VCU Health™

SICKLE CELL DISEASE ADULT MEDICAL HOME

ANNUAL REPORT

2019

SCD ADULT MEDICAL HOME EXECUTIVE SUMMARY

SITUATION

From 2012- 2016, Sickle Cell Disease (SCD) readmissions steadily increased at Virginia Commonwealth University Medical Center, after a long history of decline. The VCU Adult Sickle Cell Medical Home was funded and launched to address this issue, based on the success of a pilot that showed cost savings of $333,000 for 5 patients in 12 months.

BACKGROUND

The program officially began in January of 2018. Initial program costs came from both the hospital ($425,000, 80%), the Department of Internal Medicine, and expiring grant funds ($110,000, 20%). Over the 12 months of FY 2018, for the 50 highest utilizing patients, 30-day readmissions were reduced from 47.1% to 36.4%. Average length of stay was reduced from 6.1 days to 4.8 days. Total inpatient days were reduced by 100 days (206 to 106). This resulted in a 25.43% reduction in costs (charges) of $1,347,056, and a net savings of $865,000 after program costs.

The hospital therefore expanded its initial annual investment by $390,456 in FY 2019. Program goals expanded as well: further reduce SCD readmissions, average LOS, and costs; improve compliance with SCD care guidelines; improve reports of quality, safety, and financial metrics, and; improve the patient experience. A new program goal was to establish an adult SCD infusion program to further decrease hospitalizations and ED visits and improve the SCD urgent care patient experience. This required a net new investment of $21,500.

PROJECT EXECUTION

In year two of the Adult Sickle Cell Medical Home, the program appointed an infusion center director. It hired a third Patient Navigator, two new dedicated nurses, a third nurse practitioner, a full-time prior authorization specialist, and a quality improvement analyst. The program expanded interventions to include not only the 50 highest SCD utilizers, but also the next 100-200 highest utilizers, who threatened to break into the top 50 without prophylactic intervention. Based on analyses showing that social determinants of health and behavioral diagnoses were huge drivers of need and utilization, the program intensified case management to better manage those drivers. The program more effectively integrated the care of hospitalists, the ED, and clinic ambulatory staff. Last, the program began collaboration with SCD case managers working for managed care organizations.

RESULTS

Similar to FY 2018, in FY 2019 the VCU Adult Sickle Cell Medical Home further reduced utilization and costs for the top 50 highest utilizers. But new in FY 2019, the program reduced the entire SCD population's number of inpatient days by 1,096, the average length of stay by 0.86 days, the readmission rate by 10%, and the ED 3-day return rate by 2.8%, leading to a reduction of $1.182 million in charges at VCU Health. In total, the program averted $2.465 million in charges in FY 2019. Using QI principles, documentation, process mapping and improvement, measurement and evaluation, dissemination, and scholarship all took major leaps forward, as illustrated in this report.

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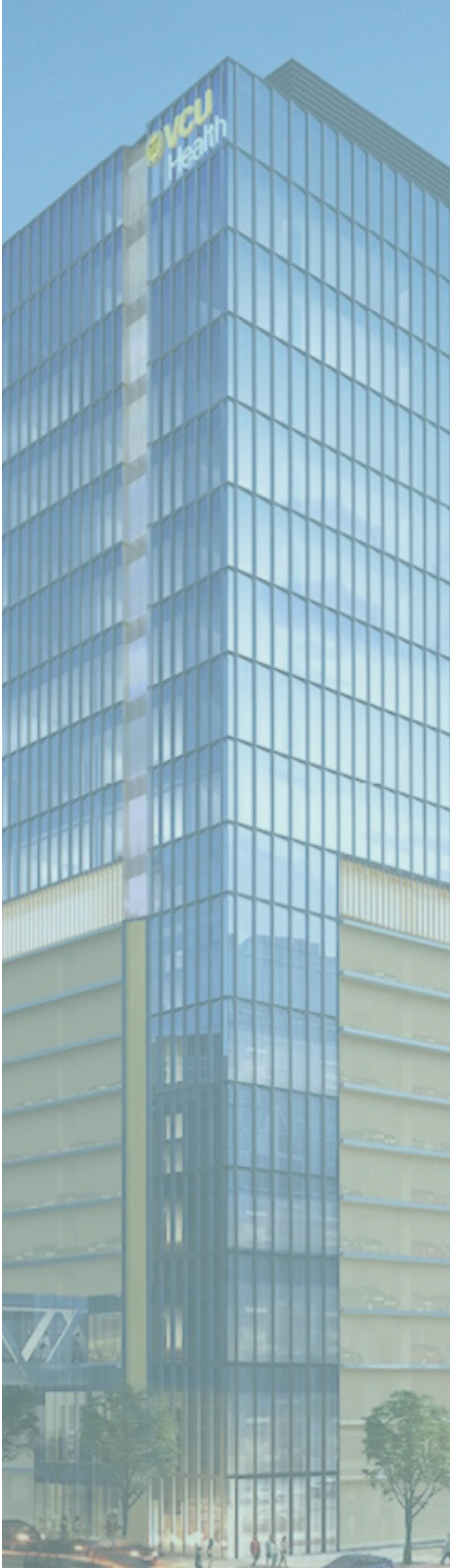


A MESSAGE FROM DR. SMITH

The year 2019 witnessed a worldwide explosion of interest in sickle cell disease (SCD), marked by the investor-ballyhooed approval of two novel compounds to prevent complications of SCD, by fast acceleration of both hematopoietic stem cell transplantation and various gene therapy approaches to aid disease remission, and by a bolus of foundation and federal support to thwart the disease in Africa and third-world nations.

Meanwhile, US adults with the disease, though beneficiaries of excellent pediatric care and medical advances, have had little relief in their ongoing struggle to survive and thrive amid the ravages of pain and organ failure this chronic disease has thrusted on them. These adults, many of them quite young, still require a vast multidisciplinary army of professional and lay caregivers. They still have huge psychosocial burdens, in the form of poor social support and self-efficacy, anxiety, depression, catastrophizing, and post-traumatic stress-like symptoms. They still bear current prejudice and stigma from friends, family, and caregivers, as well as the burden of historical prejudice and stigma. They still are chastised for frequent use of emergency and hospital resources because of their disease, as well as for frequent use of opioids because of their pain. And they still die prematurely from organ complications from SCD, for lack of preventive care and application of existing therapies.

To meet these challenges, in 2019 the Adult Sickle Cell Medical Home significantly enlarged its staff, through generous, additional support from VCU Health, based on savings in our first year of operation. We developed a more robust approach to the transition from pediatric to adult SCD care. We sought to improve our behavioral health SCD resources, including treatment of the few patients who misuse their opioids or recreational drugs. We provided special housing for some homeless SCD patients. Not only did we increased access to the adult SCD clinic, but also we improved and enlarged our home visiting, emergency department management, and hospital management programs, thereby integrating more and more VCU care units into our program. Joined by our community advocates, we successfully improved state policy, and obtained better state and national support for SCD care resources, treatment, and research. We participated in almost every clinical trial for anti-sickling agents. We made plans to open and operate a sickle cell infusion center that will administer not only palliative but also remittive SCD therapies.

Last, our staff collaborated to lead, teach, and mentor other professionals regionally and nationally, via days-long workshops and followup sessions that laid the groundwork to reproduce SCD medical homes like ours around the country.

For 2020, we remain undaunted in our quest to improve the quantity and quality of lives for adults with SCD in the VCU catchment area. We expect this coming year to show continued savings to the hospital and medical center budgets, to managed care organizations with which we collaborate, and to the taxpayers of Virginia, all the while improving patient and provider satisfaction. As the ultimate result, we expect our patients will, in new and greater ways, celebrate life, and lessen their pain.

Wally R. Smith, MD

Florence Neal Cooper Smith Professor of Sickle Cell Disease
Vice Chair for Research, Division of General Internal Medicine

A MESSAGE FROM DR. LIPATO

2019 saw the acceleration of our efforts to create an outpatient infusion clinic where patients can get treated for vaso-occlusive crises, avoiding the need to utilize the emergency room. We successfully recruited a nurse practitioner and hired two highly qualified registered nurses to work exclusively in the infusion clinic. Much time during this year was spent engaging with other stakeholders within the health system to development protocols and procedures for the clinic. A major barrier was finding a location to house the pilot. Within the health system we found a lot of apprehension to having intravenous opioids administered in the outpatient setting. Fortunately by the end of year we identified a potential location; the North 8 Clinical Research Center within North Hospital here at VCU Medical Center. We believe that North 8 is an ideal location for the pilot program because it is where many of the clinical trials at the medical center occur. The nursing and administration staff of North 8 are comfortable and experienced with the administration of novel intravenous drug. Our infusion clinic pilot, we believe, will fit well in North 8.

Regarding our on-going clinical practice, Caitlin McMannus, NP, who was recruited to work with Dr. Smith and me in the outpatient clinic began working in February. By the end of the year she was fully integrated into the practice.

My own clinic practice did not change much in 2019, except for getting the much needed help from Miss McMannus. I did spend more clinical time this year on a multi-centered, industry-led clinical trial that finally led to the FDA-approval of a new sickle cell disease drug called Oxbyrta in December.

Thokozeni Lipato MD

Assistant Professor

Division of General Internal Medicine

STATE OF SICKLE CELL DISEASE

What is the current state of SCD nationally?

The year 2019 was a landmark year for SCD patients, researchers, and advocates. The year ended with two landmark FDA approvals of new sickle cell drugs, voxelotor (Oxbryta, GBT) and crizanlizumab (Adakveo, Novartis), each creating brand new classes of therapy, and each validating new drug targets for subsequent sickle cell agents. The number of compounds/procedures under investigation for treatment or remission of SCD remained above 40. Gene therapy became more of a hope as several patients underwent successful therapy and outcomes beyond a few months were measured. Hematopoeitic stem cell transplantation continued to expand its reach to SCD patients including adults. The National Institutes of Health (NIH) launched the CURE SCI initiative, patterned after the 1960's moonshot, intended to bring a cure to patients worldwide.

Earlier in the year, several states or localities, most notably California, passed or expanded landmark legislation to create new SCD adult medical homes, or developed initiatives to subsidize adult SCD care at high-volume academic medical centers. Virginia began to entertain such legislation, that would hold the state accountable for assuring preventive care is rendered to adults with SCD, and for improving outcomes of adults with SCD. This legislation would build on current legislation that supports care at 4 pediatric SCD centers of excellence around the state, who are held accountable for preventive care and outcomes of children up to age 18.

In mid-year, Virginia's attorney general issued a ruling that opioid prescribing for patients with sickle cell disease would not fall under the restrictive guidelines for opioid prescribing issued in 2016 by the Centers for Disease Control (CDC). Physicians would not be limited to the number and strength of opioid tablets they can prescribe for SCD patients. This ruling came amidst an outcry from engaged SCD advocates in the community. Indeed, the CDC began to reconsider its own 2016 ruling when it comes to morphine-equivalents prescribed SCD patients, though by the end of the year no official revision had been issued.

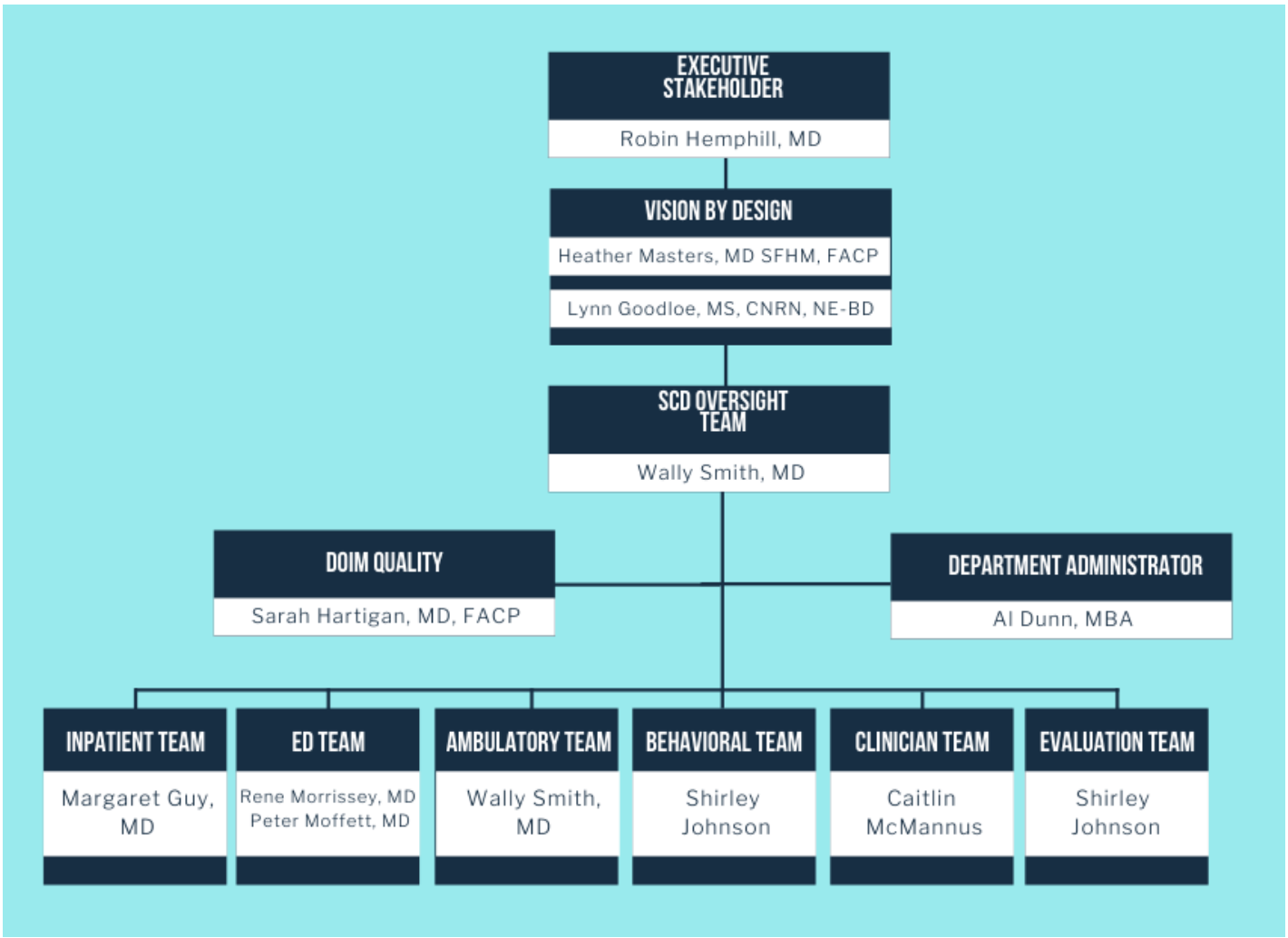
In parallel, a number of national entities, including the American Society of Hematology, CDC, the NIH, and the Patient Centered Outcomes Research Institute (PCORI), all began or expanded initiatives to recognize more the lethality, social and economic impact, and disparities in care related to adult SCD. Each initiative sought in some way to mitigate the problem that we don't have a medical care system ready to care for SCD adults, despite the fact that the large majority of SCD patients are adults.

SCD ADULT MEDICAL HOME MULTIDISCIPLINARY TEAMS

The SCD Adult medial Home provides a multidisciplinary clinic offering a patient-centered approach to care for adult patients with SCD. There are 3500 adult sickle cell patients who are living in Virginia and our adult program cares for over 600 of these patients, but there is still work to do to reach each one. Our program is providing a better state of health for the sickle cell patients in Virginia.

Dr. Wally Smith is the lead clinician for the adult SCD program at VCU. Formal Co-Investigators include India Sisler, MD, and leader of the Pediatric sickle cell program, Nadirah El-Amin, DO a pediatric sickle cell provider, and Thokozeni Lipato, MD, co-investigator in the adult program. Shirley Johnson, LSW, is the program manager for the adult sickle cell program who oversees the day to day operations of the medical home. Available adult study coordinators include Daniel Sop, MS and Esoterica Berry, AnD,BS,CCRC. We also have three available sickle cell providers who see our patients, Mica Ferlis, MSN,ACNP-BC, and Caitlin McManus, MSN,AGPCNP-B and our newest clinical provider, Emily Sushko, MSN,AGNP-C,CEN. We also added two dedicated Registered Nurses, Justin West and Kate Osborne to the team and we will be hiring a clinical psychologists and another physician in 2020.

All adult VCU SCD physicians have extensive experience in management of SCD. Dr. Smith has cared for adults with SCD almost exclusively since 1984 at two institutions, the University of Tennessee (1984-1991) and VCU Health (1991-present). Dr. Lipato has cared for SCD patients for more than 10 years at U Minnesota and VCU.



INPATIENT TEAM

The Inpatient Team is comprised of academic hospitalists and advanced practice providers, clinical pharmacists, nursing leadership and bedside nurses who are all independently interested in care and management of sickle cell disease. The inpatient team was created by an engaged group of individuals several months prior to becoming an arm of the overall Adult Medical Home. The group has worked to expand their base knowledge of sickle cell disease and as a result apply innovative practices to inpatient pain management. The team has completely revamped inpatient management of sickle cell vaso-occlusive crises with a novel tiered oral therapy approach as well as a focus on function and mobility for the patients. The team has been able to do this through collaboration with the outpatient and ER teams and works to regularly update patients' individualized treatment plans based on clinical changes as well as psychosocial factors affecting the patient's care. In 2020, the team hopes to expand their collaboration with the medical home through providing improved inpatient transitions of care for our graduates from the pediatrics program.

Meet Our Inpatient Champions

Margaret Guy, MD

General Internal Medicine Hospitalist
Physician Lead of Inpatient Sickle Cell Committee

Lauren Cherry Magee, Pharm.D, BCPS

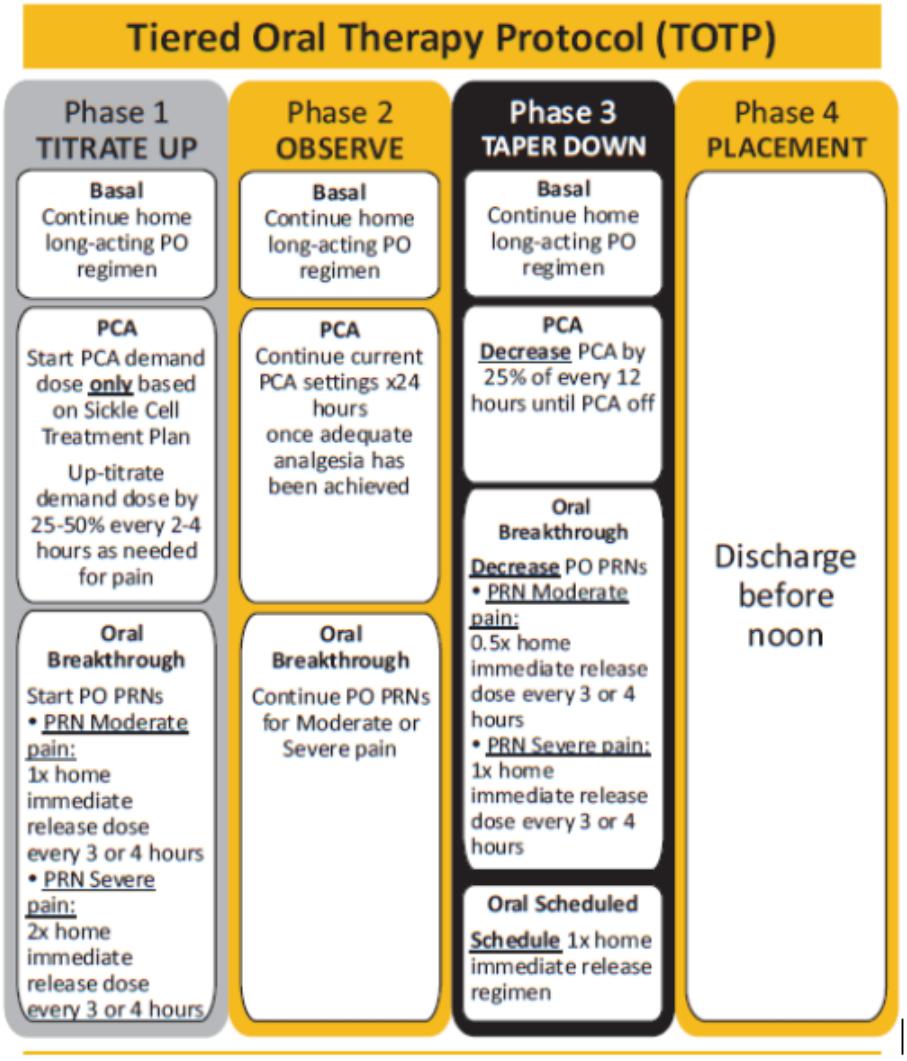
Clinical Pharmacy Specialist, Internal Medicine
Clinical Assistant Professor, VCU School of Pharmacy

VCU Clinical Pharmacists, Lauren Magee and DaleMarie Vaughan, present their poster entitled Development of a Standardized Treatment Protocol for Sickle Cell Vaso-Occlusive Crisis by an Interprofessional Inpatient Committee at the Emswiller Interprofessional Symposium in Richmond, VA.

INPATIENT TEAM
Tiered Oral Therapy

Tiered Oral Therapy Protocol (TOTP) is a standardize pain management algorithm that is a novel concept in inpatient pain management for sickle cell patients experiencing a vaso-occlusive crisis (VOC). This algorithm was created and implemented by a multi-disciplinary team with goals to:

- Standardize the treatment of patients experiencing a vaso-occlusive crisis across the hospital system by improving the coordination of inpatient and outpatient treatment
- Improve patient satisfaction
- Decrease Length of Stay
- Decrease Readmission Rate



Results Highlights

Following initiation of the tiered oral therapy protocol, we evaluated 31 patients who received therapy and compared their TOTP admissions with their own historical controls. As a result we found utilization of TOTP resulted in reductions in LOS (21%, 4.7 days controls vs. 3.7 days TOTP, $p<0.014$), and hospital charges ($1,627,497.73 controls vs. $944,528.96 TOTP, $p=0.1403$), and an insignificant increase in the 30-day readmission rate (35.6% controls vs. 42.7% TOTP, $p=0.5027$). Overall there was a reduction in total MME administered during the inpatient admission: 361,824 MME pre-TOTP vs. 255,036 MME post-TOTP. Additionally, there were no TOTP vs. historical control differences in opioid-related safety events which were measured by opioid-related rapid responses, naloxone administration, or falls.

INPATIENT TEAM
Fuctional Pain Assessment

The Inpatient Team chose to pursue a Functional Pain Assessment:

- Currently, there exists no valid and reliable method of objectively quantifying an individual's experience of pain .
- The need to move away from a 0 – 10 pain score as it is not the best indicator of pain especially within in a chronic pain population.

Patient Label

Patient's REALM-R Score: _____ (On Admission)

Functional Pain Assessment

Date: _____ Time: _____

How is my pain **today**?

a. What is your current pain score on a scale from 0 – 10? _____

b. How hard is it for you to do the activities listed below?
- Circle the word that matches how you feel **right now.**

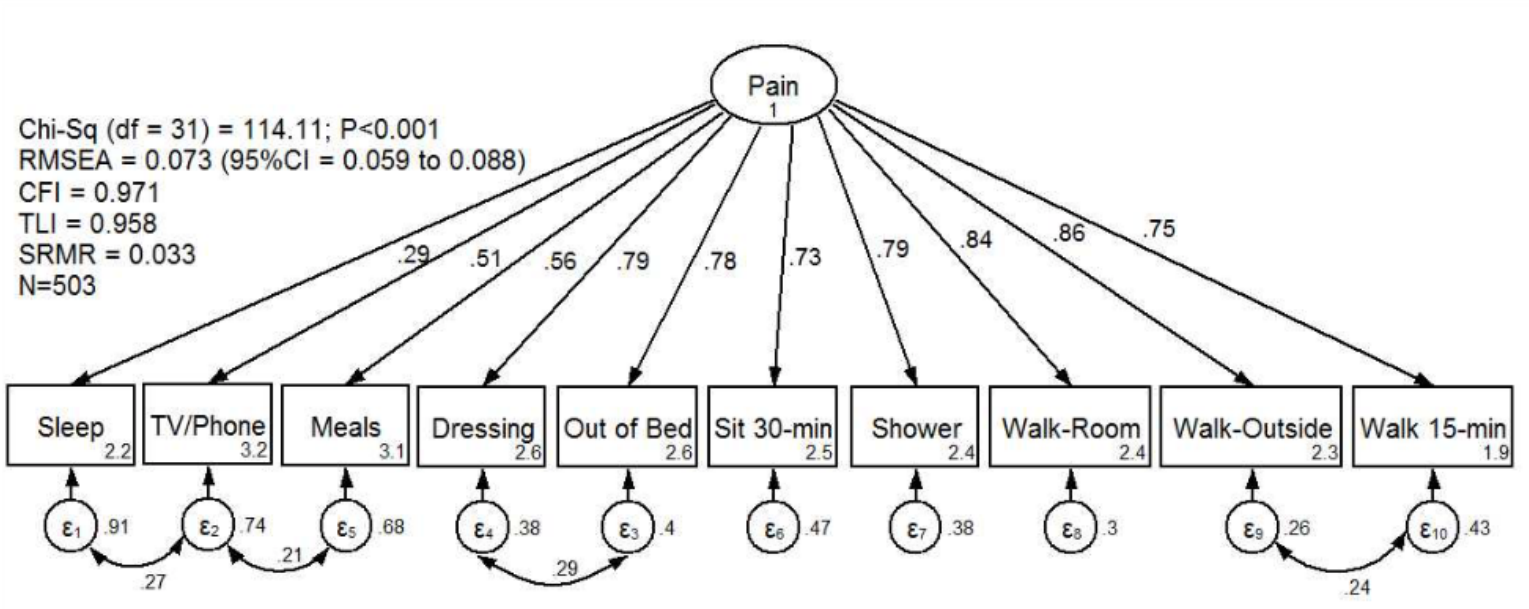
Questions					
1. Stay asleep at night	Very Difficult	Difficult	Neutral	Easy	Very Easy
2. Watch TV, talk/text on the phone, or read	Very Difficult	Difficult	Neutral	Easy	Very Easy
3. Get up from the bed	Very Difficult	Difficult	Neutral	Easy	Very Easy
4. Put on or change your hospital gown or clothes	Very Difficult	Difficult	Neutral	Easy	Very Easy
5. Eat your meals	Very Difficult	Difficult	Neutral	Easy	Very Easy
6. Sit in a chair for 30 minutes	Very Difficult	Difficult	Neutral	Easy	Very Easy
7. Take a shower	Very Difficult	Difficult	Neutral	Easy	Very Easy
8. Walk around in the room	Very Difficult	Difficult	Neutral	Easy	Very Easy
9. Go outside your room	Very Difficult	Difficult	Neutral	Easy	Very Easy
10. Walk without stopping for 15 minutes	Very Difficult	Difficult	Neutral	Easy	Very Easy

☐ Check if patient is nonverbal or if patient was not able to complete form

INPATIENT TEAM
Functional Pain Assessments Results

Results Highlights

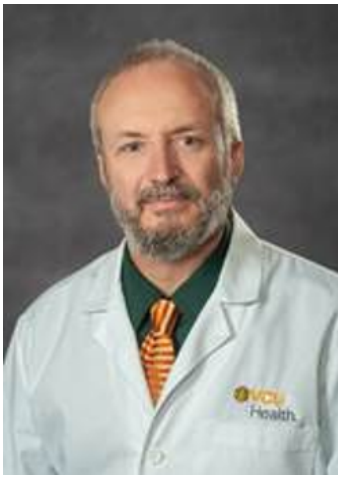
During the study period, 504 assessments from 86 unique patients over 170 distinct admissions were completed. Of the 86 unique patients, 54% were females with mean age of 31.5 (SD8.0) years. The length of stay was 7.1 (SD6.9) days; minimum 0 days, max 38 days. NRS mean was 6.8 ±1.9 and FSPA mean was 27±8.0. Correlation was moderate and highly significant (Pearson's r = -.4342, p <.0001). The CFA indicated that the one-factor structure was a good fit for the data using routine diagnostic statistics (Figure). Using item response theory analysis, we found that the item discrimination varied from 0.56 to 4.1 while difficulty of the items covered broadly the latent variable of the functional status with pain with values ranging from -2.8 to 7.5.



Development and validation of FPSA, while not complete, has yielded a brief assessment tool which may be used daily to improve communication between adult SCD VOC patients and their inpatient clinicians. FPSA may aid the judgment and negotiation of readiness for discharge of these patients, in order to prevent unnecessarily short or long hospital lengths of stay as well as improve patient and provider satisfaction. Future validation could compare FSPA to other longer-term pain and functional assessment tools, determine its ability to predict VOC discharge, and determine whether its use changes VOC discharge behavior.

ED TEAM

Meet Our ED Champions



Rene Morrissey, MD
Assistant Professor in Emergency
and Internal Medicine

Peter Moffett, MD
Associate Professor
Emergency Medicine Residency

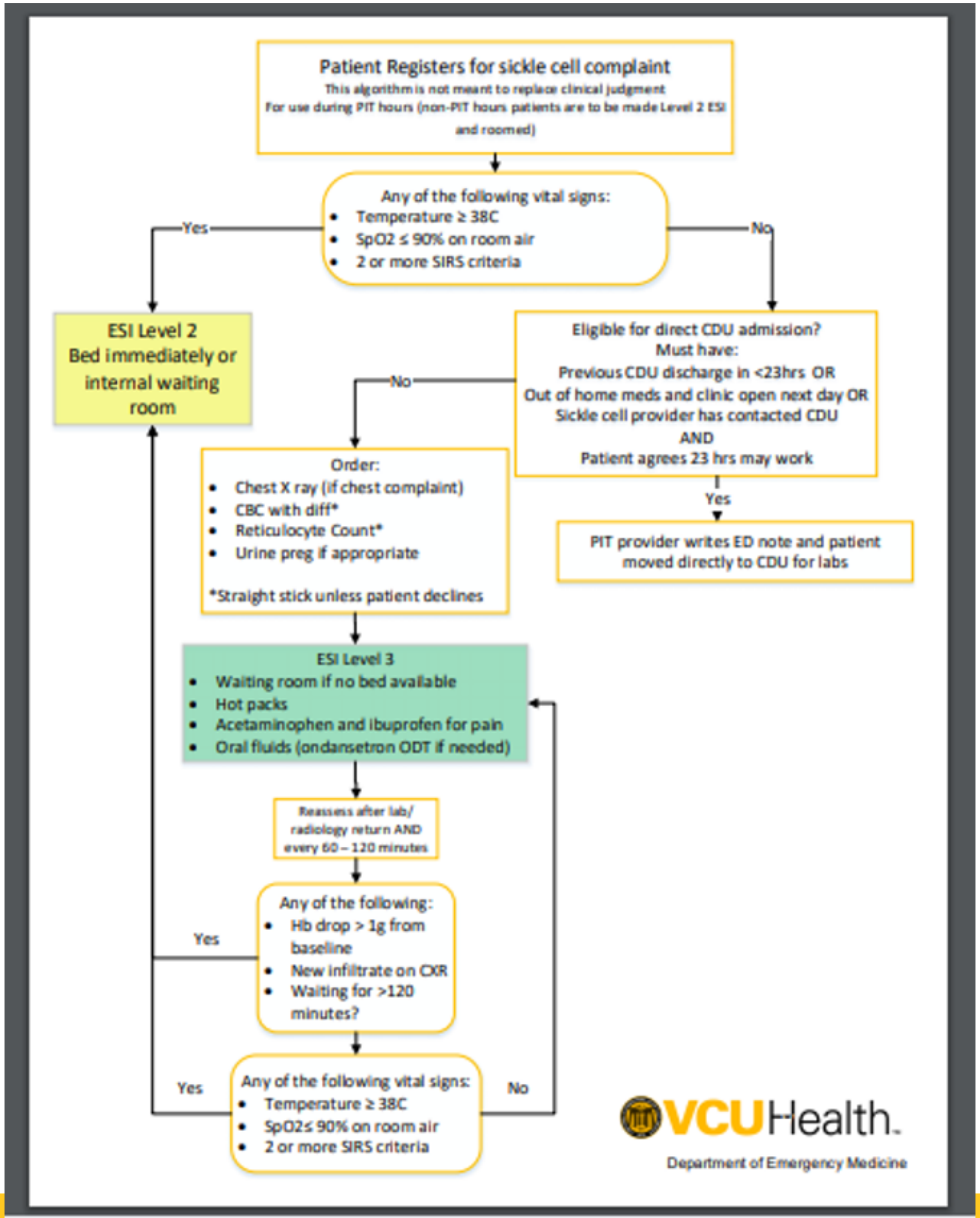
The ED Sickle Cell Committee has a number of providers working hard behind the scenes to help optimize the care of the sickle cell patient in the emergency department, and to collaborate across the continuum of sickle cell care to improve patient outcomes while decreasing healthcare costs. This has been accomplished by creating novel pathways for triage, standardizing care in the department, absorbing increased care in the emergency department to further the health system goal of decreased inpatient costs, and analyzing data to ensure our goals are met.

Create

- A novel triage process was created to streamline care for acutely ill sickle cell patients, while also providing expedited care while in the waiting room for our middle acuity patients.

- Implemented a direct to ED Clinical Decision Unit (CDU) process for select patients (see map on Page 13).

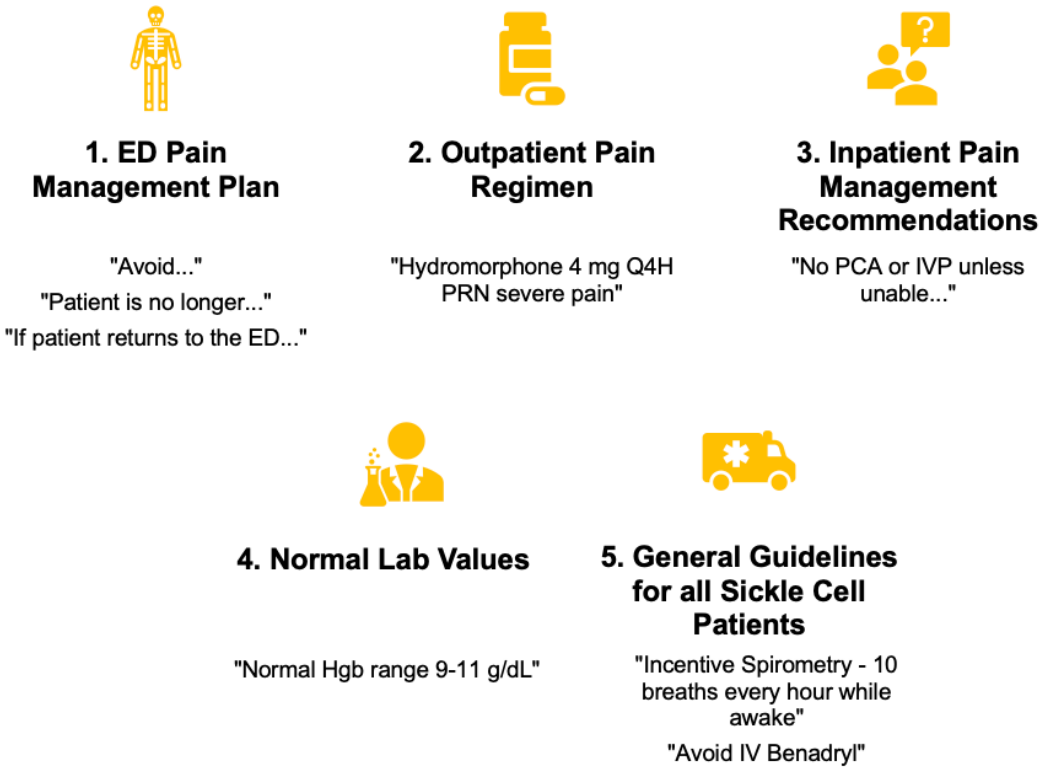
ED TEAM
Create



ED TEAM
Standardize and Support

Standardize

- Work with the sickle cell team to adjust standardized care plans for patients to support consistent, quality, and appropriate care for each patient.
- Created a Sickle Cell Power Plan which allows orders to be standardized, and allows for administration of multiple doses of pain medication by the bedside nurse (with provider initiated instructions).
- Frequent communication to department staff to re-emphasize care plans and standardized approach to patients.



Support

- The emergency department supports the health system goals of reducing overall costs, by absorbing increased number of patient visits within 72 hours of discharge (from the ED or hospital) but managing to decrease the number of admissions to inpatient beds.
- The emergency department supports the continuum of care for each patient and the committee works hard to help address psychosocial barriers for individual patients.

ED TEAM
Analyze

- This year we have worked with Enterprise Analytics to create a monthly report to help the ED team analyze such metrics as time to provider, time to first narcotic, and disposition location.
- Co-authored an abstract about the interventions that was accepted by the Journal of Sickle Cell Disease and Hemoglobinopathies.

Results Highlights

Prior to the interventions there were 3,352 ED visits by 681 patients. After the interventions, this number decreased to 2,518 visits among 659 patients (Table 1). There was a significant decrease in the inpatient length of stay from 137.3 hours to 107.9 hours (difference of -29.4 hours 95%CI -15.7 to -43.1 hours) (Table 2). Additionally, the number of admissions from the ED to the hospital decreased from 19.3% to 15.2% (difference of -4.1% 95%CI -1.8% to -6.4%).

Table 1: Demographics

	Pre-Intervention	Post-Intervention
Age in years, mean (SD)	38 (14)	38 (14)
Female n (proportion)	395 (58%)	389 (59%)
Total ED visits per year	3,352	2,518
Unique patients per year	681	659

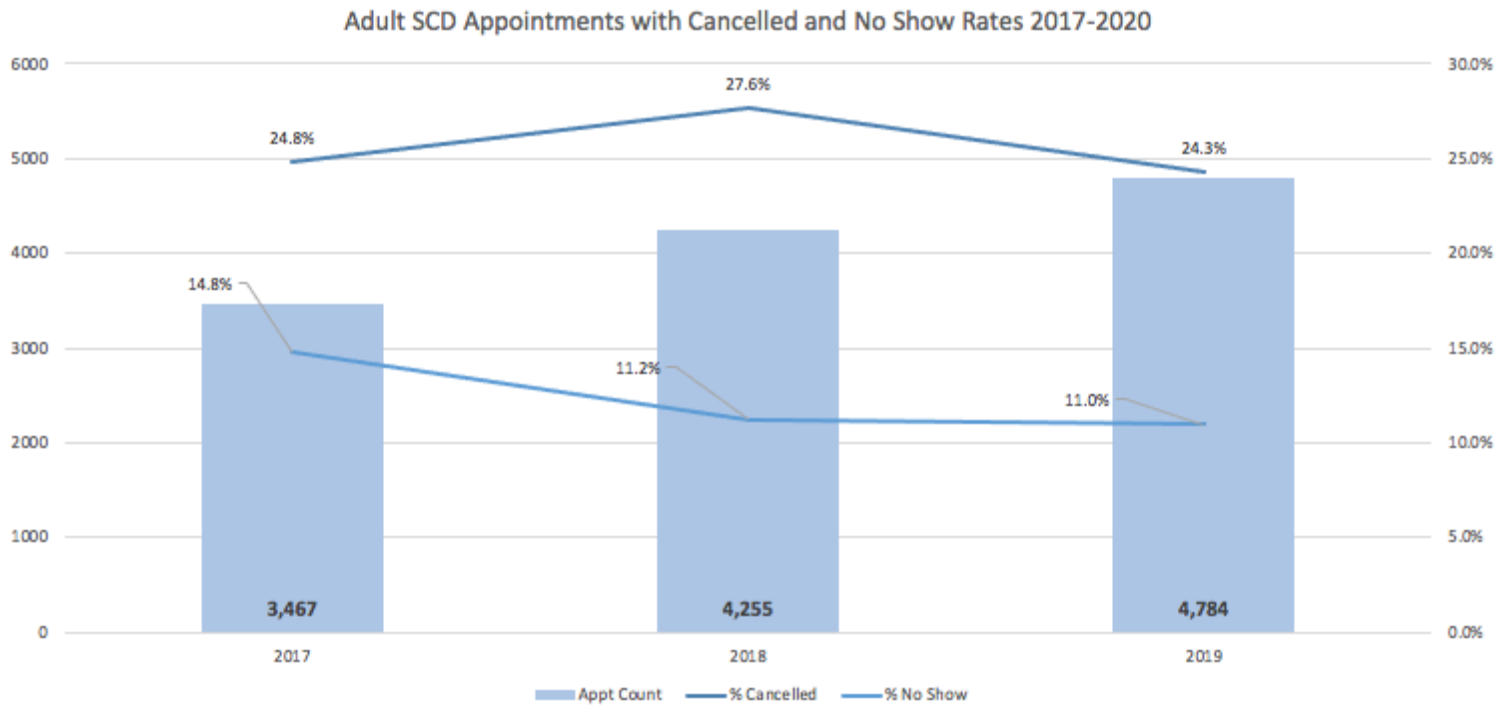
Table 2: Key Metrics

	Pre-Intervention	Post-Intervention	Different (95% CI)
ED length of stay, mean (hours)	2.3	2.5	0.1 (-0.1 to 0.4)
Admitted (%)	19.3%	15.2%	-4.1% (-1.8% to -6.4%)
Inpatient LOS, mean (hours)	137.3	107.9	-29.4 (-15.7 to -43.1)
ED returns within 72 hours of discharge (from ED or hospital)	14.1%	17.7%	3.6 (1.4% to 5.9%)

AMBULATORY TEAM

The Ambulatory Team team began meeting monthly after the ED team. It consists of SCD clinicians, the project manager, and ambulatory administrative and clinical staff. It meets in the SCD clinic space. It intervenes to improve clinic patient visit flow processes, scheduling concerns including waiting times, "bumps" due to provider scheduling changes, no-shows, prior authorizations for prescriptions, patient complaints, ambulatory transfusion scheduling, preparation, and policies.

Results Highlight: Cancellation rate improved by 11.9% from 2018 to 2019. Ambulatory care visits increased by 529 visits from 2018 to 2019.



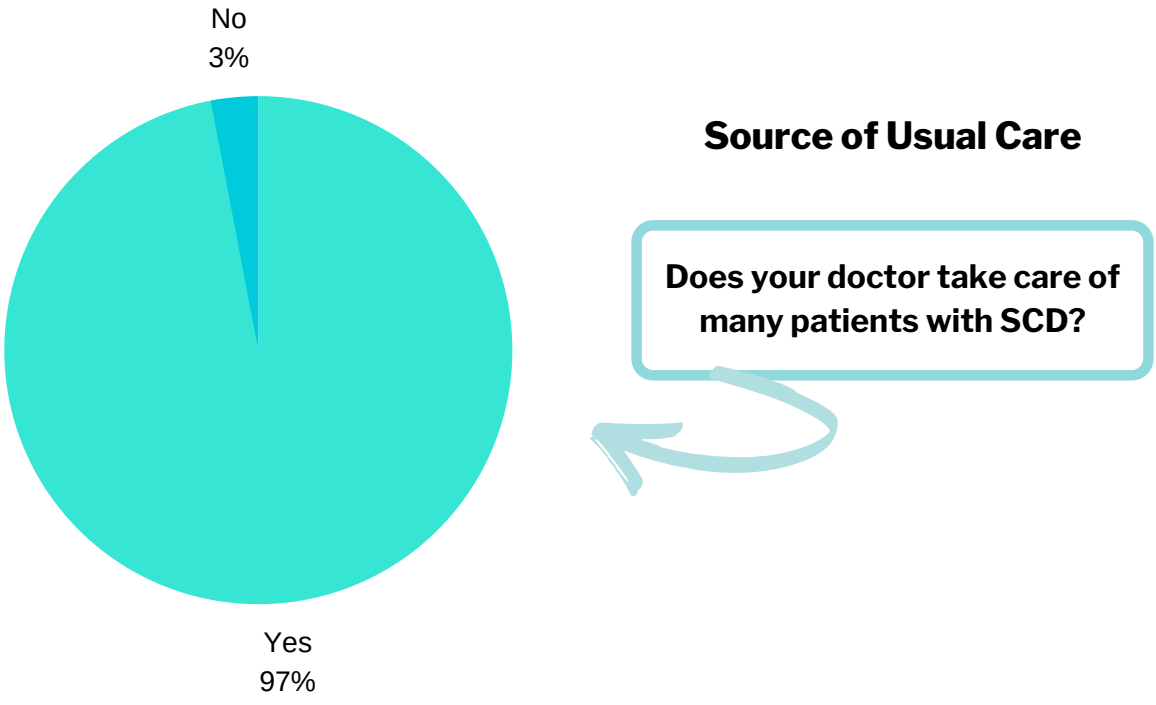
In 2019, additional measures and effort support were put in place to ensure visit compliance.

AMBULATORY TEAM

Ambulatory care of adults with SCD requires helping patients navigate past the pitfalls of transition from an embattled, illness-oriented childhood to a healthy, responsible adulthood , improve their sickle cell knowledge, attitudes, confidence, and skills, engage in adult ambulatory hematology and specialty care, not overutilize costly emergency care, adhere to disease remission therapies such as hydroxyurea, deal with pain and organ failure as they express themselves throughout the disease course, and find meaning and value in their relationships, employment or school, and other aspects of their lives.

The paucity of adult care providers makes comprehensive care within an Adult Medical Home a critical service. SCD patients often lack a primary care provider, or view their SCD doctor as their primary care provider. (Figure below) The outpatient setting is where medical care is most embedded in a comprehensive plan of care and life-goal building that takes into account the SCD history and patient's current state of health. Improvisations to provide the comprehensiveness and goal building include utilizing community-based organizations, "borrowing" from existing resources for cancer care, and obtaining grant, state, or private support to build resources. We have done each in the Adult Medical Home. To manage SCD patients otherwise is to invite them to resort to using the Emergency Department as their source of care, thereby further alienating themselves from physicians, and the health care system's willingness to care for them.

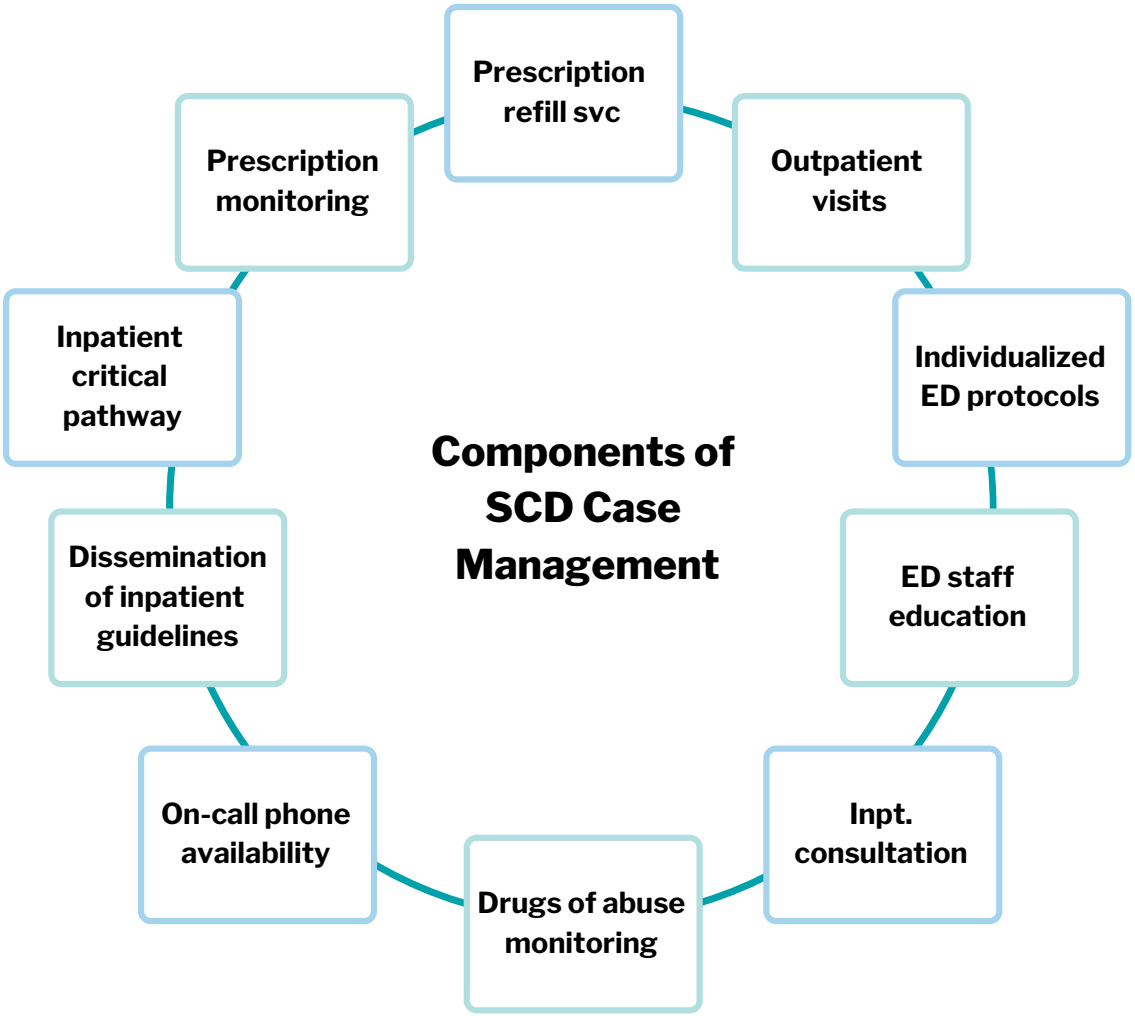
SCD patients often lack a primary care provider, or view their SCD doctor as their primary care provider.



AMBULATORY TEAM
Structure

Thus, our ambulatory care team is structured to provide not only medical care but also medical Case management (CM). CM is an evidence-based intervention strategy that can use patient centered care (PCC) to reduce ED and hospital utilization, enhance clinic utilization, enhance disease awareness, self-efficacy, self-advocacy, and self-care, and improve social and behavioral aspects of health-related quality of life. Components of case management are outlined in the figure below, and clearly cross various levels of care and points of entry into the health care system. But they *originate with a care plan born in the ambulatory setting.* Community health workers (CHWs, currently 3 in our system) and Clinical Social Workers (CSWs, currently 1 in our system) are evidence-based health management strategies used in case management to build trusting relationships and build holistic treatment plans. We have integrated these workers into a team that includes 2 physicians and an advanced practice provider, currently a nurse practitioner, who prescribe for and care for the patients in the ambulatory setting, for a holistic approach to ambulatory care.

We have also recruited two nurses who assist with medical triage of phone inquiries and complaints, assessing the need for medication or medication changes, proposing prescription refills, requesting prior authorizations for prescriptions, arranging appointments, or referring patients to urgent care.



AMBULATORY TEAM
Structure Cont.

Process

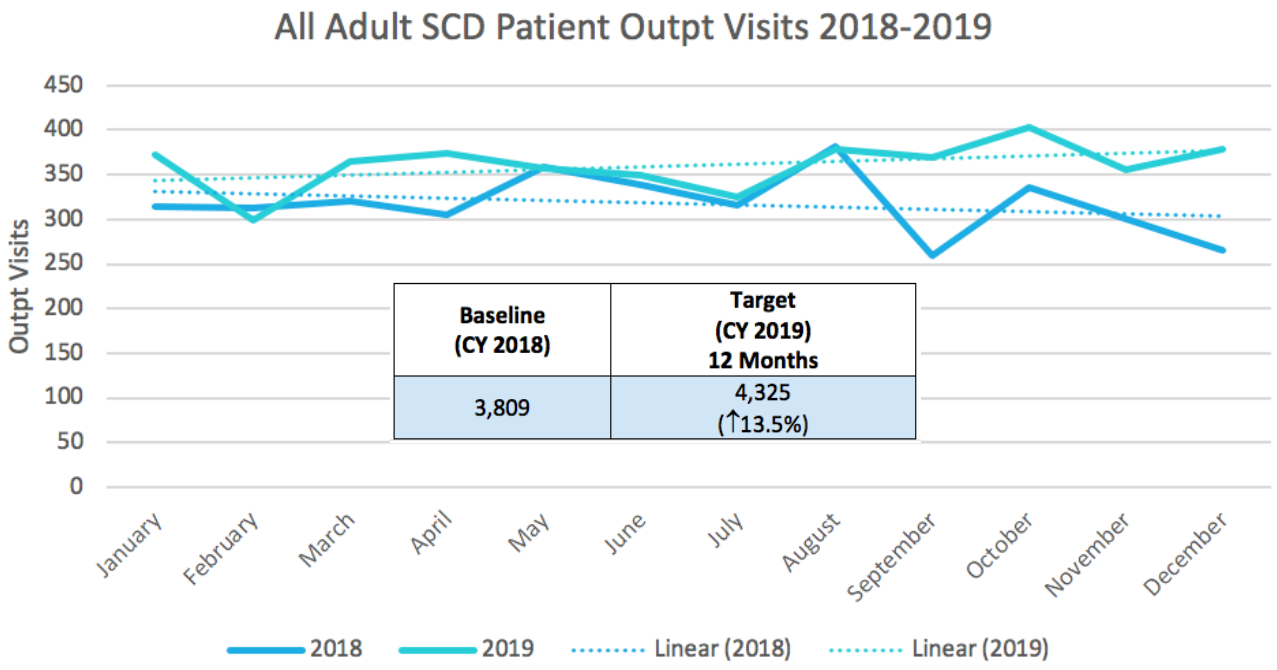
Patients are seen 5 days per week by either a physician or an advanced care provider. The clinic opens at 8 am and closes at 5 pm. Visits last from 20-40 minutes usually, but may be extended for occasional group visits, which may include a patient navigator, social worker or therapist assigned to the SCD team, and other prescribing SCD providers who have input into the patient's ambulatory or inpatient care. Reception, laboratory and appointment scheduling are each available on the 4th floor of the Ambulatory Care Center. Research visits/protocols are conducted coincidental to or contiguous to these visits when feasible.

Transfusions

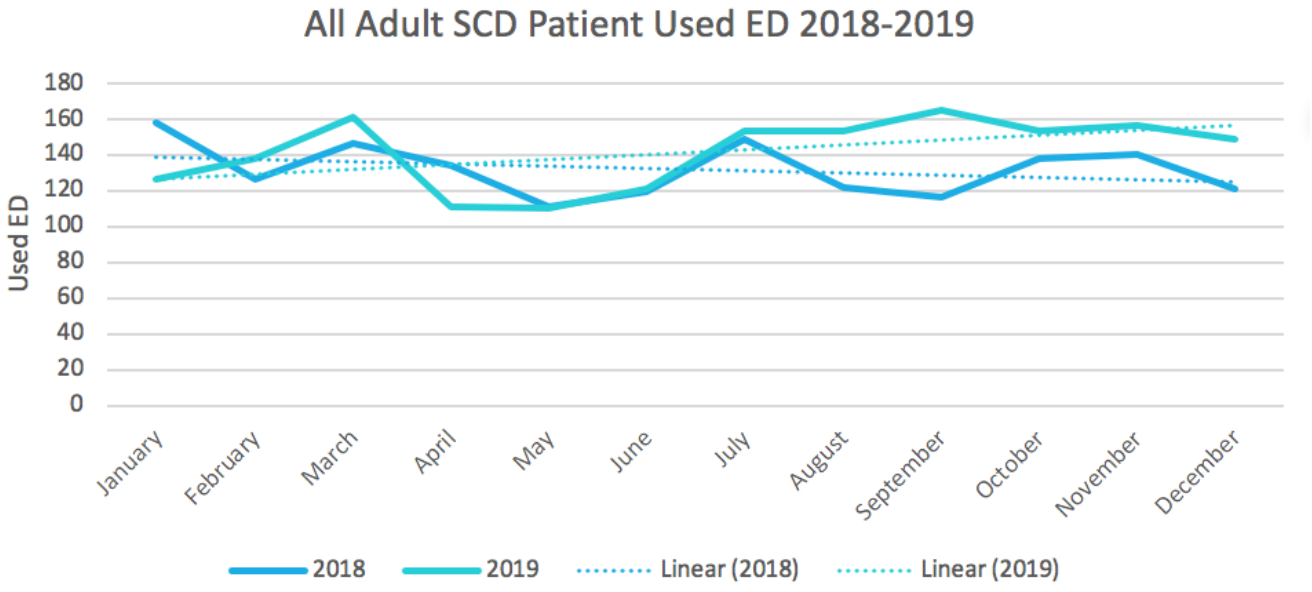
Simple transfusions are conducted on the 5th Floor of the Ambulatory Care center, usually not on a clinic day. Exchange transfusions are conducted in the Aphaeresis unit in the hospital, not on clinic days. But pre-procedure CBCs are drawn in the SCD clinic laboratory, and may be done on clinic days.

AMBULATORY TEAM
Results

Outpatient Visit Volume vs. ED Visit Volume



Baseline (CY 2018)	Target (CY 2019) 12 Months
3,809	4,325 (↑13.5%)



Year-to-year, outpatient visits climbed from 2018 to 2019. We consider that an improvement, although ED for care went up in that same period. The average number of outpatient visits per patient was 7.0, whereas the average number of ED visits per patient was 2.8 in 2019. In general, the ED reliance ratio is considered a measure of the efficiency of care for ambulatory-sensitive-conditions like Asthma and SCD. Our ED reliance ratio was 0.39.

AMBULATORY TEAM
Results

Outpatient Experience of Care

46 patients were surveyed about their outpatient experience using the Feedback Survey. In general patients found the care to be respectful and reported high rates of satisfaction. Of patient who had sought care in the previous six months from the suvey, 89.6% reported being always or usually satisfied with the care they received from their outpatient provider.

Lessons Learned

We have learned that setting up an adult medical home takes time, energy, planning and staff support. The ideal adult plan for care for each patient begins with at least annual, but possibly more frequent, case management discussion by the Adult Medical Home care team, where details of prior and future planned management are discussed. At the outset of the medical home, these plans were not all in place, but two years into the program, they are far along, even for patients with little contact with our system.

We have also learned that winning the patients' trust is an invaluable asset when managing ambulatory patients. Ambulatory patients are free to not come to clinic, to not follow suggested treatments and tests, and to disagree with diagnoses and seek second opinions, including from the internet and each other.

We have also learned we may sometimes set unrealistic rules for our patients, who are quite vulnerable. The ideal adult care model involves an autonomous patient that makes sound independent judgments. We have therefore encouraged and tried to enforce near-complete patient autonomy for patients, only to learn they need family to help them navigate not only when they are acutely infirm, but also often when at their best. Issues such as cognitive impairment due to cerebral ischemia, delayed puberty, social isolation or maladjustment, anxiety and depression, are the norm for these patients. We still encourage families to back off, and to give their patients room to assume the adult patient role, in order not to cripple them for life. But ofen we cannot "turn off" the autonomy transfer process. We welcome families to join patients for ambulatory visits, and patients fare well because of the extra information significant others provider about patient history, physical complaints, emotional state, and caregiving experience. Advocacy becomes second nature to these families. Transportation, assistance with activities of daily living, encouragement to adhere to medical therapies, and reporting acute illness episodes to providers are a few of the invaluable roles these family members play. Adult patients of all ages often fail to recognize their own limitations and mortality, and need this kind of help.

CLINICIAN TEAM

The Sickle Cell Clinical Team is now fully staffed with two physicians, an inpatient nurse practitioner, an infusion nurse practitioner, and an outpatient nurse practitioner. Communication and collaborative care for patients has developed over the year and now includes treatment plans for a number of patients, an increase in clinic visits, and increase in patient satisfaction. The providers aim to discuss the following topics on a regular basis to allow for improvements and revisions:

Visit Protocols

The frequency of visits in the clinic are determined based on individual need, but range between weekly visits to every four months. In addition to the state of the patient's sickle cell disease, there are other factors that are considered in scheduling the next visit and when present, a sooner clinic visit may be necessary. These factors include:

- Admission in the hospital
- Higher than normal utilization of the emergency room
- Concern for opiate misuse
- Behavioral health needs

Additionally, the clinic also accepts new patients. New patients are seen by either the outpatient nurse practitioner or one of the physicians in the clinic. Now that the sickle cell team has a fully staffed provider list, clinic visits have increased in frequency and patients are able be seen more often for assessment and evaluation.

Transition

For over 10 years, the adult SCD team has met with and collaborated with the pediatric SCD team, led by Dr. India Sisler, in order to formally hand off patients from one care setting to the next. Pediatric to Adult SCD Transition has a national concern, and has been the topic of two external grants to VCU. The first pilot grant created an intervention curriculum and a readiness assessment scale that is now used nationally—the TIP-RFT. The second external grant is a PCORI intervention grant, a site cluster-randomized controlled trial of peer-mentoring plus QI interventions, vs QI interventions alone. VCU is in the QI interventions alone arm of the trial. This PCORI grant has moved the pediatric and adult SCD teams towards working more intently with the 15-25 year old transition age patients.

During 2019, we held monthly support groups for 18-25 year olds, led by the MSW from the Behavioral Health Team. Activities consisted of education and social outings. Further, we have developed more thorough introduction procedures to receive these patients into the adult SCD clinic from the pediatric clinic. The outpatient nurse practitioner sees the transition age patients and introduces them to the adult clinic, the changes in process, and ways to communicate with adult providers to make the transition as easy and comfortable as possible. The TIP-RFT and other evaluation tools are being administered to assess patients' readiness and ability to function as adults, both at the time of care transfer, and yearly until age 25. While we seek to fill the MSW position, it is the hope that the support groups can continue for individuals at this vulnerable age.

CLINICIAN TEAM

Inter-Provider Communication

Communication occurs within the provider team, within the whole Sickle Cell Medical Home (patient navigators, nurses, prior authorization specialist), and also with emergency room providers, specialists, and non-VCU providers. There are weekly Medical Home team meetings where specific patient cases are discussed and treatment plans can be made with input from all providers. Additional communication occurs on a day-to-day basis via texting or calling between team members and serves as the most efficient way of sharing information. Cerner electronic medical record messaging makes communication with other VCU providers easy and efficient in collaborating care. For those providers outside VCU, the 24/7 on-call pager is available if a provider needs to speak to another provider, and can also call the clinic and leave a message with the triage nurse.

Call Schedule

There is 24 hour, 7 day per week on-call pager that is covered by one of the providers at all times. The pager is covered during the day by the inpatient nurse practitioner (8am to 5pm) and overnight (5pm to 8am the following day) and weekends are rotated between the providers. The on-call provider schedule is formed in a collaborative manner to allow for work-life balance and is coordinated by the inpatient nurse practitioner. This has helped patients reach a provider in emergencies and allows a provider to be available for any inpatient, emergency department, pharmacy or outside hospital concerns.

Treatment Plans

Individualized treatment plans were started as a way to assist Emergency Department providers with dosing opiate medications to adequately treat our patients' pain and potentially avoid admission to the hospital. These treatment plans are based on outpatient opiate dosing, but serve to allow increases in opiates when necessary. When a patient has been seen by the inpatient nurse practitioner either in the emergency department or inpatient setting, efficacy of opiate dosing can be evaluated through assessment and patient report. The intravenous dosing is calculated by the inpatient nurse practitioner, along with frequent conversation with the patient to ensure adequate pain control is being achieved.

The treatment plans include:

- Emergency department pain management plans
- Admission criteria for individualized patients
- Objective signs of sickling for provider reference
- Outpatient pain regimen for reference
- Inpatient pain management recommendations
- Individualized "normal" lab value ranges
- General guidelines for sickle cell patients

CLINICIAN TEAM

Treatment Plans Cont.

Tiered oral therapy protocol

- Inpatient management relies on the use of intravenous and oral opioid doses
- This phased approach allows upward dose titrations to achieve rapid and adequate analgesia (goal <24-36 hours), holding pattern to allow for rest and recovery and dual phase process to down titrate medications in preparation for discharge
- Intravenous doses are calculated based on home use and prior tolerance/necessity and can be adjusted per patient report and physiologic indicators (AKI, hypoxia, hepatic injury etc)
- Oral doses are typically derived from the outpatient prescription (may be adjusted based on patient reports of actual use pattern)
- This aims to be effective, efficient, and safe for patients as well as a guideline to make management of vaso-occlusive pain a little easier for our colleagues

Focus on Opioid Management

Many sickle cell patient require chronic opiate management for their pain, due to this, frequent monitoring is done in the outpatient setting to ensure safety while prescribing. While in clinic, a urine drug screen is done at least every 3-6 months or more frequently if there is concern for diversion or substance abuse. Clinic visits occur at least every 2-3 months to evaluate pain, use of opiates, and management of prescriptions.

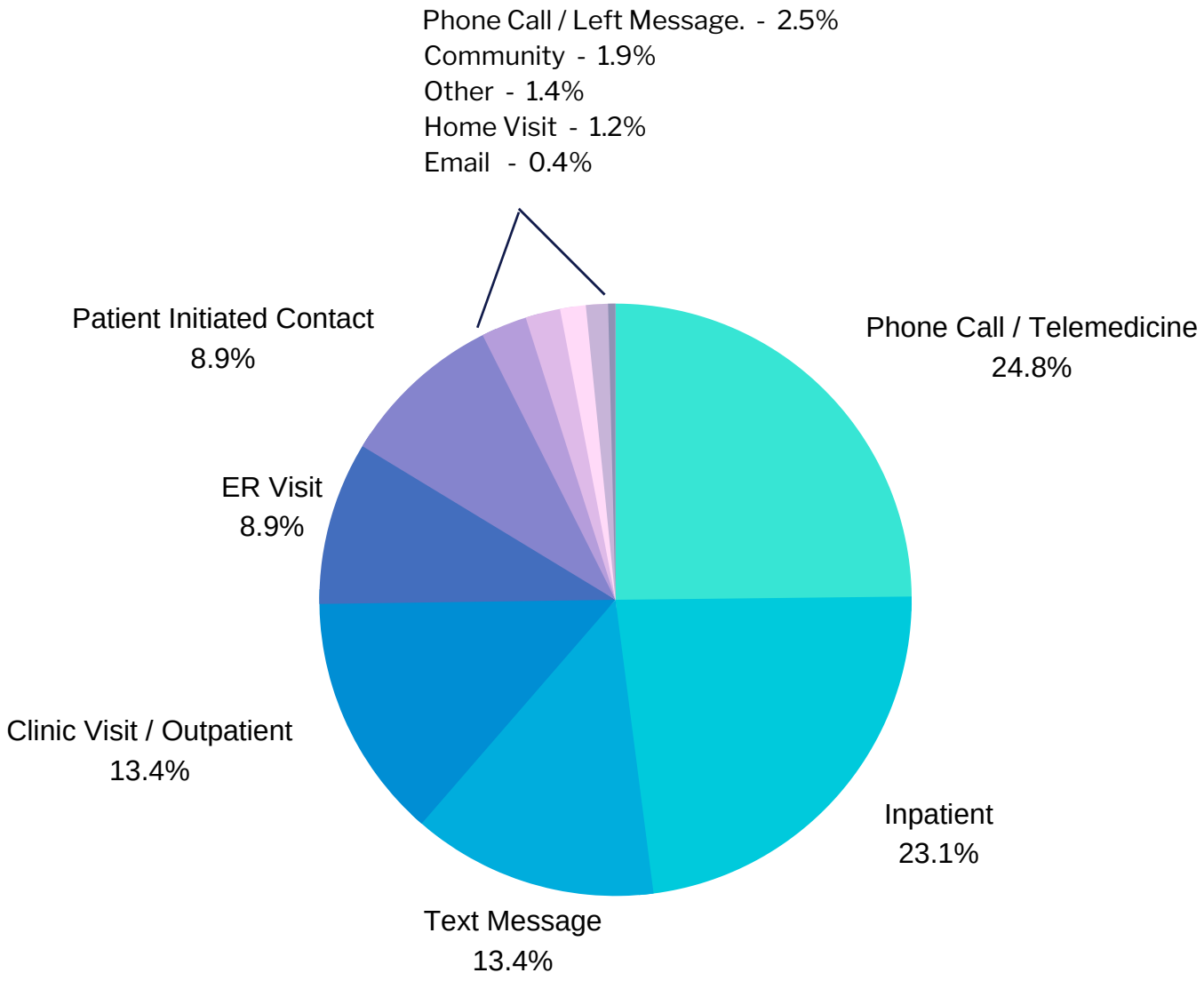
Categorization of patients has started that groups patients based on hospital/emergency room utilization and opiate medication titration. This categorization is still being perfected but helps in determining what behavioral health or clinical interventions are necessary.

Transfusion Management

The use of monthly exchange transfusions (apheresis) or simple blood transfusions is abundant for Sickle Cell Disease patients. These interventions are used for stroke prophylaxis, profound anemia, and in rare cases, pain control. For those getting monthly exchange transfusions, the Transfusion Medicine team is involved and works with the SCD team in management of these patients. For those getting simple blood transfusions, the outpatient nurse practitioner works closely with the Infusion Center staff to place orders for blood for the Blood Bank, infusion orders for the nurses, and lab work that may be necessary. The Infusion Center scheduler keeps these patients on a set schedule. Annual check-in meetings with the transfusion program allow revisions of protocols and in the quality of blood resources. The infusion nurses communicate with the nurse practitioners via page or Cerner message if issues arise.

PATIENT NAVIGATORS

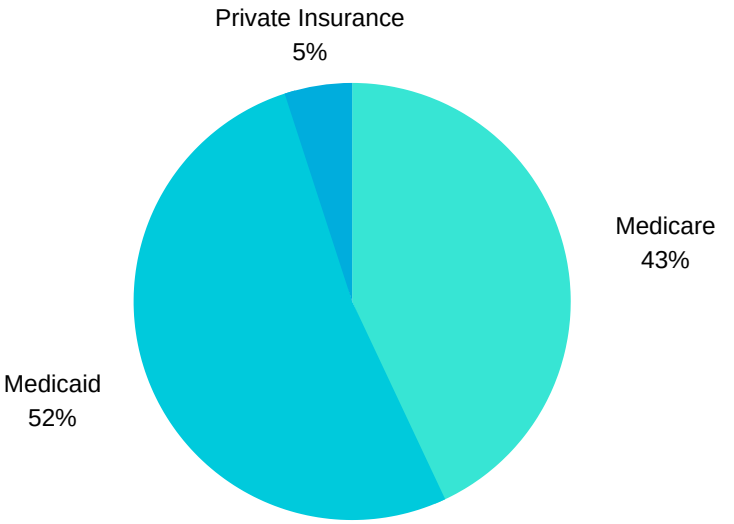
A Month in the Life of a Patient Navigator



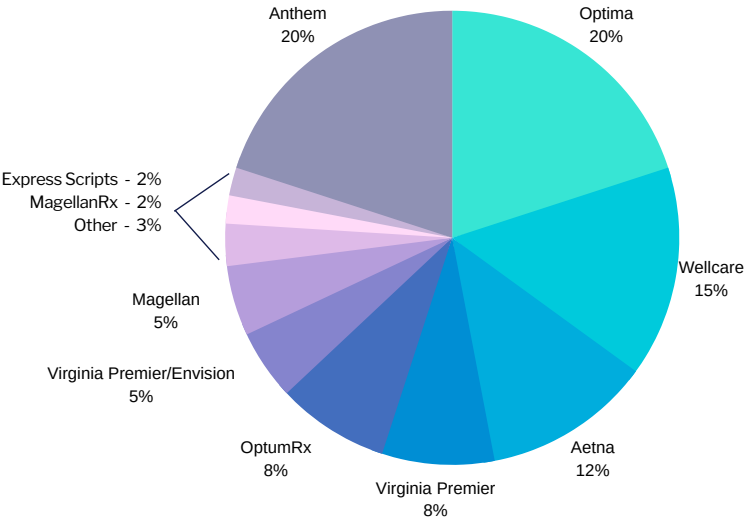
PRIOR AUTHORIZATION

Typical Effort for a Prior Authorization Specialist

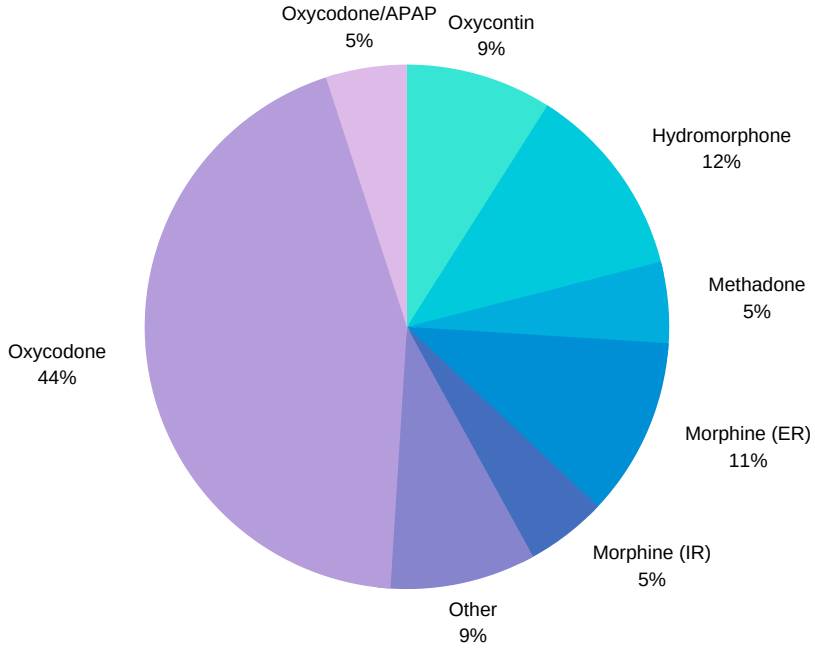
Prior Authorization Primary Payers



Prior Authorization MCOs



Prior Authorization Medications



TRANSITION TEAM

Meet Our Transition Champions

India Y. Sisler, MD
Associate Professor, Medical Director
Pediatric Hematology Oncology

Jennifer Newlin, PA
Physician Assistant
Pediatric Hematology Oncology

Nadirah El-Amin, DO
Assistant Professor
Pediatric Hematology Oncology

Alma Morgan
Education Coordinator
Pediatric Hematology Oncology

Alesha R. Lieser
Licensed Clinical Social Worker
Pediatric Hematology Oncology

TRANSITION TEAM

The Transition Team is a collaborative effort between the Pediatric and Adult Programs with the focus of care, for young adults ages 18-25, which is an extremely vulnerable population for patients with Sickle Cell Disease. While children are in high school, the pediatric program begins working with the patients to prepare them for young adulthood following high school, including services such as clinical care, psychological evaluations, education coordination and a disease specific education on how to care for their disease. There have been years of concern that once a patient graduates, exactly how prepared they are for compliance of care for themselves, where limited resources in adult programs lack the support they had been receiving since birth in pediatrics. Throughout past transition process, there has been a feeling of disservice to the patients on educating them on the complexity of the disease as their bodies are maturing, the issues of social stigma and the importance of patient-centered goals for the patients. Under the leadership of Dr. India Sisler and her team, programs have been developed to begin this preparation, including a partnership with the adult program. Other key members of this team include Nurse Practitioner, Jennifer Newlin, Social worker, Alesha Lieser, Educational Coordinator, Alma Morgan psychologist from the pediatric program and the addition of a new physician, Dr. Nadirah El-Amin.

With the ongoing support of the healthcare system resources the adult program have provided financial support for staff to establish the development of a formal transition program. With years of data supporting our need for this program, we have determined that up to age 25, patients continue to need ongoing support in clinical, educational and psychological services.

TRANSITION TEAM

Clinical Social Worker, Taylor Elliott was key personal in this role and was tasked to work on programs for this age group. One of the programs was to work on a support group dedicated to the adult transition patients, which includes rising seniors from pediatrics. The groups were held monthly throughout the year but attendance continued to be sparse. A partnership was formed with the local community-based organization (CBO), OSCAR overseen by parents of sickle cell care. They had recently become a partner with a nation-wide grant, PCORI( ), whose goal is to bridge the gap between pediatrics, adults and CBO. We began having monthly meetings with them in summer of 2019, to establish some goals to for this program.

Once the patient transferred to adult care, the teams recommendation for an overall assessment of the patients skills involved a two part clinic visit with the clinical social worker to identify needs in transition readiness, depression and anxiety. There was also a substance abuse screening tool was added as well. These assessments helped to identify areas of growth to set goals for patients to achieve their goals for their future(data here).

As indicated, the VCU team has received funds from PCORI to address the specifics of transition. Each month the two teams met and reviewed the progress of enrollment, assessments and development of processes to enhance an informal adult program to provide an overall inclusive program involving all members of the clinical team and the incorporation of metrics and patient-centered care with the goal of teaching patients to empower themselves in their disease and future.

QUALITY IMPROVEMENT TEAM

Meet Our Quality Improvement Champions

Sarah Hartigan, M.D.

Associate Chair of Quality and Safety

Emily Holt

Quality Improvement Project Coordinator

Chantal McHenry

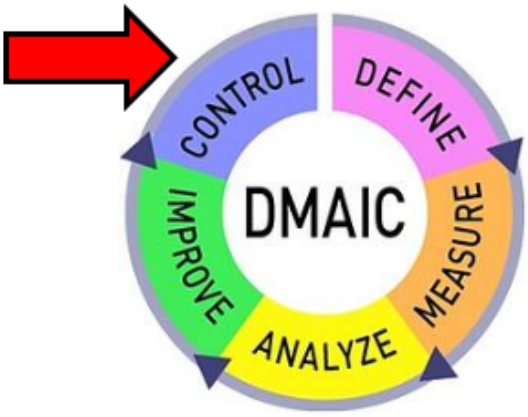
Quality Improvement Program Manager

The quality improvement team worked with the Oversight Team to develop the PCMH proposal and gain the support of hospital leadership. Next, they constructed a multi-phase plan for project development and implementation. The Lean Six Sigma DMAIC methodology was used to give teams a systematic and structured approach to process improvement.

The various SCD committees gained experience with valuable QI tools such as project charters, structured brainstorming techniques, process maps, and communication plans. These tools helped the teams improve coordination of care by eliminating inefficiencies, streamlining workflows and improving communication between providers. They also helped identify opportunities for improvement in clinical care and addressed these through development of standardized care pathways. The QI team oversaw implementation of these pathways using rapid-cycle tests of change known as the PDSA cycle.

QUALITY IMPROVEMENT TEAM
Processes

DMAIC Process

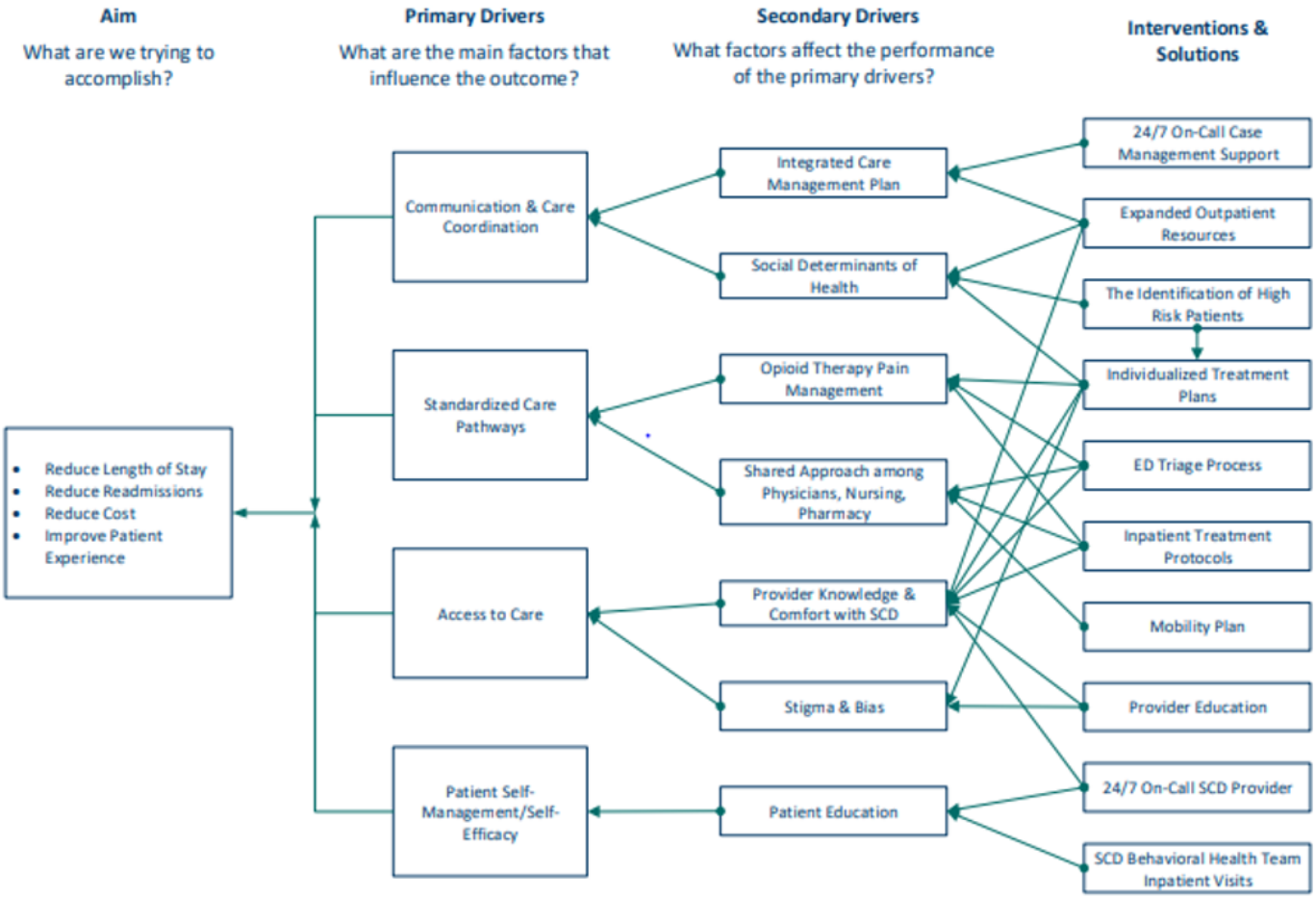


In 2019, Quality Improvement Team transitioned into the Control Phase of the DMAIC Process.

Elements of the Control Phase:

- Goal is to establish standards and controls to sustain improvement
- Ingrain into normal operations
- Operating procedures are consistent

Key Drivers



WHERE BEST PRACTICE MEETS PATIENT PREFERENCE:

COMBINING A STANDARDIZED CARE PATHWAY WITH INDIVIDUALIZED CARE PLANS TO IMPROVE PATIENT OUTCOMES

SARAH HARTIGAN MD, MARGARET GUY MD, JESSICA KEISER MD, NICOLE CARTER RN, LAUREN C MAGEE PHARMD, DALEMARIE VAUGHAN PHARMD, CHANTAL MCHENRY, EMILY HOLT, MICA FERLIS, SHIRLEY JOHNSON, DANIEL M SOP, WALLY R SMITH, MD

BACKGROUND

Sickle cell disease (SCD) is a rare disorder, affecting only 100,000 Americans, but it imposes an outsized burden on urban hospitals and emergency departments due to frequent acute care visits for highly painful vaso-occlusive crises (VOC), infections, anemia, and organ failure. Adult patients with sickle cell disease have complex needs that are not adequately addressed in fragmented healthcare systems. The false perception of a high prevalence of substance use disorders in this population leads to systematic under treatment and prolongation of hospitalizations for the pain crisis, which negatively impacts the patient experience and diminishes trust in the healthcare system. Limited knowledge of SCD among healthcare professionals and lack of clear evidence-based recommendations for pain management contribute to inappropriate variation in care and poor patient outcomes.

PROBLEM STATEMENT

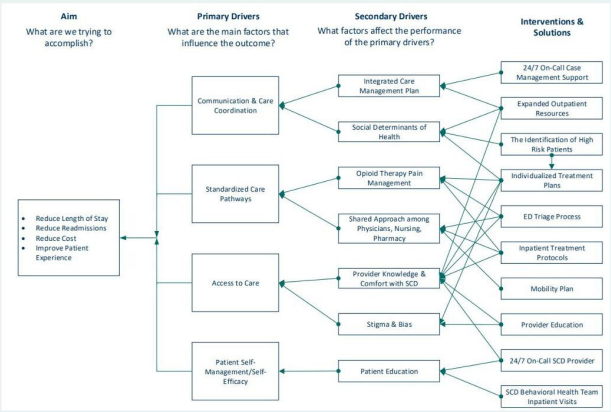
An urban tertiary care medical center struggled with higher than expected length of stay, readmission rates, and costs for adult inpatients with SCD. Patients expressed dissatisfaction with several elements of the care experience, most notably the inability to receive timely and adequate analgesic therapy. Physician leaders recognized an opportunity to improve patient outcomes by creating shared expectations between patients and providers, ensuring adherence to guideline-based therapy, and meeting the unique needs of individual patients.

Primary Aim:

Reduce the observed length of stay for adult patients with a vaso-occlusive pain crisis due to sickle cell disease from a baseline of 6.2 days to 5.2 days in 12 months.

ACTIONS TAKEN

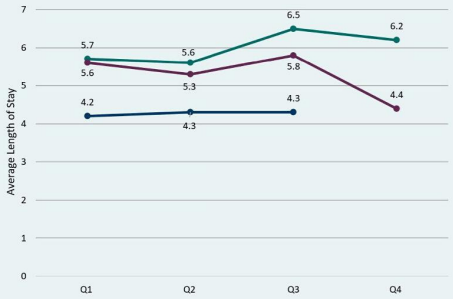
- Established interdisciplinary committees with outpatient, ED, and inpatient physicians, advanced practice providers, nurses, pharmacists, social workers, and a quality improvement project manager
- Used lean six sigma DMAIC methodology to guide overall improvement efforts with IHI PDSA cycles for implementing changes
- Performed chart reviews and assessed adherence to guideline-based care
- Administered surveys of patients and providers
- Used lean process redesign for ED triage, outpatient medication refills, and discharge planning
- Developed and implemented standardized care pathways that emphasized the need for rapid initiation and titration of analgesic therapy
- Implemented changes to ensure communication and coordination with outpatient providers
- Identified high risk patients and built individualized care plans addressing psychosocial and clinical care needs



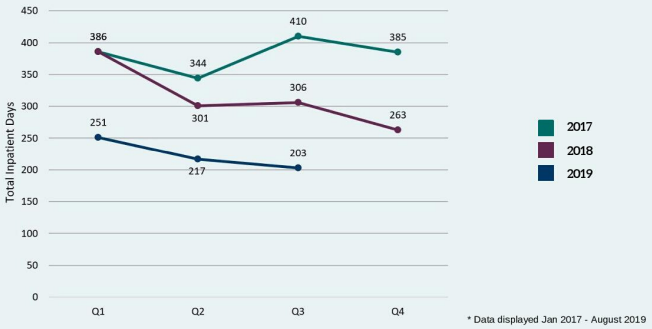
Summary of results:

In the first year of implementation, the average LOS for hospitalized adults with SCD was reduced by 20%, 30-day all-cause readmissions were reduced by 23%, total hospital days were reduced by 50%, and total cost was reduced by 25%. During the pilot of the new inpatient pain plan, total morphine milligram equivalents were reduced by 30%. Patients reported more satisfaction with their care, including time to adequate analgesic therapy. Standardized care pathways created clear expectations between providers and patients, helping to build more collaborative relationships to meet patients' needs.

Average LOS (2017- 2019)



Total Inpatient Days (2017- 2019)



* Data displayed Jan 2017 - August 2019

* Quarters by calendar year

LESSONS LEARNED

- Creating standardized care pathways improved the patient experience by creating a shared set of expectations between providers and patients
- Individualized care plans addressing pain management needs helped overcome barriers to timely and adequate analgesic therapy
- Involvement of primary outpatient providers was vital to building trust and enhancing patient engagement with improvement efforts

CONTACT

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Associate Professor, Division of Hospital Medicine
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REFERENCES

- Co JPT, Johnson KB, Duggan AK, Casella JF, WilsonM . "Does a clinical pathway improve the quality of care for sickle cell anemia?" The Joint Commission Journal on Quality and Patient Safety 29.4 (2003): 181-190.
- Evidence Based Management of Sickle Cell Disease; Expert Panel 2014[Scholarly project].(2014). Retrieved September 22, 2017, from https://www.nhlbi.nih.gov/sites/default/files/media/docs/sickle-cell-disease-report%20020816_0.pdf

Using Lean Six Sigma to Develop a Patient-Centered Home for Adults With Sickle Cell Disease

Shirley Johnson, BA, LSW, Sarah Hartigan, MD, Emily Holt, BS, Daniel Sop Mouaffo, BS, MS, Chantal McHenry, BS, Thokozeni Lipato, MD, Taylor Elliott, MA, Mica Ferlis, ACNP, Caitlin McManus, ANP and Wally R Smith, MD
Virginia Commonwealth University Health System, Richmond, VA

Introduction

Adults with Sickle Cell Disease(SCD) suffer poor quality of life, higher utilization and mortality, and unmet medical needs. Thus, in 2017, Virginia Commonwealth University Health System,(VCUHS) used pilot results and axioms of the Patient-Centered Medical Home(PCMH) and Lean Six Sigma quality improvement to build an Adult Sickle Cell Medical Home.

Methods

Define: Describe the opportunity and form a team

- Identify the opportunity
- Determine project scope, goal, and benefit statements
- Define team member roles and responsibilities
- Confirm resources are available

VCU Implementation

VCU Implementation
- Implemented the design of the program (15 months to develop)
- Developed program based on Now, Later, Latest as our targeted marks

Measure: Measure current processes and their performance

- Measure current processes and their performance
- Collect "Voice of the Customer" (VOC)
- Identify key measures
- Collect key measure data

VCU Implementation

VCU Implementation
- Identified 567 adult SCD patients (targeted top 50 highest utilizers)
- Identified key measures (reduce LOS by 1.5%, reduce charges by 15%, improve patient experience)

Analyze: Find key process factors and determine root cause of the problem

- Analyze data and process
- Analyze root causes

VCU Implementation

VCU Implementation
- Utilized tools such as Fishbones and 5 Whys to determine root causes

Improve: Implement and verify the solution

- Generate and test possible solutions
- Select best solutions
- Design implementation plan

VCU Implementation

VCU Implementation
- Referenced best practices, institutional priorities, and walking through processes to generate, test, and select best solutions

Control: Control future process performance

- Monitor plan
- Standardize process
- Document procedures

VCU Implementation

VCU Implementation
- Consistent communication plan with key stakeholders
- Processes consistently reviewed and amended as necessary

Results

- Reduced SCD readmissions by 10% among intervention patients by 6 months, and by 15% among **intervention*** patients by 12 months.
- Reduced SCD readmissions by 10% among intervention patients by 6 months, and by 15% among **intervention*** patients by 12 months.
- Improved costs related to care of **intervention*** patients by 10% in 6 months and by 15% in 12 months.

*Intervention patients=50 highest cost and high utilization patients

Discussion

The Lean Six Sigma QI principles were effective in developing and implementing an Adult SCD Medical Home. The team believes the above processes can be replicated elsewhere . We have also learned how to identify additional improvements to the program that will assist the team and program with further positive outcomes.

Lessons Learned

- When preparing your presentation to Executive leadership, have more than one proposal identifying the needs of your program. Identify different costs and return on investment, and do not leave out any staffing that may be needed. Leadership will then have several options to choose from based on the overall picture of return on investment(ROI) that is shared with them.
- Anticipate the program start date around when the staff is all hired, so that your first year of reporting to leadership has an accurate reflection of the team and their responsibilities to impact on the patient population
- Focus on collaborations with community-based organizations and establishing a life span program for consistent care from pediatric to adults.
- Focus on the huge impact of the behavioral health team and ensure that the processes for assessment and implementation are in place as the program is beginning.

Next Steps

- Establish the Behavioral Health team, to include assessments and processes for all patients who transition into adult care, and are new patients to the clinic and existing patients.
- Develop a housing proposal for leadership to assist with the homelessness population and ED utilization
- Develop an Infusion day program to treat patients the same day with pain crisis.. Request additional staff for these positions.
- Request a business analyst who internally works with the team to review and recommend ongoing QI and data reports to leadership. In addition, add to the behavioral health team with another patient navigator and clinical psychologist.

Acknowledgements

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- Co JP, Johnson KB, Duggan AK, Casella JF, Wilson M . "Does a clinical pathway improve the quality of care for sickle cell anemia?" The Joint Commission Journal on Quality and Patient Safety 29.4 (2003): 181-190.
- Evidence Based Management of Sickle Cell Disease; Expert Panel 2014[Scholarly project].(2014). Retrieved September 22, 2017, from https://www.nhlbi.nih.gov/sites/default/files/media/docs/sickle-cell-disease-report%20020816_0.pdf

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SCD ADULT MEDICAL HOME TEAM MEMBERS

Wally Smith, MD

Dr. Smith is a primary physician specializing in internal medicine, pain management, and care of adult patients with SCD. He holds the Florence Neal Cooper Smith professorship for SCD and is a national and international expert in SCD and pain management.

Thokozeni Lipato, MD

Dr. Lipato is a physician specializing in SCD, pain, and addiction. He and a team of providers including inpatient and outpatient nurse practitioners work together to see the patients during their clinic visits and as inpatients as needed.

Shirley Johnson, LSW

Shirley is a project manager in charge of supervising the interdisciplinary SCD Adult Medical Home including behavioral health team. She works to reduce hospital readmissions and length of stay, improve quality and outcomes of care, and improve satisfaction for identified patients.

Al Dunn, MBA

Al is the administrator for the Department of General Internal Medicine. For the last 5 years, he has worked with Dr. Smith in the SCD Program to successfully improve the care of patients and significantly reduced the cost of care for the health system.

Daniel Sop. MS

Daniel is a biomedical engineer who serves as the senior clinical research analyst for the adult SCD program. He uses his engineering training to improve analytical and systematic processes for the SCD program.

Mica Ferlis, ACNP

Mica is a nurse practitioner that works in collaboration with the physicians to deliver health care services to patients with SCD in the inpatient setting.

Caitlin McManus, MSN, RN, AGPCNP-B

Caitlin is a nurse practitioner that works in collaboration with the physicians to deliver health care services to patients with SCD in the outpatient setting.

Emily Sushko, MSN, RN, AGPCNP-C

Emily is the nurse practitioner for our outpatient Infusion Clinic, providing urgent and accessible care for our patients. She works in collaboration with the sickle cell team to manage and implement treatment plans for patients who are experiencing an acute sickle cell crisis.

Kate Osborne, BS, RN

Kate is nurse working with our Adult Sickle Cell Disease Team. She has 15 years ICU bedside experience and still works inpatient in the Medical Respiratory ICU a few times a month. Kate is also part of the SCD infusion center team.

Justin West, BSN, RN, CMSRN

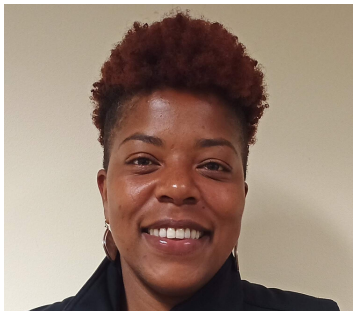
Justin isis a registered nurse who shares outpatient Infusion Clinic and triage nurse duties, providing direct care and helping to address patient questions and concerns. He has also been involved in ongoing efforts to improve care of patients with SCD in the inpatient setting.

Benjamin Jaworowski, BS

Ben is a health informatician who is the data and business analyst for the SCD Medical Home. He performs analyses, reporting, and quality improvement for the entire clinical staff.

Stefani Vaughan-Sams, Nakeyia Williams, BSW, & Marla Brannon, BSW

Stefani, Nakeyia, and Marla are patient navigators, also working in the clinic every week to assist patients and their families regarding health-related expenses not covered by insurance, transportation costs, and employment options. They are also essential in facilitating transition of care.



Austin Hardy, CPHT

Austin is a prioritization specialist. He was hired as a pharmacy tech to handle approvals for opioid medication, check medication fills, incompliance, coordinate with nursing staff on ACC4, and input data for approvals in any medication compliance.

Donna Casey

Donna facilitates day to day administrative, personnel and program oversight for the Sickle Cell Program Manager and Medical Director. She supports fiscal and time management objectives by coordinating administrative services through effective interactions with the healthcare system team, administration, and support staff as well as hiring, leave and personnel management tasks.

ADULT SCD POPULATION AT VCU

GENDER

445
FEMALES

320
MALES

AGE

UNDER 41 — 471

41-60 — 245

OVER 61 — 49

TYPE OF INSURANCE

83
ANTHEM

16
ANTHEM MC

9
COMMERICAL

75
HMO/PPO

22
INDIGENT CARE

50
MEDICAID

230
MEDICAID MC

150
MEDICARE

49
MEDICARE MC

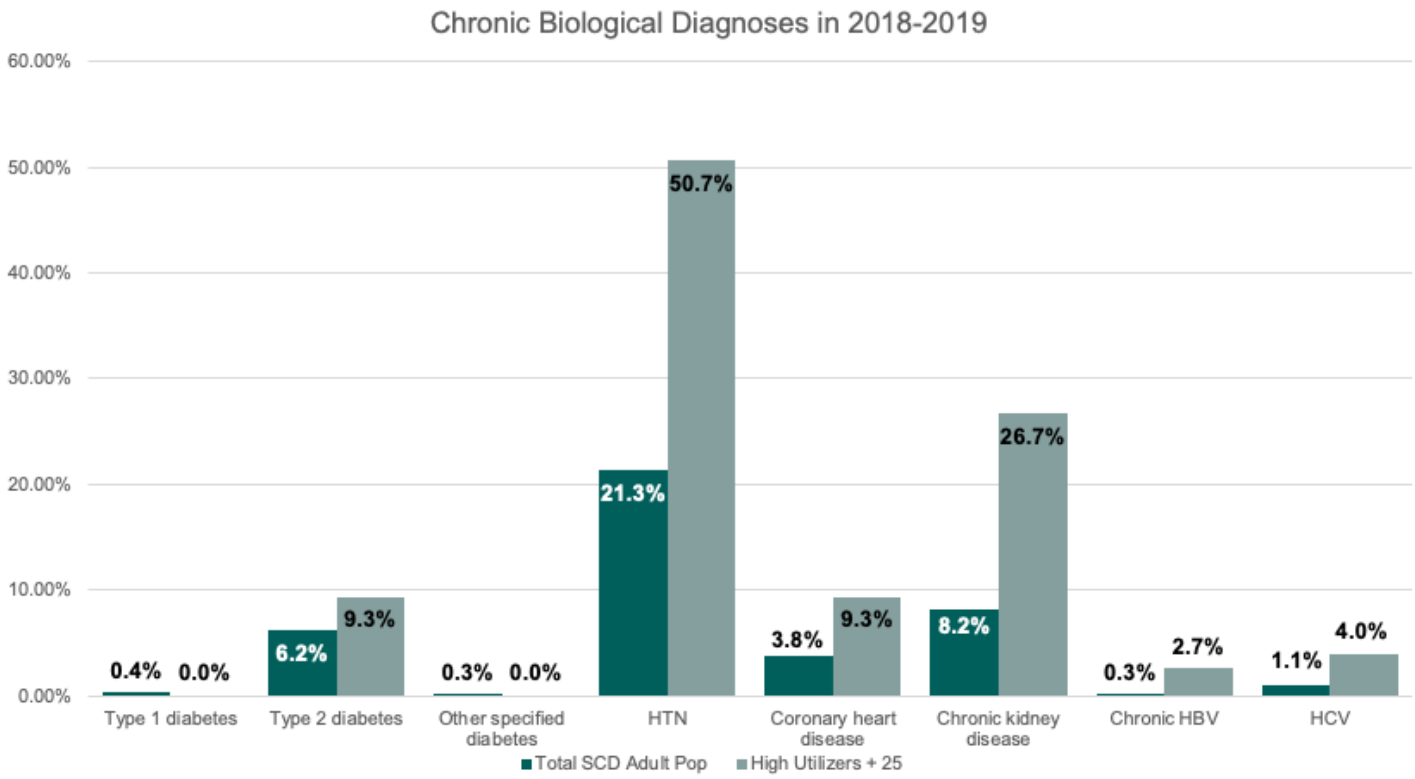
35
OTHER

46
SELF PAY

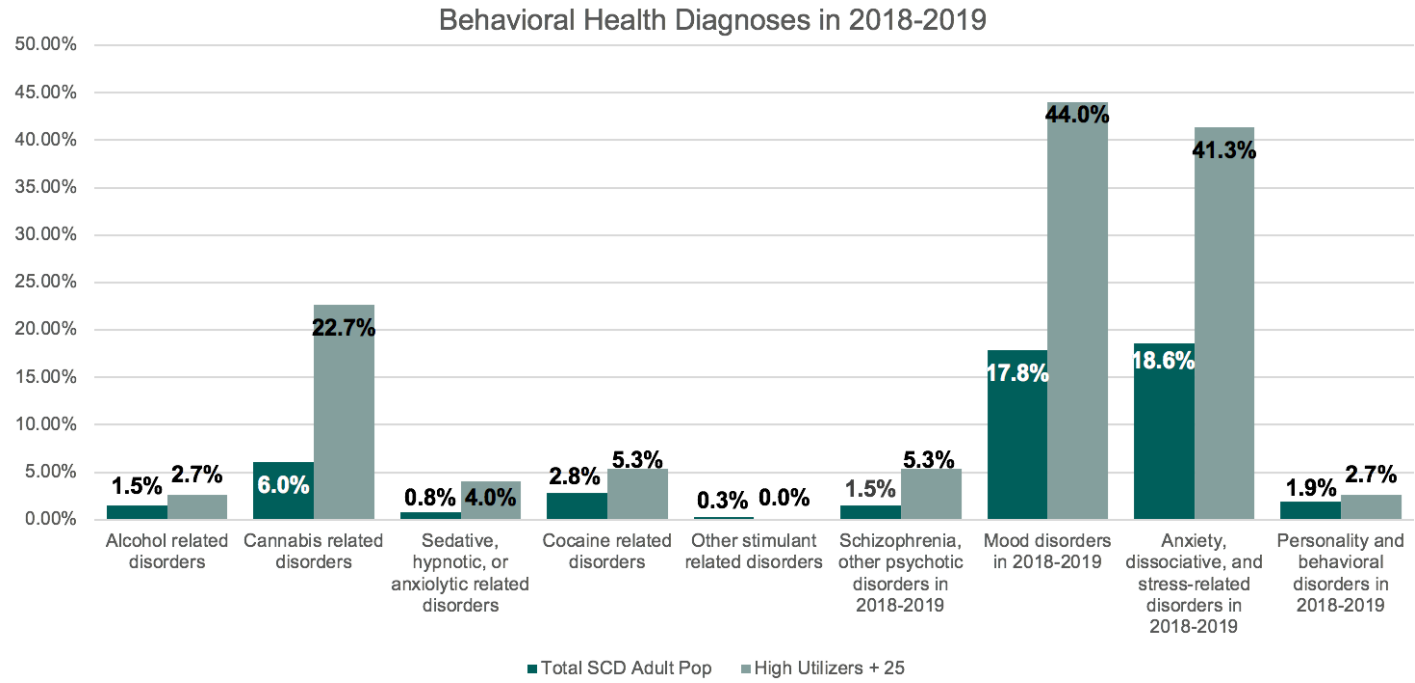
MC = Managed Care

ADULT SCD POPULATION AT VCU

Comorbidities and Complications



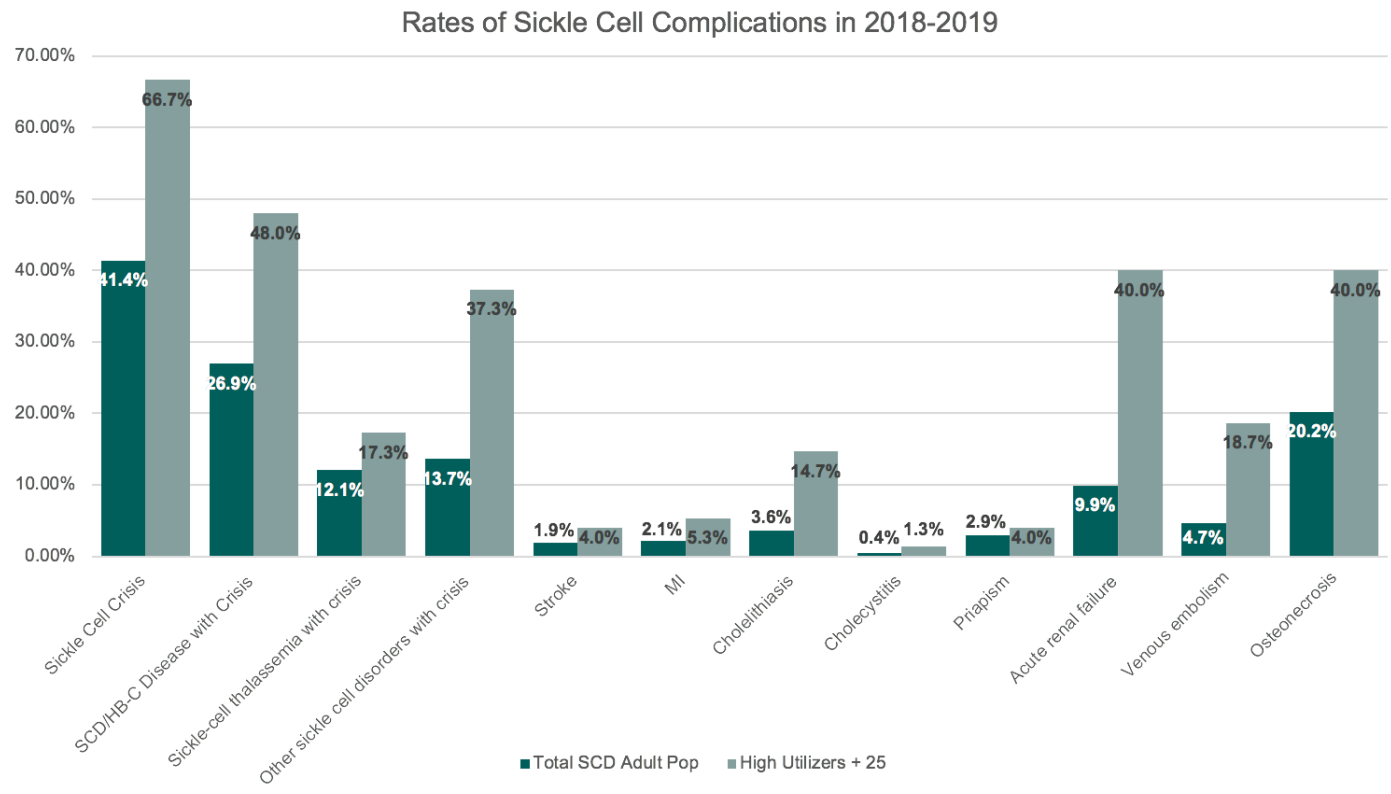
Behavioral Health Comorbidities 2018-2019



ADULT SCD POPULATION AT VCU

Comorbidities and Complications Cont.

SCD Complication Diagnoses 2018-2019



RESULTS FOR ENTIRE ADULT SCD POPULATION

NUMBER OF INPATIENT DAYS

1,096 FEWER DAYS

AVERAGE LENGTH OF STAY

0.86 FEWER DAYS

30 DAY READMISSION RATE

10.0 %

ED 3 DAY RETURN RATE

2.8 %

CHARGES AVERTED

$1.182 MILLION

RESULTS FOR TOP 50 UTILIZERS

NUMBER OF INPATIENT DAYS

1,247 FEWER DAYS

AVERAGE LENGTH OF STAY

1.7 FEWER DAYS

30 DAY READMISSION RATE

17.9 %

ED 3 DAY RETURN RATE

4.1 %

CHARGES AVERTED

$2.465 MILLION

EDUCATION AND OUTREACH

Project ECHO

Project ECHO, launched in February 2019, is virtual network on presentations, discussion and didactic exchange for clinicians and other SCD providers around Virginia and elsewhere to obtain support for caring for patients with SCD. The program will launch in February 2019.

Results Highlights

9 clinics	**18** case presentations	**26** spokes
13.5 hours	**9** total didactics	**173** total participants
8 unique didactics	**8** unique didactic presenters	**76** unique participants

EDUCATION AND OUTREACH

Sickle Cell Care Coordination for Achieving Patient Empowerment (SCCAPE) Conference

VCU Health
SCCAPE 2019

On September 17, 2019, the first annual SCCAPE (Sickle Cell Care Coordination for Achieving Patient Empowerment) Conference was held in Richmond, Virginia. This four day event was designed to enhance the knowledge, skills, and attitudes towards assessment, care coordination, medical management, and patient-centered , self-care using a person-centered approach for treatment adherence in patients with Sickle Cell Disease to improve their quality of life. This conference was supported through the MCV Foundation and Global Blood Therapeutics and took place at The Hilton in Richmond, Virginia. Attendees included nurses, social workers, community-based organizations, patient navigators, patients, advocates and other staff who traveled from Virginia, North Carolina, Michigan, Pennsylvania, Washington DC, South Carolina, New Jersey, West Virginia, and Minnesota.

This four day event was designed to provide training and support to professionals and family member advocates to enhance their knowledge, skills, and attitudes towards assessment, care coordination, medical management, and using a person-centered approach for treatment adherence in patients with Sickle Cell Disease. SCCAPE focused on enhancing disease knowledge, pain and drug development, effective communication, advocacy, stigma and bias, transition, and mental health to improve patients' quality of life.

The members of the VCU pediatric and adult programs provided the content for the program, and the co-facilitators who led the program were Shirley Johnson (Program Manager), Joan Corder-Mabe (Program Educator), Daniel Sop (Clinical Research Analyst) and Dr. Wally Smith (Medical Director).

There was interactive engagement, content of program, music and dancing and giveaways to keep the attendees engaged and excited. Our second annual SCCAPE conference was scheduled to be held in Fort Lauderdale, Florida in June 2020 prior to COVID 19 cancellations. For more information, visit https://www.sccape.org/.

SCHOLARSHIP
Publications

Case Management Featuring Community Health Workers Reduces Inpatient Health Care Utilization in Adults with Sickle Cell Disease

Smith, Wally R and Sop, Daniel and Johnson, Shirley and Lipato, Thokozeni and Ferlis, Mica and Mcmanus, Caitlin and Guy, Margaret and Hartigan, Sarah and Holt, Emily and McHenry, Chantal and others
2019
American Society of Hematology Washington, DC

Responsivity of Utilization Rates to the Intensity of Case Management over Time Among High-Utilizing Adults with Sickle Cell Disease

Smith, Wally R and Sop, Daniel and Johnson, Shirley and Lipato, Thokozeni and Hartigan, Sarah
2019
American Society of Hematology Washington, DC

Development and Validation of a Functional Status-Based Pain Assessment Tool

Guy, Margaret and Qayyum, Rehan and Derby, Pamela and Carter, Nicole and Keiser, Jessica and Ulbing, Alexandra and Sop, Daniel and Smith, Wally R
2019
American Society of Hematology Washington, DC

Using Lean Six Sigma to Develop a Patient Centered Medical Home for Adults with Sickle Cell Disease

Johnson, Shirley and Hartigan, Sarah and Holt, Emily and Sop, Daniel and McHenry, Chantal and Lipato, Thokozeni and Elliott, Taylor and Ferlis, Mica and Mcmanus,
Caitlin and Smith, Wally R
2019
American Society of Hematology Washington, DC

Tiered Oral Therapy Protocol for Sickle Cell Vaso-Occlusive Crisis

Guy, Margaret and Magee, Lauren and Keiser, Jessica and Carter, Nicole and Vaughan, Dale Marie and McHenry, Chantal and Sop, Daniel and Hartigan, Sarah and
Smith, Wally R
2019
American Society of Hematology Washington, DC

Essential Features for Sickle Cell Disease Patients and Utilization of Community Health Workers

Corder-Mabe, Joan and Johnson, Shirley and Sop, Daniel and Elliot, Taylor and Smith, Wally R.
2019
Journal of Sickle Cell Disease and Hemoglobinopathies
Foundation for Sickle Cell Disease Research

SCHOLARSHIP
Publications

Development of a Framework to Describe Functions and Practice of Community Health Workers

Corder-Mabe, Joan and Johnson, Shirley and Mazmanian, Paul E and Smith, Wally R
2019
Journal of Continuing Education in the Health Professions
LWW

Systematic Design and Revision of a Mobile Application for Enhancing Adherence to Prescribed Opioids in Sickle Cell Disease

Sop, Daniel and Smith, Wally and Rafig, Azhar and Alsalman, Abdulkhaliq and McClish, Donna and Johnson, Shirley and Lipato, Thokozeni and Elliott, Taylor and Fei, DingYu
2019
Journal of Sickle Cell Disease and Hemoglobinopathies
Foundation for Sickle Cell Disease Research

Feasibility and Quality Validation of a Mobile Application for Enhancing Adherence to Opioids in Sickle Cell Disease

Sop, Daniel and Smith, Wally, and Rafiq, Azhar and Alsalman, Abdulkhaliq and McClish, Donna and Johnson, Shirley and Lipato, Thokozeni and Fei, Ding-Yu
2019
Journal of Sickle Cell Disease and Hemoglobinopathies
Foundation for Sickle Cell Disease Research

Tiered Oral Therapy Approach for Sickle Cell Disease Vaso-Occlusive Crisis Management

Guy, Margaret and Magee, Lauren and Hartigan, Sarah and Ferlis, Mica and Smith, Wally and Sop, Daniel
2019
Journal of Sickle Cell Disease and Hemoglobinopathies
Foundation for Sickle Cell Disease Research

Lessons Learned from Building a Pediatric-to-Adult Sickle Cell Transition Program

Smith, Wally R and Sisler, India Y and Johnson, Shirley and Lipato, Thokozeni J and Newlin, Jennifer S and Owens, Zakiya S and Morgan, Alma M and Treadwell, Marsha J and Polak, Kathryn
2019
Southern Medical Journal

SCHOLARSHIP
Presentations

ORAL PRESENTATIONS

Crisis Averted: Inpatient Management of Sickle Cell Disease
Society of Hospital Medicine Annual Conference; San Diego, CA; April 2019

Innovations in Inpatient Management of Acute Pain
Foundation of Sickle Cell Disease Research Conference; Ft. Lauderdale, FL; June 2019

Development and Validation of a Functional Status–Based Pain Assessment Tool
American Society of Hematology Annual Conference; Orlando, FL; December 2019

Systematic Design and Revision of a Mobile Application for Enhancing Adherence to Prescribed Opioids in Sickle Cell Disease
Foundation of Sickle Cell Disease Research Conference; Ft. Lauderdale, FL; June 2019

Feasibility and Quality Validation of a Mobile Application for Enhancing Adherence to Opioids in Sickle Cell Disease
Foundation of Sickle Cell Disease Research Conference; Ft. Lauderdale, FL; June 2019

POSTER PRESENTATIONS

Tiered Oral Therapy Approach for SCD Vaso–occlusive Crisis Management
Foundation of Sickle Cell Disease Research Conference; Ft. Lauderdale, FL; June 2019

Where Best Practice Meets Patient Preference: Combining a Standardized Care Pathway with Individualized Care Plans to Improve Patient Outcomes
IHI National Forum on Quality Improvement in Health Care; Orlando, FL; December 2019

Tiered Oral Therapy Protocol for Sickle Cell Vaso–Occlusive Crisis
American Society of Hematology Annual Conference; Orlando, FL; December 2019

Case Management Featuring Community Health Workers Reduces Inpatient Health Care Utilization in Adults with Sickle Cell Disease
Foundation of Sickle Cell Disease Research Conference; Ft. Lauderdale, FL; June 2019

Using Lean Six Sigma to Develop a Patient Centered Medical Home for Adults with Sickle Cell Disease
American Society of Hematology Annual Conference; Orlando, FL; December 2019

WHAT'S COMING IN 2020?

We have many exciting goals for the 2020 year, including:

EXPAND

- Opening up an Infusion Center to treat patients in pain.
- New drug therapies that can be prescribed for patient care from Global Blood Therapeutics and Novartis
- Beginning of Gene Therapy Research
- Continue to expand the community-based organizations role to mentor and support adult patients.
- Continue to work with legislature to expand funding for the SCD care around the Commonwealth
- Continue to expand SCD Research, including FMRI studies on impact of SCD on brain function

INNOVATE

- Expand the role of behavioral health to further identify psycho-social needs for patients and provide on-site therapeutic services to patients and have a well rounded behavioral health approach.
- Expand ECHO program outside of VCU.

COLLABORATE

- Develop relationships with Managed Care Organizations(MCO) to provide continuity of care and cost reductions to the MCO and cost savings to the hospital
- Continue partnership with School of Engineering and Pharmacy for research
- Expand partnership with Virginia Supportive Housing and Health System for stability of existing homeless patients and other locating placement for new patients in need of housing.

VCU Health™
Sickle Cell Disease Program

We would like to acknowledge the following research projects that assisted us with development of the Adult SCD Medical Home at VCU:

- **National Heart Lung and Blood Institute: R18HL112737, Enhancing Use of Hydroxyurea in Sickle Cell Disease Using Patient Navigators, NCT02197845**
  NHLBI awarded a five year, three million dollar dissemination grant testing the use of patient navigators assisting patients with compliance of Hydroxyurea.

- **Health Resources and Services Administration: SiNERGE, Sickle Cell Disease Treatment Demonstration Program Regional Collaborative for the North East Region**
  John Hopkins University selected VCU as a site to test the effectiveness of CHW's around the state, as well as securing new physicians to treat patients for Sickle Cell Disease.

- **Patient-Centered Outcomes Research Institute**
  Virginia Commonwealth University is a sub-site to a grant issued to Atrium Health to work on a "Cooperative Effectiveness of Peer Mentoring Vs. Structured Education-Based Transition Programming for the Management of Care for Transition in Emerging Adults with Sickle Cell Disease."

This annual report was produced by the Sickle Cell Disease Program at Virginia Commonwealth University.

For more information, visit https://www.virginiasicklecell.org/