patients was 31.9%, which was higher than any other recorded diagnosis excluding cancer (cancer was excluded from the 2010 analysis as readmissions are often planned).[12]

Admissions Data

This section discusses data from the Maryland Health Services Cost Review Commission. Table 1 shows the number of Maryland hospital inpatient and outpatient visits by adult patients with SCD from 2013-2015. The numbers shown for "Total Admissions" represent all people with a sickle cell diagnosis who were admitted to an inpatient setting. The admitted from the ED category refers to patients with SCD admitted directly from the ED to inpatient care. The unduplicated patients category refers to patients who were admitted once within a 180 day period and excludes multiple admissions or visits by the same patient.

Table 1. Hospital Visits with any Sickle Cell Disease Diagnosis, Maryland, 2013-2015

INPATIENT	**2013**	**2014**	**2015**
Admitted from ED (% of total admissions)	3,242 (84.1 %)	3,073 (82.6 %)	3,138 (77.7 %)
Unduplicated (unduplicated Medicaid patients)	1,968 (825)	1,956 (885)	2,456 (1,098)
Total Admissions	3,853	3,719	4,037
OUTPATIENT	**2013**	**2014**	**2015**
ED visits	699	1,370	1,354
Admitted to Inpatient Care	158	175	181
Unduplicated (unduplicated Medicaid patients)	3,305 (1,482)	3,008 (1,366)	3,463 (1,606)
Total Visits	6,641	7,480	8,059

[9] Quinn, C.T., Rogers, Z.R., McCavit, T.L., and Buchanan, G.R., "Improved survival of children and adolescents with sickle cell disease," Blood, 115(17) (2010): 3447-3452, NCBI, 9 December 2016, <https://www.ncbi.nlm.nih.gov/pubmed/20194891>.

[10] Lanzkron, S., "Need for Specialized Centers to provide acute care to adults with Sickle Cell," Southern Medical Journal, 9(9) (2016): 566-567, Southern Medical Journal, 9 December 2016, <http://sma.org/southern-medical-journal/article/need-for-specialized-centers-to-provide-acute-care-to-adults-with-sickle-cell-disease/>.

[11] Lotstein, D.S., Inkelas, M.I., Hays, R.D., Halfon, N., and Brook, R., "Access to care for youth with special health care needs in the transition to adulthood," Journal of Adolescent Health, 43(1) (2008): 23–29, NCBI, 9 December 2016, <https://www.ncbi.nlm.nih.gov/pubmed/18565434>.

[12] Elixhauser, A. and Steiner, C., "Readmissions to U.S. Hospitals by Diagnosis," April 2013, Agency for Healthcare Research and Quality, Healthcare Cost and Utilization Project, Statistical Brief #153, 5 December 2016, <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb153.pdf>.

From 2013-2015, there were 22,180 outpatient hospital visits with a diagnosis related to SCD in Maryland. [13] Table 2 shows rates of SCD-related outpatient hospital visits for 2013 and 2015. The rate of SCD-related visits for all patients increased 20% during this time, while the rate for Black non-Hispanic patients increased 145%. During the same time, SCD-related outpatient hospital visit rates (all patients) were highest for adult patients ages 18-44 (243.5 visits per 100,000 population), and 15% of outpatient hospital visits were in the ED. Black non-Hispanic patients accounted for 79% of SCD-related outpatient hospital visits and 97% of ED visits.

Table 2. Rate of Outpatient Hospital Visits with a diagnosis related to Sickle Cell Disease in Maryland, 2013 and 2015

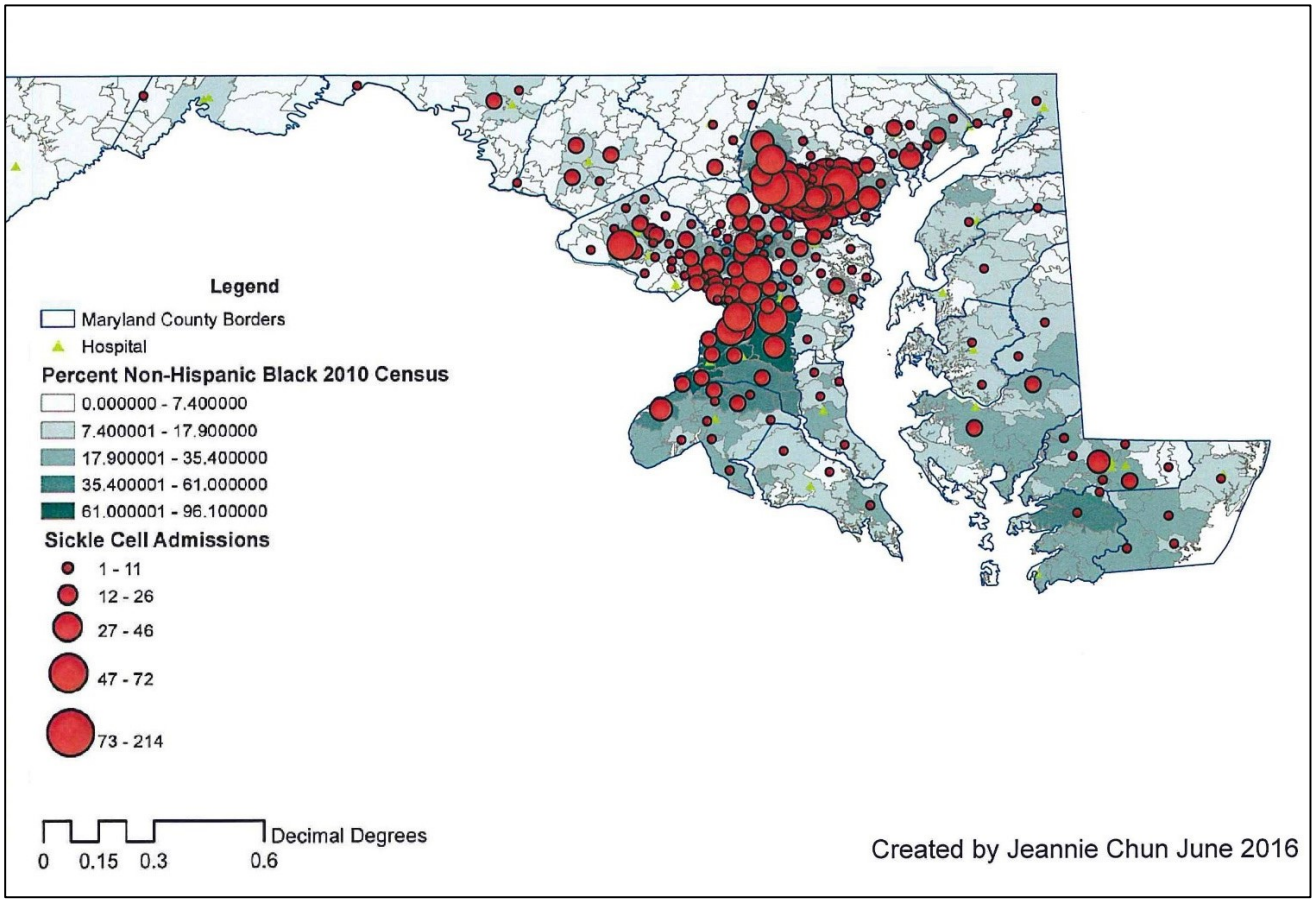
	Visits per 100,000 population		Rate change between 2013 and 2015[a] (%)
	2013	**2015**	
Outpatient Hospital Visits - All Patients	112.0	134.2	**20%**
Outpatient Hospital Visits - Black Non-Hispanic Patients	172.3	421.7	**145%**

[a] Calculated as (2015 rate - 2013 rate) / 2013 rate

Figure 1 is a "heat map" that overlays the frequency of SCD admissions to the ED for all patients in Maryland with percent non-Hispanic Black population per 2010 Census data.

[13] Diagnoses considered sickle cell disease related include ICD-9 codes beginning with 282.6x or ICD-10 codes of D57.0, D57.00, D57.01, D57.02, D57.1, D57.2, D57.20, D57.21, D57.211, D57.212, D57.219, D57.3, D57.4, D57.40, D57.41, D57.411, D57.412, D57.419, D57.8, D57.80, D57.81, D57.811, D57.812, or D57.819.

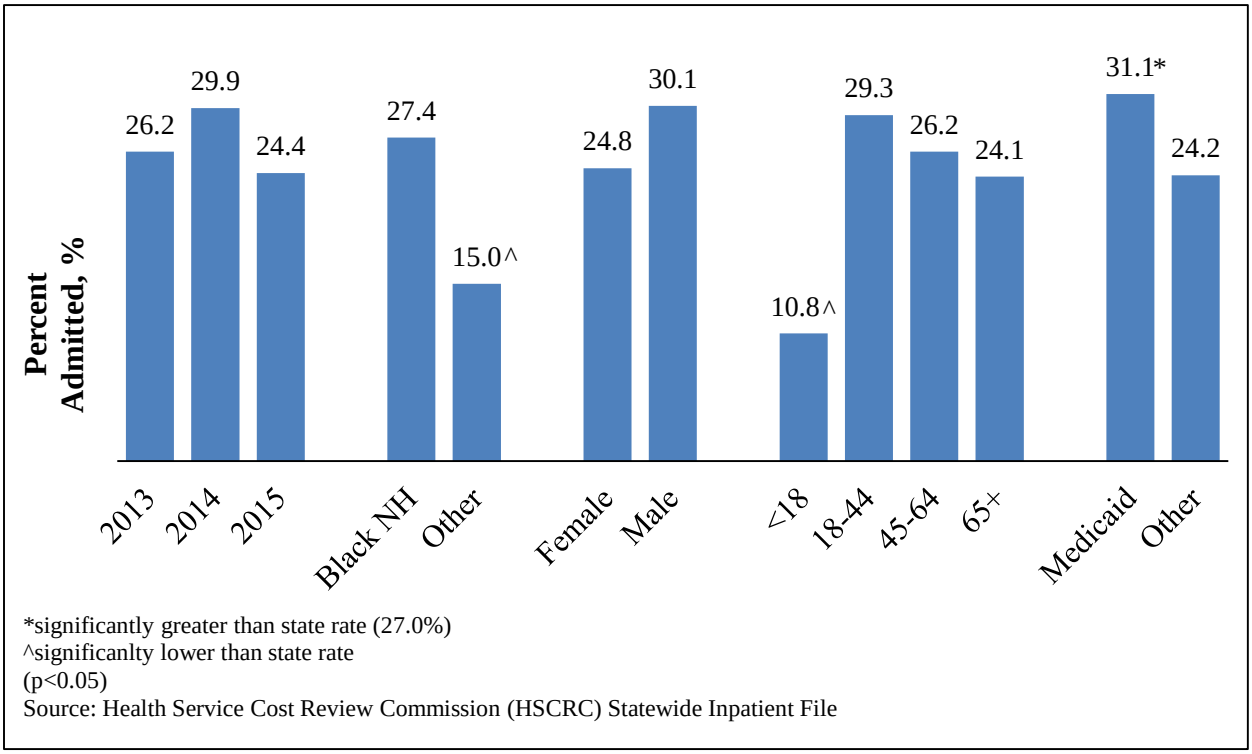
Figure 1. 2013 Maryland Sickle Cell Admissions



Overall, the cost for providing care for the 22,180 SCD outpatient visits is estimated at $1,327 per visit, which is 47% higher than the $904 estimated cost per non-SCD visit. Similarly, among ED visits the mean cost per visit for SCD is $1,151.20, which is 22% higher than the mean cost per ED visit for non-SCD patients ($943). Further, ED visits for SCD patients who were admitted had a higher mean cost per visit ($1,272) than those not admitted ($1,105).

Twenty-seven percent (912) of ED patients seen for SCD were estimated to have been admitted to the same hospital within 180 days of the ED visit from 2013-2015. This value likely underestimates the true prevalence of hospital admissions for SCD patients seen in the ED for two reasons. First, patients who are admitted to a different hospital than the ED visit hospital are not included because of data confidentiality. Second, these data do not include care received at urgent care facilities. Five percent of the linked hospitalizations (patients who visit the ED and are admitted to the same hospital within 180 days) did not include a SCD diagnosis. Based on this linkage process, the admission rate among ED visits for SCD (27.0%) was more than four times the admission rate for non-SCD ED visits (6.5%) from 2013-2015. Figure 2 presents the admission rates for aggregate data from 2013-2015. Based on these data, the admission rate from the ED for SCD patients was highest in 2014, among Black non-Hispanic patients, males, patients ages 18-44, and Medicaid insured patients.

Figure 2. Percent of ED Visits with a Sickle Cell Disease Diagnosis Admitted within 180 Days of ED Visit, Maryland 2013 – 2015, by Maternal Characteristics



*significantly greater than state rate (27.0%)
^significanlty lower than state rate
($p<0.05$)
Source: Health Service Cost Review Commission (HSCRC) Statewide Inpatient File

Some variables that may affect these data but have not been controlled for include: whether patients have insurance, whether they have been advised to see a primary care provider after their ED visit, time since their last visit to a primary care physician, whether they were referred from a primary care provider's office or self-referred, and the number of patients who visited an urgent care or hematology center prior to or instead of seeking care in an ED. Public transportation availability and cross county access to care may also affect ED admission rates in Maryland.

Some of the challenges that SCD patients experience, including ED reliance, may be addressed by access to a comprehensive, multidisciplinary health care team. Grosse et al. state that SCD patients should be managed by a team including "a physician familiar with the multiple complications and presentations of SCD, an advanced practice provider (such as a physician assistant or nurse practitioner), a health educator, and a medical social worker, and should have access to laboratory services, radiology services, and a 24-hour blood bank."[14] Additionally, for acute care needs, "data from sickle cell day hospitals demonstrate success in avoiding inpatient hospitalization for patients with sickle cell pain crisis when rapid, aggressive, analgesic management practices are implemented," which suggests that ED utilization and reliance can be reduced by increasing SCD patient access to outpatient acute care facilities.[15]

[14] Grosse, S.D., Schechter, M.S., Kulkarni, R., Lloyd-Puryear, M.A., Strickland, B., and Trevathan, E., "Models of Comprehensive Multidisciplinary care for individuals in the United States with genetic disorders," Pediatrics, 123(1) (2009): 407-412, Pediatrics, 9 December 2016, <http://pediatrics.aappublications.org/content/123/1/407>.
[15] *Id* fn 4.

Adult SCD Infusion Center Models

Care Models for Individuals with SCD

Historically, there have been three models of care for individuals with SCD. These include the medical home approach (also referred to as the comprehensive care model), the chronic care model in primary care, and disease-specific, multidisciplinary specialty clinics:[16]

> *Medical Home/Comprehensive Care Model:* The medical home model is defined as a source of both sick and well care that is "family-centered, culturally effective, accessible, and actively engaged in the coordination and provision of primary and subspecialty health care services within the health care system and across other community-based agencies and services."
>
> *Chronic Care/Primary Care Model:* The chronic care model is intended to improve the management of patients with chronic conditions, specifically within the primary care setting. Like the medical home model, this model involves a multidisciplinary team that coordinates both primary and chronic/specialty care.
>
> *Multidisciplinary Specialty Clinic Model:* The multidisciplinary specialty clinic model includes centers or clinics that provide coordinated, disease-focused care to patients with a particular condition. Clinics operating within this model bring together providers from multiple specialties and disciplines to provide coordinated care and case management; these clinics generally do not provide primary care.

Models that embrace co-management promote "ongoing communication and coordination between primary care and subspecialty services, particularly during the transition from pediatric care to adult care."[17] Research has indicated that the chronic/primary care model may not be ideal for patients with SCD, as many family physicians report that they are not comfortable treating this patient population and many patients encounter barriers in finding a primary care physician as they transition from pediatric to adult care.[18,19] For this reason, the primary care model has been excluded from this study.

Of the three previously mentioned models for SCD coordinated care, two will be analyzed for feasibility of implementation: the comprehensive care model and the disease-specific, multidisciplinary specialty clinic model. Comprehensive models of care for patients

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[16] *Id* fn 14.
[17] *Id* fn 14.
[18] Ballas, S.K. and Vichinsky, E.P., "Is the medical home for adult patients with sickle cell disease a reality or an illusion?" Hemoglobin, 39(2) (2015):130-3, NCBI, 9 December 2016, <https://www.ncbi.nlm.nih.gov/pubmed/25806421>.
[19] Mainous III, A.G., Tanner, R.J., Harle, C.A., Baker, R., Shokar, N.K., and Hulihan, M.M., "Attitudes toward Management of Sickle Cell Disease and Its Complications: A National Survey of Academic Family Physicians," Anemia, (2015): Article ID 853835, NCBI, 9 December 2016, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4352517/>.

with SCD use a multidisciplinary approach and have been shown to cost-effectively improve patient outcomes.[20]

Johns Hopkins Sickle Cell Infusion Center (Comprehensive Care Model)

Johns Hopkins Hospital opened an outpatient Sickle Cell Infusion Clinic (SCIC) in 2008 in Baltimore, Maryland as an alternative source of urgent care for patients experiencing vaso-occlusive crises.[21] The SCIC has five treatment slots for acute care visits and provides services for patients 21 years and older; services are available to patients 18 years and older who are not patients of the Johns Hopkins pediatric group. The SCIC is supervised by a medical director and staffed by a clinic coordinator, clinical nurse associate, nurse, advanced practice provider, and social worker. The center operates on weekdays and weekends, and patients are encouraged to utilize the clinic before visiting an ED for care.

Upon arrival, patients are assessed by a nurse/advanced practice provider and analgesic therapy is initiated. The goal is to provide patients with their first dose of an opioid within 60 minutes of arrival. Pain management protocols depend on patient medical history; tolerant patients are evaluated and prescribed medication appropriately. Adjuvant medications and treatments such as non-steroidal anti-inflammatory medications and heat packs are also used. Patients are usually treated by opioid injection, with patient-controlled analgesia if admission is necessary.[22]

The clinic has established a close working relationship with the Johns Hopkins Hospital ED to coordinate transportation of patients with SCD. Patients that present at the ED are triaged and then referred to the SCIC. Patients that present at the SCIC who are unstable are transferred immediately to the ED. At the end of each SCIC business day, patients whose pain is not under control are assessed for hospital admission or ED referral. Discharged patients from the SCIC are supplied with appropriate pain medications and are encouraged to return to the clinic the next day if they need further care or pain management. The majority of patients who present to the SCIC are discharged home (85%).[23] In a recent study, the following cost savings were attributed to SCIC utilization:

> The SCIC model resulted in cost savings primarily due to a decrease in hospitalizations and ED visits. The number of hospitalizations decreased 52.0% (2.88 HPY [hospitalizations per patient per year]) and the number of ED visits decreased 48.4% (2.32 VPY [visits per patient per year]) in the fifth year of operating the infusion clinic model (2012). The average cost of a hospitalization and an ED visit was $10,797 and $1,024 respectively. These values did not change with the implementation of the SCIC. If we extrapolate the cost savings seen in the subset of patients using the more conservative 7.6% cost

[20] *Id* fn 10.
[21] Lanzkron, S., Carroll, C.P., Hill, P., David, M., Paul, N., and Haywood, C., "Impact of a dedicated infusion clinic for acute management of adults with Sickle Cell pain crisis," American Journal of Hematology, 90(5) (2015): 376-380, Wiley Online Library, 9 December 2016, <http://onlinelibrary.wiley.com/doi/10.1002/ajh.23961/pdf>.
[22] *Id* fn 21.
[23] *Id* fn 10.

savings to the entire patient cohort, this would result in a cost savings of $1.9 million.[24]

This comprehensive care infusion center model provides SCD patients with easy access to high quality care, which directly decreases the need for ED treatment and hospital admission. Utilizing provider expertise and patient management through case-based learning, this model provides effective hospital-to-community care transition and coordination of care.

Sickle Cell Disease Clinic at Froedtert Hospital (Multidisciplinary Specialty Clinic Model)

In Milwaukee, Wisconsin, the Froedtert & Medical College of Wisconsin Regional Health Network opened a clinic for adults with SCD in 2011. The clinic is modeled after the Johns Hopkins SCIC. The clinic operates on weekdays and provides care for more than 270 patients. The clinic offers comprehensive services including immunizations, basic contraception, transfusions overseen by a board-certified physician, drug therapy with hydroxyurea, supportive care to treat symptoms and complications of SCD, pain management, education, coaching, and follow-up support. It is staffed by physicians, nurse practitioners, physician assistants, nurses, medical assistants, social workers, and support staff. Clinic health care providers can link patients with primary care providers.

Upon arrival, patients are triaged and are either treated at the clinic, or admitted to the hospital if they need continued care beyond the clinic's hours. The clinic coordinates with the ED to receive referrals for acute care, but does not refer patients to the ED. SCD patients admitted to the ED are required to schedule a follow-up visit with the clinic within 48 hours in order to determine pain management and continued care needs. A physician and nurse visit the hospital daily to monitor admitted patients, discharged patients, and patient transitions to the SCD clinic.

Since the clinic opened, inpatient SCD admissions have been reduced by 50%, ED visits by 50%, and re-admissions within 30 days by 30%. It is estimated that the clinic costs Froedtert Hospital more than $1 million annually to operate, but saves more than $1 million annually by reducing ED visits and hospitalizations; the savings, however, often benefit government health programs like Medicaid and Medicare or private health insurers rather than the hospital, making clinic operation financially challenging.[25]

Georgia Comprehensive Sickle Cell Center at Grady Health System (Multidisciplinary Specialty Clinic Model)

The Georgia Comprehensive Sickle Cell Center at Grady Health System in Atlanta, Georgia was established in 1984 and was the first twenty-four hour comprehensive primary care

[24] Chappidi, M., Alfonso, N., Bishai, D., and Lanzkron, S., "Cost Benefit analysis of Sickle Cell Infusion Center for the Treatment of Vaso-occlusive Crisis," Blood, 122 (2013):1696, Blood, 9 December 2016, <http://www.bloodjournal.org/content/122/21/1697?sso-checked=true>.
[25] Boulton, G., "Froedtert's sickle cell clinic helps patients with painful disease," 28 July 2013, Journal Sentinel, 9 December 2016, <http://archive.jsonline.com/business/froedterts-sickle-cell-clinic-helps-patients-with-painful-disease-b9956382z1-217325121.html>.

clinic for adult patients with SCD. Acute care is available twenty-four hours a day, seven days a week for all patients over the age of 18. There is also a regular outpatient clinic open on weekdays, and a pediatric physician sees children every other Friday or when referred as necessary. Services offered include transfusions, routine health care with a primary care physician, newborn screening and genetic counseling, pain management, hydroxyurea treatment, pediatric to adult transition services, patient counseling, and sickle cell education and outreach. The center is staffed by a medical director, doctors, physician assistants, nurse practitioners trained in SCD, counselors, a psychologist, and social workers. A pharmacy, lab, and infusion center are located on the premises. The staff has case management meetings for all new and returning patients and uses an integrated approach to care and treatment options.[26]

Arrivals to the acute care center are assessed by a nurse practitioner or physician assistant with a goal of providing a first dose of opioid within 30 minutes of arrival. There are nine beds and two rooms for transfusion. The average length of stay is 7-8 hours and patients anecdotally prefer the acute center to the ED because the wait time at the center is lower. Patients are assessed for pain prior to discharge, and are admitted to the hospital if their pain cannot be managed at the center. Physicians at the center monitor the care of SCD patients in the hospital as well as their follow-up care; patients who are admitted to the hospital are required to schedule a follow-up appointment with the center prior to discharge. Patients are rarely sent to the ED.

Both the acute center and the clinic have experienced growth in recent years. The clinic has grown from providing services to 1,814 patients in 2011 to 2,660 patients in 2015, with 3,125 patients tracked between January and July 2016. The acute center has grown from providing services to 2,930 patients in 2011 to 3,655 patients in 2015, with 4,000 patients tracked between January and July 2016. Thus far in 2016, an average of 13 patients per month are transferred to the ED. The center is considering hiring more staff and expanding to include an analgesic program to accommodate its growing patient population. The center is funded by the Title V HRSA grant and costs $1.4 million annually to operate.[27]

Howard University Center for Sickle Cell Disease (Multidisciplinary Specialty Clinic Model)

A different model for SCD treatment is an outpatient infusion center exemplified by the Howard University Center for Sickle Cell Disease. With a grant from the National Institutes of Health, Dr. Roland Scott founded the center in 1972. This outpatient clinic is open each Tuesday from 8:00 AM to 12:00 PM at the Howard University Hospital in Washington, DC and services adults and pediatric patients by appointment. The university is affiliated with the District of Columbia - Greater Access to Pediatric Sickle Cell Services Project, which provides comprehensive care for children with SCD under a medical home model. Services available through the partnership include an adult transition program, hydroxyurea, and pain management, but an infusion center is not available. Patients with acute pain are transferred to the hematology oncology center for admission. The center serves 30-50 SCD patients monthly, and about one patient per week is referred to the ED. Patients who are admitted to the ED are directed to contact the center to schedule a follow-up appointment one week after their ED visit. The staff

[26] "Sickle Cell Center," Grady Health System, 9 December 2016, <https://gradyhealth.org/specialty/Sickle Cell - center/>.
[27] *Id* fn 26.

includes a director, physicians, social workers, and nurse practitioners, and patients can be referred for psychological treatment at the psychiatric clinic located at the Howard University Hospital. The center refers patients to the University of Maryland Medical Center as needed for bone marrow transplants. The center is in the process of conducting pharmaceutical and bench studies in addition to providing patient care. Patients are encouraged to have a primary care provider prior to visiting the clinic. The center, which is partially grant-funded, costs approximately $1.3 to $2.7 million annually to operate.[28]

Conclusion

Preliminary research and analysis of a select number of sickle cell centers in the United States suggests that a comprehensive infusion center with appropriately trained staff and wrap-around services can improve care quality and reduce emergency department visits by nearly 50%.[29] From 2008-2011, 85% of patients presenting to the SCIC at Johns Hopkins Hospital were discharged home, and admission rates decreased from 47% to 20% during the same time frame for all SCD patients presenting to the Johns Hopkins Hospital ED.[30] The Johns Hopkins team interpreted this decrease in admission rates to suggest that many of the SCD patients managed in the ED before the SCIC opened could have been managed successfully in an infusion clinic setting.[31] The success of the infusion center model can be attributed to expedited pain management, knowledgeable staff who provide competent services, individualized treatment and patient treatment plans that address social service needs, and underlying behavioral self-care factors.

This analysis of select care delivery models for patients with SCD provides an overview of the challenges faced in providing health care services for SCD patients and possible solutions. An in-depth statistical analysis by a health economist would further evaluate cost efficiency and equity concerns, corroborate trends, and provide final recommendations about the feasibility of a new center. Health economist input is integral to determining whether a center could be added to an existing facility, whether a new facility should be built, the projected annual operating costs of a facility, and the appropriate staffing model.

[28] "Center for Sickle Cell Disease," Howard University Hospital, 9 December 2016, <http://huhealthcare.com/healthcare/hospital/specialty-services/sickle-cell-disease-center>.
[29] *Id* fn 24.
[30] *Id* fn 21.
[31] *Id* fn 21.