VCU Health

SICKLE CELL DISEASE ADULT MEDICAL HOME

ANNUAL REPORT

2020-2022

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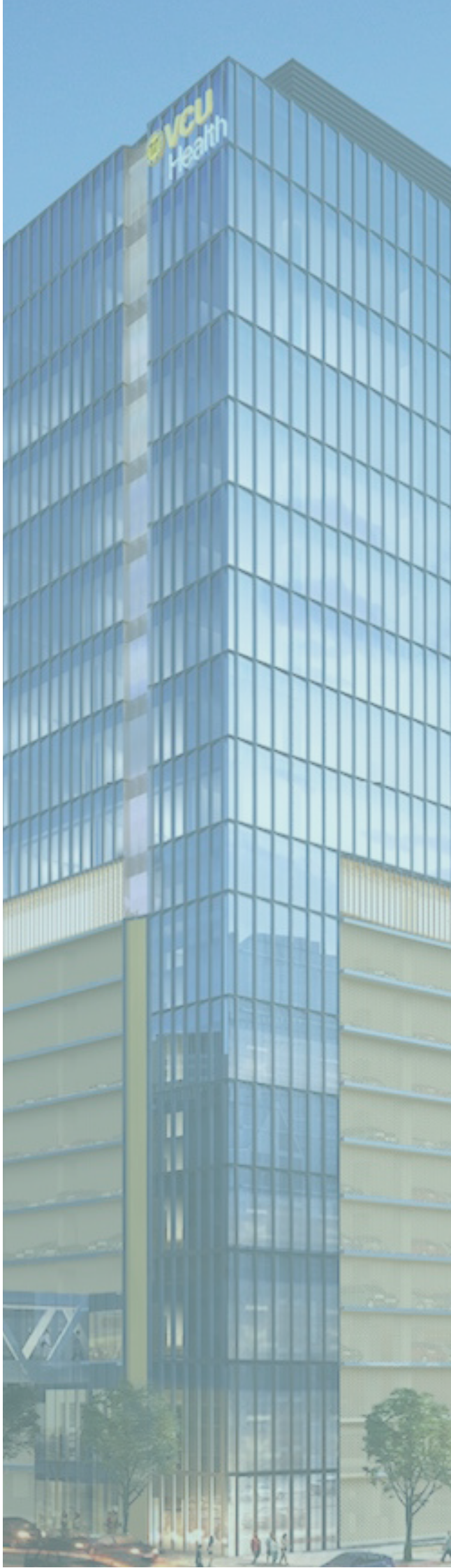


A MESSAGE FROM DR. SMITH

....and then came COVID. After a dramatic improvement in utilization and cost savings during the first two years of our Adult Sickle Cell Medical Home, we suddenly halted publishing this, our third annual report, for two years. Everyone now knows why. The whole world seemed to slow down or stop for two years. We faced a new, invisible force driving ALL health care utilization—a worldwide pandemic. As it did for all diseases, COVID drove SCD patients into hiding for nearly two years. During the first year we actually TOLD them to hide, and to not come to the hospital, fearing for even greater mortality among SCD patients with COVID than among others with COVID. We simply didn't know whether to fear COVID in SCD patients due to their already compromised humoral immunity, poor splenic function, and death from pneumococcus, meningococcus, and bacterial infections. In our surveys as well as our measures of utilization of inpatient and outpatient care, patients indicated that fear of getting sick from COVID drove them to stay home in order to manage their vaso-occlusive crises, even more so than they were already doing based on experiences of undertreatment and stigma, when they sought pain care in urgent care centers and hospitals.

Also in the first year of COVID, a second phenomenon affecting our patients was an acute shortage of blood. Donors didn't want to come to the hospital either—they were sheltering in place like the rest of us. Even vaccinations weren't enough to shield donors from the fear of catching COVID while doing their civic duty. The American Red Cross initially tried to suppress donation to SCD patients, but we along with other members of the Medical and Research Advisory Committee of the Sickle Cell Disease Association of America persuaded the CDC and Red Cross to exempt SCD from the list of diseases subject to cessation of "elective" transfusions.

Now, two years later, the potential COVID/SCD mortality scare is behind us, our patients are back into care, and the transfusion care that is critical to prevent strokes and pulmonary complications has resumed. We learned from an international database that COVID is no worse among SCD patients than others, and that SCD patients who get COVID usually recover well, get vaccinated, and most often don't get re-infected.

COVID is not over however. None of the early deaths in SCD patients with COVID were documented here at VCU. However plenty of SCD patients seeing us here, over 150, have been infected. So, we still present in this document what we started to present two years ago--our initial VCU Adult SCD Medical Home response to COVID.

We first conducted a risk and attitudes survey. We attempted to call all 700 of ourpatients at the beginning and height of the first US wave of the COVID pandemic, obtaining data on utilization during the pandemic.

A MESSAGE FROM DR. SMITH

Second, like all others, we shifted to Zoom (who knew “Zoom” would become a verb meaning “meeting virtually via telecommunications?”) and to working from home, including starting a 24/7/365 case management chat and a daily case management conference every morning from Mon-Fri. We show in this report how case management work of our patient navigators changed from some in-person to almost no in-person contacts, requiring heavy telephone work.

Third, we kept committees functioning, teams functioning, and oversight tight. We show over two years the huge gains in behavioral health staffing and case work necessitated by realization of the behavioral health burden in our patients, and by COVID itself.

Everyone has accepted COVID will never be over. Permanent hybrid or telework meetings will continue. Telemedicine adaptations will not regress.

Lastly, we report on the redesign of our infusion care, begun, and almost launched, at the beginning of COVID. Meanwhile, since COVID, our clinic space has moved. Our team has greatly expanded. Our vision for expanding our medical home to attend to the social determinants of health has been largely realized. We proudly present our now Three-year report, covering the beginning of 2020 through the end of 2022.

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

The beginning of 2023 has seen the return of our outpatient infusion clinic. For all of 2022 the infusion clinic was closed down as part of a clinical reshuffle that meant moving into a new clinic space and transitioning to a new electronic medical record system.

In this new year we also welcomed two new APPs who will be working in the outpatient clinic seeing patients with Dr. Smith and me as well as in the reopened infusion clinic.

On the research side, the university has struggled to maintain a sufficient number research staff; however this year I hope we shall be able to ramp up our clinical research efforts.

We continue to very busy in the clinic with new patients transitioning from pediatrics, and we continue to see new adult patients transferring their care from outside clinics.

I am pleased to have played a part in enrolling one of our adult patients into a gene editing clinical trial here at VCU and look forward to more opportunities such as this.

Thokozeni Lipato MD
Assistant Professor
Division of General Internal Medicine

STATE OF SICKLE CELL DISEASE

What is the current state of SCD nationally?

While there were no new disease modifying therapies introduced for SCD during 2020, 2021, or 2022, there were major therapeutic advances in therapies with curative intent . Both haploidentical stem cell transplantation, gene addition, and gene modulation therapies made significant scientific stirs in the SCD community by showing new positive results with long-term, disease-free survival. Companies are now racing to become commercially accepted and viable. However, the procedure cannot be mass produced, and this creates a new form of barrier to care for the masses.

Further setbacks in the form of a handful of malignancies in patients receiving chemotherapy for immunosuppression prior to stem cell transplantation were discovered in early 2021, adding to one existing report of mildly increased cancer risk at baseline in SCD. Some also used the word “cure” for these procedures, but patients were still left with the damage already done by SCD, even after a transplant or gene therapy. Debate ensued about the worldwide implementation of these therapies planned by the Bill Gates Foundation and others.

Meanwhile, prescription grade L-glutamine- approved in 2017- and voxelotor and crizanlizumab- approved in 2019- were prescribed to thousands of patients for the first time. Over forty pipeline therapies remained in clinical and research development. Almost every month, we got word of a new potential clinical trial being implemented in SCD.

During 2020 and 2021, SCD registries emerged with rapidity. The crisis of crosstalk between registries emerged in 2022, as SCD centers were asked to send the same data to multiple, seemingly competing entities starting registries. How to make these registries talk to one another became a “big data” puzzle the SCD community must solve.

Specifically, the Centers for Disease Control continued its Sickle Cell Disease Data Collection (SCDC) project, expanding from including data about Georgia and California to include data from Virginia as one of eleven states in its project in 2021. SCDC used algorithms to calculate the probabilistic certainty of SCD diagnosis for its patients, and similarly probabilistic genotype ascertainment based on claims data. Not only did it enumerate the number of sickle cell patients in these states, it simultaneously created a registry that logged health care utilization and some clinical elements.

STATE OF SICKLE CELL DISEASE

But also, the American Society of Hematology, the Health Resources and Services Administration, the National Institutes of health, the Sickle Cell Disease Association of America, and some individual and collaborating academic institutions, all independently created or further developed registries of children and adults with SCD.

Earlier in 2020, the most important advance in SCD was the publication by the National Academies of Science, Engineering and Medicine (NASEM) of a mandate to fix the broken SCD health care delivery system and to improve SCD policy nationwide. The report "Improving Health Outcomes for Sickle Cell Disease Care Requires Comprehensive Team-Based Care, New Payment Models, and Addressing Institutional Racism in Health Care" was released on September 10, 2020.

The report outlined reforms necessary to guarantee safe, effective, patient-centered, timely, ethical, equitable, and efficient care for patients with SCD. Recommendation B, *Establish organized systems of care assuring both clinical and nonclinical supportive services to all persons living with SCD*, included a recommendation to assemble a panel of relevant stakeholders to delineate the elements of a comprehensive system of sickle cell disease care, including community supports to improve health outcomes, quality of life, and health inequalities. It also included a recommendation to work with state Medicaid programs in order to develop and pilot reimbursement models for the delivery of coordinated sickle cell disease health care and support services.

Since the report, several bills have been proposed or introduced into the US Congress by various SCD stakeholders. In late 2021, Virginia got into the act with its own legislation and funding for centers. Each national or state bill intends to enhance the numbers of providers delivering SCD care nationally, improve SCD care quality, or enhance reimbursement for SCD individual and team care. The Secretary of Health and Human Services, as well as the Centers for Medicare and Medicaid Services, invited SCD stakeholders (including VCU) to testify during listening sessions, in order to find out how they can best respond to the NASEM Blueprint. CMS published a report card in 2019- just prior to the publication of the Blueprint- which gave a partial estimate of the number of SCD patients receiving Medicare services, and the rates of receipt of needed care. While crude, the report highlighted gaps in care and urged better data collection.

Our Adult Sickle Cell Medical Home took advantage of the Virginia funding and legislation, receiving $200,000 annually beginning in 2022, and continuing for 5 years, as one of four state organized systems of holistic adult SCD care. We intend to model our care using one of the four models published in January 2020, of which Dr. Smith was an author. Of the proposed four structural models of SCD Care: Classic Comprehensive, Embedded, Specialized Medical Home, and Hub and Spoke, we aspire to be a Specialized Medical Home.

STATE OF SICKLE CELL DISEASE

A new organization, the National Alliance of Sickle Cell Centers, was created in 2021-2022 to bring centers like ours together, and further the recommendations of the NASEM Blueprint above. We will join other centers in collecting information using the GRNDAD registry, comparing indicators of quality of care and outcomes, making recommendations for policy improvements, and acting as a watchdog to see that the NASEM recommendations are indeed implemented.

SCD ADULT MEDICAL HOME MULTIDISCIPLINARY TEAMS

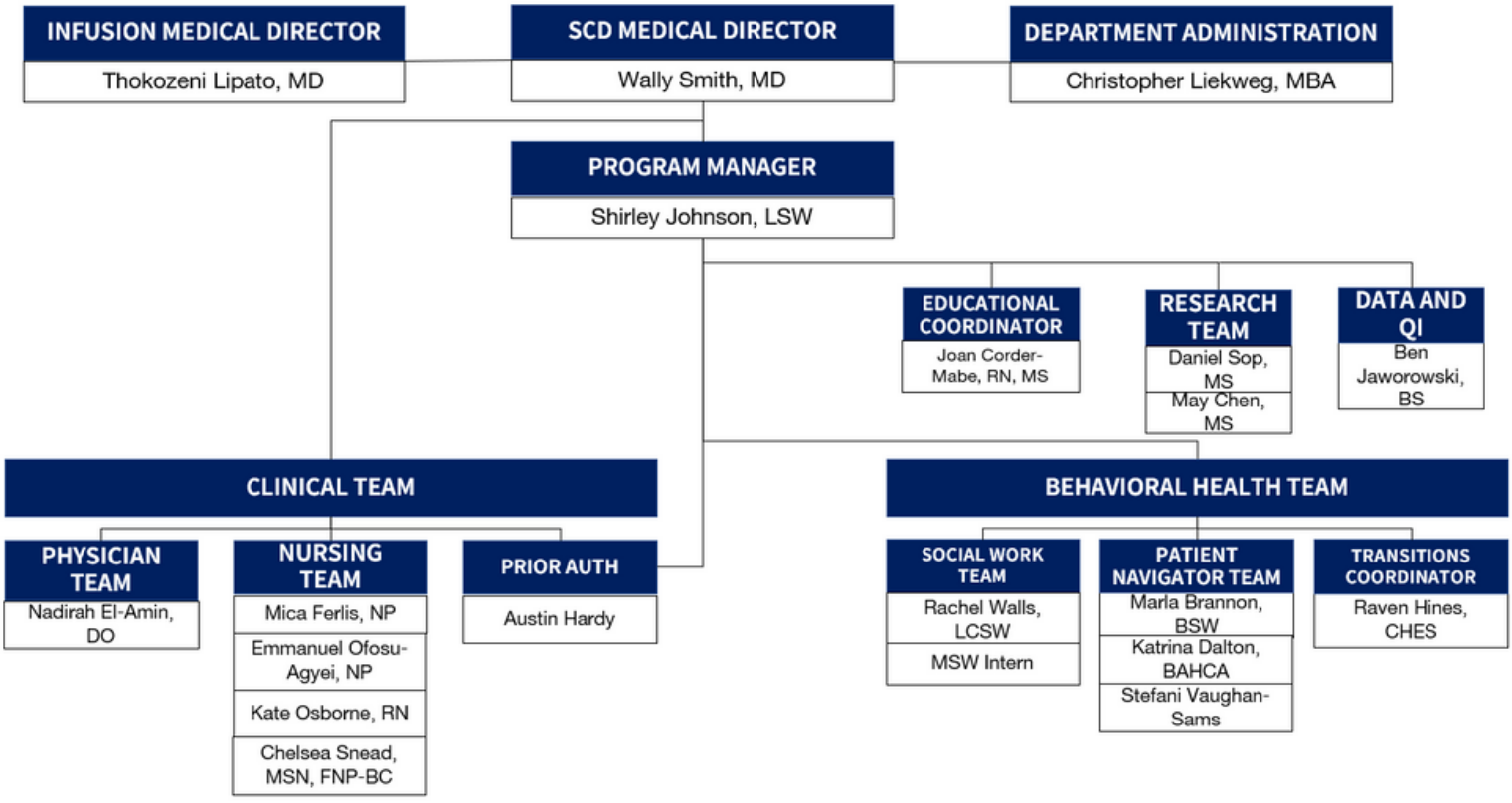
The SCD Adult medial Home provides a multidisciplinary clinic offering a patient-centered approach to care for adult patients with SCD. There are 3,500 adult sickle cell patients who are living in Virginia and our adult program cares for over 600 of these patients, but there is still work to do to reach 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.

Our adult study coordinator is Daniel Sop, MS. We also have three available sickle cell providers who see our patients, Mica Ferlis, MSN,ACNP-BC, Emmanuel Ofosu-Agyei, NP, and Chelsea Snead, MSN, FNP-BC. We also have a dedicated registered nurse, Kate Osborne.

To provide behavioral health and counseling services, we added a dedicated LCSW, Rachel Walls in 2021.

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 the University of Minnesota and VCU.



INPATIENT TEAM

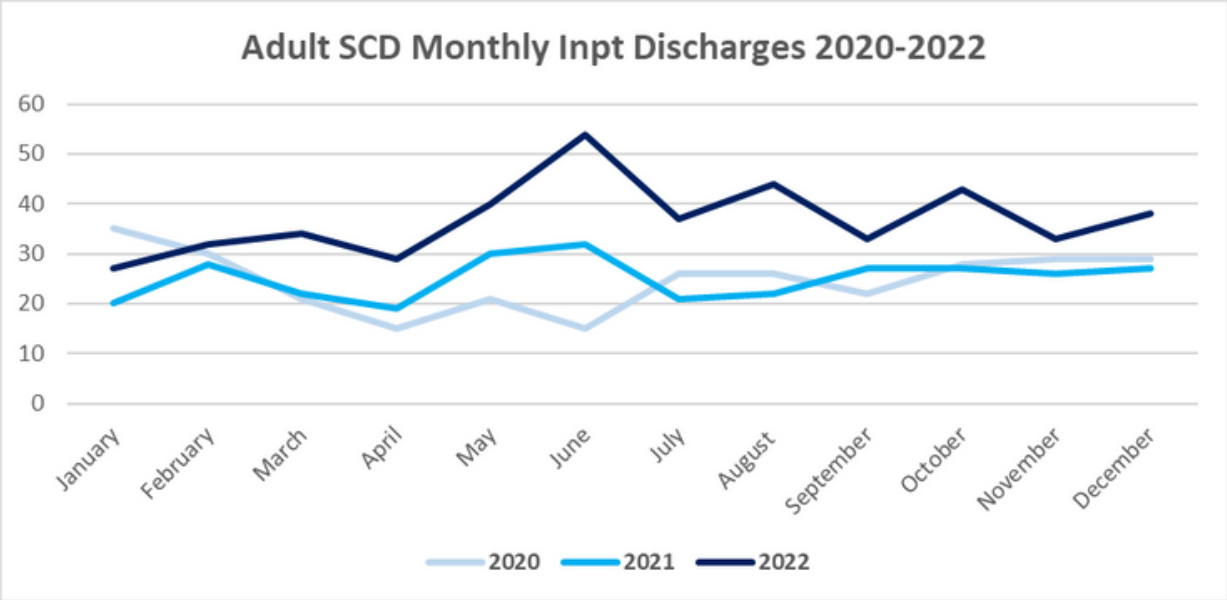
As for all hospitals, the Inpatient Team was dramatically affected by COVID pandemic. One of our three SCD Advanced Practice Providers was volunteered to staff COVID screening clinic. The inpatient unit was overwhelmed by dying COVID patients and respiratory isolation unit duties. SCD patients essentially stopped coming to the ED or hospital for VOCs for 18 months. Academic hospitalists, advanced practice providers, clinical pharmacists, nursing leadership and bedside nurses were all distracted by COVID from the care and management of sickle cell disease.

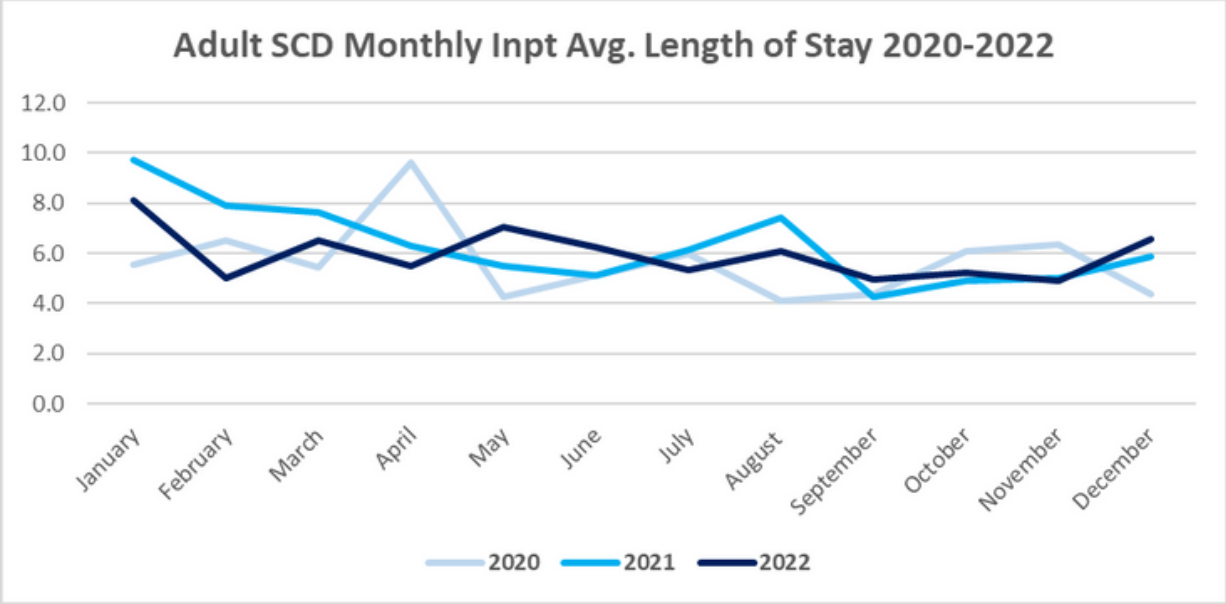
Nonetheless, the inpatient team continued to apply innovative practices to inpatient pain management. Having already completely revamped inpatient management of sickle cell vaso-occlusive crises with a novel tiered oral therapy approach as well as a focus on function and mobility for the patients, the team strove to continue the new TOTP treatment algorithm and the new functional pain assessments on new geographic nursing units, training up new staff on their use. The units of care moved constantly, as did the epidemic and the need for isolation rooms.

Meanwhile, Mica Ferlis, our inpatient SCD APP continued to regularly update patients' individualized treatment plans based on clinical changes as well as psychosocial factors affecting the patient's care. Now guideline-recommended, an individualized treatment plan remains the bedrock of inpatient SCD care.

The graphs on the next page demonstrate flat inpatient utilization for 2020, 2021, and the first few months of 2022. The growth of inpatient volume in 2022 was palpable- as was an objective growth in the complicated versus uncomplicated DRGs (Diagnosis Related Groups) recorded for those admissions. We are conducting additional analyses to disentangle whether COVID or geographic case mix contributed somehow to this phenomenon or whether admissions are simply returning to pre-COVID levels.

INPATIENT TEAM





INPATIENT TEAM

Meet Our Inpatient Champions

Margaret Guy, MD

General Internal Medicine Hospitalist
Physician Lead of Inpatient Sickle Cell Committee

Heather Goldston, AGACNP

General Internal Medicine Hospitalist

Mica Ferlis, ACNP

Inpatient Nurse Practitioner, Adult Sickle Cell Clinic

ED TEAM
Analyze

Meet Our ED Champion

Peter Moffett, MD

Associate Professor
Emergency Medicine Residency

As shown in the graphs on the next page, starting in April of 2020, and continuing through 2022, the COVID 19 pandemic dramatically lowered the volume of patients with sickle cell disease presenting to the VCU emergency department. At COVID onset and since, boarding times in the hospital have driven up wait times in our waiting room to far beyond the guideline-specified 1 hour from arrival to treatment for pain.

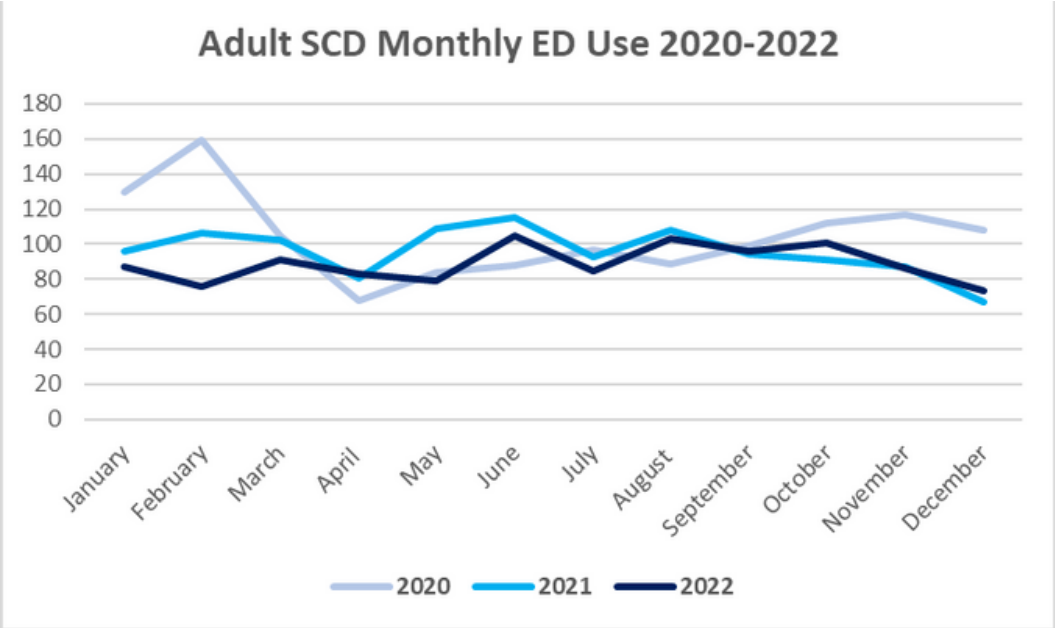
The majority of SCD ED volume during 2020 came from habitually high utilizers of care, rather than from occasional users, who chose to manage their vaso-occlusive crises at home because of fear of COVID exposure. Special surveys performed by the SCD team documented this fear and ED avoidance. In late 2020, ED use from SCD gradually drifted higher, as COVID cases and fear decreased. Still, in 2021 and 2022, ED volumes for SCD, unlike volumes for all patients did not return to pre-pandemic levels. One reason for this was the emergence of a new SCD infusion center, small though it was. In early 2022 however, with the transition of ambulatory services to the Adult Outpatient Pavilion, the initial infusion service was ended.

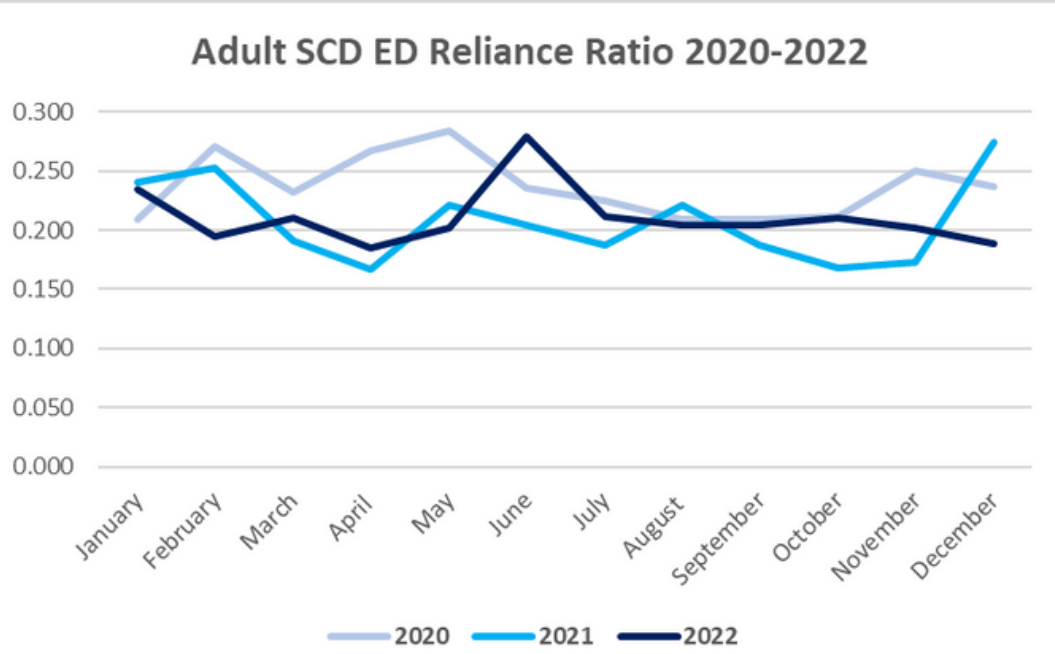
The advent of EDIE- the Emergency Department Information Exchange- on ED flow for SCD among Emergency Departments in the VCU, Richmond, and central Virginia region has been palpable. EDIE offers Real-Time ED information exchange among various hospitals in the region, allows notification when high utilizer/complex needs patients show up in participating EDs, improves communication and care coordination, and allows proactive, concise, actionable data at the point of care among participating EDs.

ED TEAM
Analyze

One particular actionable data item now at the point of care is the individualized pain action plan and usual medications list we have developed for VCU SCD patients. It is available to all members of the EDIE collaborative, and we have had numerous compliments and notes of thanks from outlying EDs seeing our patients.

ED Visit Volume vs ED Reliance Ratio





ED use declined from 2020 to 2021 We consider that an improvement, although COVID was a factor in this utilization decrease. 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 in 2021 was 0.21. In 2020, it was was 0.24

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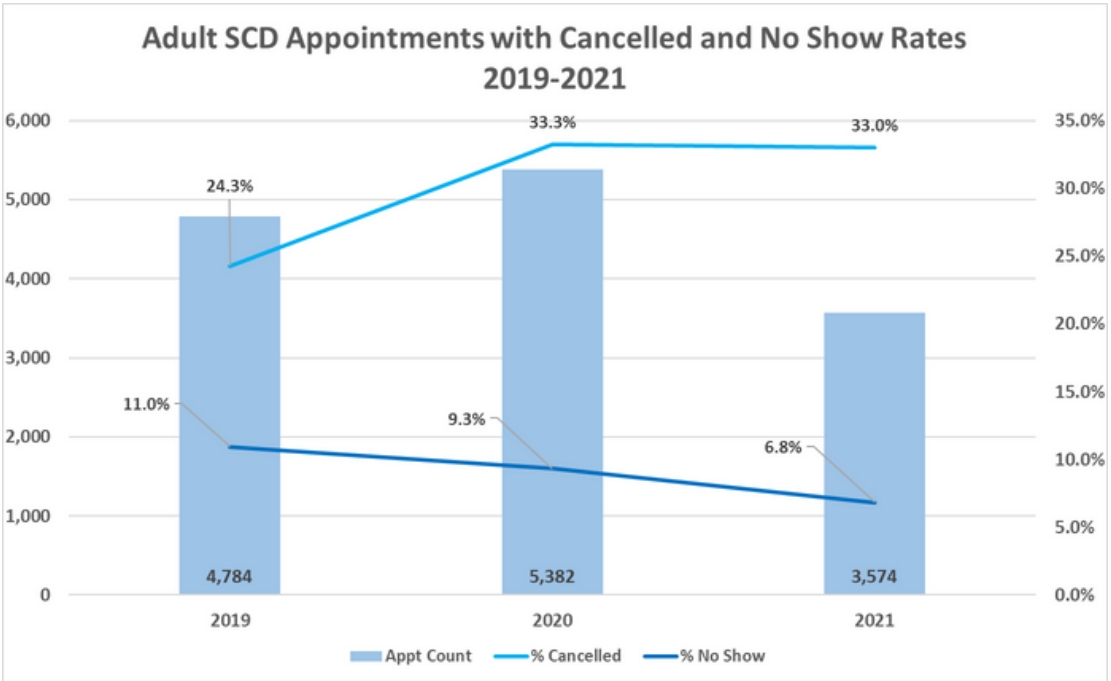
AMBULATORY TEAM

The ambulatory team resumed meeting after COVID restrictions were lifted and the move to the new Adult Outpatient Pavilion was completed in 2022. These meetings occur monthly and are a collaboration with personnel on the dedicated floor for sickle cell patients and the clinical sickle cell team and program manager. This relationship has been positive for both outpatient and sickle cell personnel as we can address any issues, collaborate on program matters, and review outstanding concerns. We also have a dedicated care coordinator for our program and a pharmacist who works with our team to ensure specialty medications are ordered and distributed as needed. She works with our providers to try and approve sickle cell patients on these lifesaving medications. In addition, the collaboration of the outpatient team members on AOP 13 along with the sickle cell providers, navigators, nurses, and others. are bringing value to VCUHS from the perspective of someone not employed by the sickle cell program.

Results Highlight: No Show rates decreased from 2019 to 2021. Despite challenges faced during COVID, the medical home was able to contain cancellations in 2021.



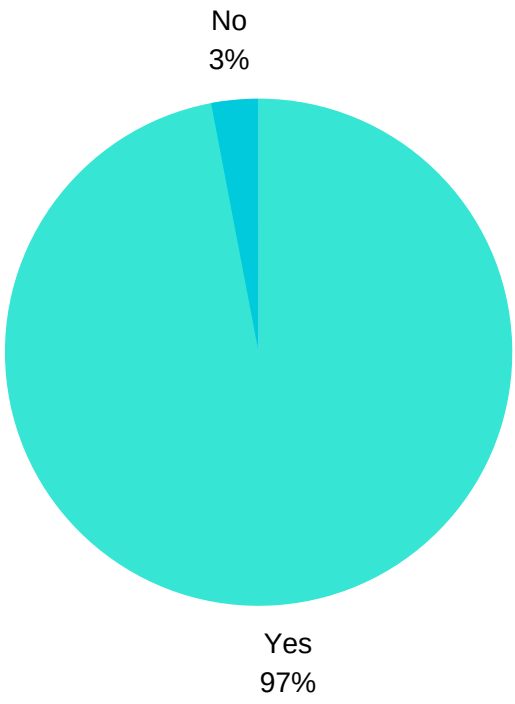
In 2019, additional measures and effort support were put in place to ensure visit compliance.

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.



Source of Usual Care

Does your doctor take care of many patients with SCD?

AMBULATORY TEAM
Structure

Process

Patients are seen four 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 13th floor of the Adult Outpatient building. 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

Lessons Learned

Setting up an adult medical home takes time, energy, planning, and staff support that takes at least one to two years to truly understand the dynamics of the flow to make the function of the of the program flourish.

Through the past five years, we have continued to strive to maintain a winning trust with our patients, which is invaluable in treating patients with sickle cell disease. Unlike patients in emergency departments or hospitals, 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. When we began our program in 2018 and worked towards establishing a comprehensive outpatient medical home, we were determined to meet the needs of the patients and improve their experience in coming to the clinic all while ensuring proper prescribing of medications, treatment plan development and access to safe care. We were on a trajectory of success when in March 2020, COVID-19 happened.

We continued to strive for these same goals while having to change our practice of care to adhere to safety protocols for patient care. As indicated previously, patients were scared to come into the clinic and care required a change to a virtual model for some time. Our team continued to provide supportive services to our patients through virtual, phone and texting methods (see Behavioral Health Team and Patient Navigators). As the pandemic evolved so did our practice, and we continued to improve on patient care and continuity throughout COVID. Just like in Pre-COVID times, we continue to learn we may have 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 often 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.

AMBULATORY TEAM
Results

Lessons Learned

As we continue to adjust to COVID guidelines we maintain a more in-person presence with patients in the ambulatory setting in 2022 and this has been a benefit to providers. The struggles continue to be real for patients to deal with social determinants of health in maintaining good care, but through the efforts of our team, we have made progress in assisting with these needs so they obtain the medical care they need.

CLINICIAN TEAM

The sickle cell clinical team now consists of three physicians three nurse practitioners, and two nurses providing care across three pivotal settings – inpatient care for patients who are admitted, outpatient management in the sickle cell clinic, and care in the infusion clinic for patients in acute need of pain management, blood, or disease modifiers. The two supporting registered nurses are 100% devoted to the sickle cell team. In addition, the team is supported b several ambulatory care staff who are not sickle cell-only. They register room, and perform pre-visit routines for patients, make appointments and draw blood. As of 2022, the SCD ambulatory clinic moved to the new Ambulatory Outpatient Clinic building, and we obtained sickle cell space exclusive to our patients.

Inter-provider Communication

Prior to COVID there were weekly Medical Home team meetings where specific patient cases are discussed and treatment plans can be made with input from all providers. Additional communication occurred on a day-to-day basis via texting or calling between team members. Cerner (now Epic) electronic medical record messaging made communication with other VCU providers easy and efficient in collaborating care. For those providers outside VCU, the 24/7 on-call pager was available if a provider needs to speak to another provider. Outside providers also regularly called the clinic and left messages with the triage nurse about shared patients.

Communication and collaborative patient care among staff changed dramatically due to COVID. Forced by the COVID-19 pandemic, we started to participate in daily Zoom case management huddles with the whole team to discuss patients care or follow up on patient needs. Huddles actually enhance continuity between inpatient/outpatient care.Because they involve social work, patient navigators, analysts, our prior authorization specialist, and managers, they include more holistic care discussions that affect clinical care. Behavioral or psychosocial needs are discussed alongside clinical needs. We have two different case management text chat groups, including one for clinicians only to discuss clinical care progress and issues, and one for all team members to discuss any general case management and communication.

The providers also conduct a separate monthly Zoom clinicians-only meeting to discuss the following topics plus others:

1. Clinical caseload management and staffing
2. Guideline-driven care implementation and quality improvement: ambulatory, infusion, emergency, and inpatient
3. Prescription refill and documentation issues, opioid safety and prescribing issues
4. Electronic medical record documentation and issues
5. Interface with other clinical staff in hospital, outside hospitals
6. On-call responsibilities and scheduling

CLINICIAN TEAM

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:

1..Admission in the hospital
2. Higher than normal utilization of the emergency room
3. Concern for opiate misuse
4. 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. Diminished clinical team staffing due to the loss of two nurse practitioners has affected the frequency with which patients are able to be seen.

Other Adaptations due to COVID-19

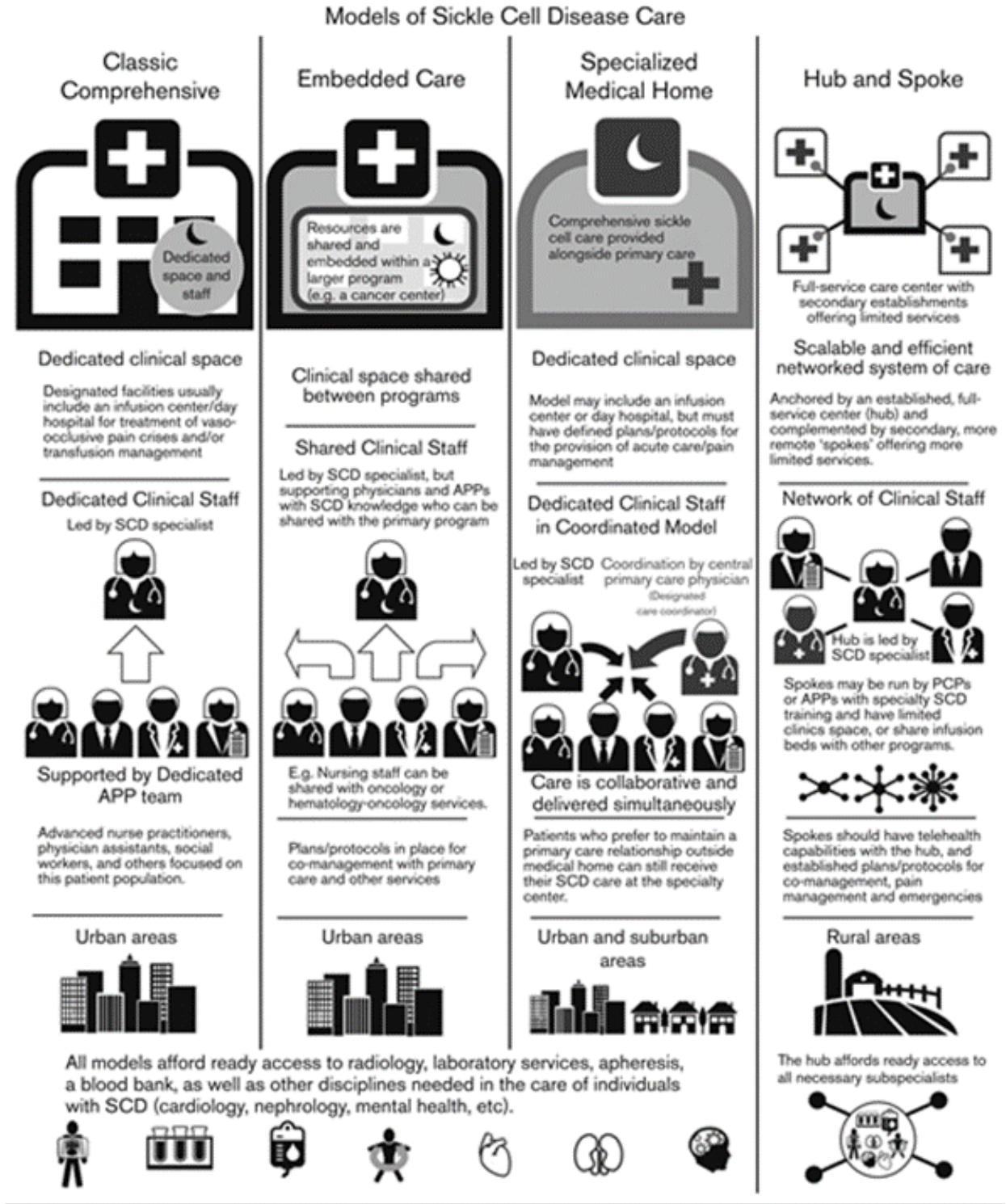
The frequency of visits with an outpatient provider decreased due to patients' decisions to cancel visits at the start of the COVID pandemic. We still strove for a goal to see patients on average every 1-3 months. In person visits decreased significantly to reduce the transmission of COVID-19 virus. Telemedicine replaced in-person visits 100%, then gradually decreased over 2 years based on waves of the pandemic and hospital policies according to infectivity and COVID caseloads locally. Telemedicine occurred over several virtual video platforms, but mostly occurred by phone.

At the height of the pandemic, we developed an algorithm to determine whether visits should be in person or by telemedicine. Providers assessed the individual patient's disease severity, chronicity or acuity of illness, their need for lab work or urine drug screening for prescription management. Using those parameters, providers:

1. Kept the visit in person visit if provider judged it would be harmful otherwise (e.g., if their opioid prescription regimen required it, or if they were physically ill)
2. Required new patient visits to be seen in person
3. Used the above acuity parameters case-by-case to determine whether post-hospital-discharges could be seen virtually
4. Allowed but didn't require patients be seen in person if they were due for routine labs or urine drug screens to monitor chronic opioid use. (After 2 phone visits we required in-person visits.)
5. Allowed laboratory-only in-person visits for patients post-virtual visit.

CLINICIAN TEAM

The Specialized medical home model, (see Figure below, adapted from Kanter, Smith, et al., Blood Advances 2020) most closely describes our team structure and clinical care model.We have dedicated clinical space, an infusion center, defined plans for acute care and pain management, dedicated clinical staff in a coordinated model, led by a SCD specialist, +/- coordination by a primary care physician. Care is collaborative and is delivered simultaneously. Patients who prefer to maintain a primary care relationship outside our medical home can still see their primary care physician.



VCU Adult SCD Medical Home Care Model (Specialized Medical Home), in context of other possible models. From Kanter, Smith, et. al. Blood Advances, 2020.

CLINICIAN TEAM

We have debated about how closely our medical home fits this model in relationship to primary care provision. Do we provide primary care for our patients the way an adult primary care medical home normally does? Not completely. We informally prescribe medications for other diseases, refer patients to multiple specialists to deal with their sickle cell complications of multiple organ systems, and we are the physicians that our sickle cell patients see the most usually.Where we differ is in provision of preventive care primary services. We have not tracked this activity nor intended to provide it, hoping patients sought primary care outside of our center.

As such, in late 2020, we informally surveyed about 20 of our patients about their views of our primary care roles and service, using the following questionnaire:

1. Do you consider a provider in the sickle cell clinic (Dr. Smith, Dr. Lipato, Caitlin McManus) to be your primary care provider?
   a. Yes
   b. No
   c. I don't have a primary care provider
2. Where do you go for a sick visit (if you had cold symptoms, symptoms of a urinary tract infection, symptoms of a sexually transmitted disease, etc)?
   a. Sickle cell clinic
   b. Patient first or urgent care
   c. My current primary care provider
3. Where do you go to receive immunizations?
   a. Sickle cell clinic
   b. Patient first or urgent care
   c. My current primary care provider
   d. Pharmacy
   e. I don't get immunizations
4. Where do you go to receive screening for cancer, such as getting a colonoscopy?
   a. Sickle cell clinic
   b. My current primary care provider
   c. I don't know
5. Where do you for your breast exam, pap smear, annual gynecological exam, or mammogram?
   a. VCU OB/GYN
   b. OB/GYN at another facility
   c. n/a
6. Where do you go for management of health conditions other than sickle cell disease (hypertension, diabetes, asthma, etc)?
   a. Sickle cell clinic
   b. Patient first or urgent care
   c. My current primary care provider
   d. n/a
7. 1. If the Sickle Cell clinic offered primary care services, would you like to get primary care from a provider in the Sickle Cell clinic?
   a. Yes, I would like to get my primary care at VCU with a provider from the sickle cell team
   b. No, I would rather see a primary care provider elsewhere
   c. No, I have a primary care provider and I would like to continue seeing that provider

CLINICIAN TEAM

The majority of patients considered us to be their primary care provider (#1).Many did not, however, go to receive screenings (#4, #5). They sometimes went elsewhere for their other health conditions (#6). Of course, they would welcome the chance to get primary care from us (#7).

This survey was conducted at the beginning of the COVID pandemic. We are now able to again consider how organize services to accommodate the provision of primary care for our patients within VCU.

Pediatric-to-Adult Transition of Care

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 the pediatric to the adult care setting. This is a risky time in the life of patients with SCD. During this period, they use the Emergency Department more, are more like to die, and report more pain and vaso-occlusive crises. Pediatric to Adult SCD Transition has thus become 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 Transition Intervention Program-Readiness For Transition scale (TIP-RFT, soon to be included in the PhenX database of recommended evaluations). The second external grant is a PCORI-funded intervention grant, ST3P-UP, 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. ST3P-UP has moved the pediatric and adult SCD teams towards working more intensely with the 15-25 year old (adolescent and young adult, AYA) patients and they grow into independence and transfer to adult care. All 14 sites in the ST3P-UP grant use patient responses to the TIP-RFT as an outcome of interest.

During 2019, we held monthly support groups for 18-25 year-olds, led by the social worker from the Behavioral Health Team. Activities consisted of education and social outings. Unfortunately, we were unable to continue these support groups initially due to lack of a Behavioral Health Specialist, and then due to COVID-19 restrictions. However, we developed more thorough introduction procedures to receive these patients into the adult SCD clinic from the pediatric clinic. The transition age patients now have their first visit with the outpatient nurse practitioner or Dr. Nadirah El-Amin, who works in pediatrics and sees patients up to age 30 in the adult clinic one day per week. This visit introduces them to the adult clinic, the changes in process, and ways to communicate with adult providers and other members of the team to make the transition as easy and comfortable as possible.

CLINICIAN TEAM

Pediatric-to-Adult Transition of Care con't

The TIP-RFT and other evaluation tools are administered by the Licensed Clinical Social Worker to assess patients' readiness and ability to function as adults, both at the time of care transfer, and yearly until age 25. The newest evaluative tool is called tiers of engagement. This new implicit assessment consists of four domains: medical engagement, vocational/educational engagement, behavioral engagement and capacity, and social engagement/capacity. It was adapted from a nearly identical set of evaluations created by our pediatric social worker and used by the pediatric team. These tiers evaluations are now performed annually for approximately 120 transition-aged patients by the entire team, and not only recorded for use as a quality improvement project in ST3P-UP, but also kept on file for clinical, behavioral, and case management care.

Call Schedule

There continues to be 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.

Safe Prescribing and More Selective Chronic Opioid Management

Safe prescribing of opioids for chronic pain is one of the most hotly debated topics among SCD providers.The VCU clinical team takes the philosophy, not shared by all, that most sickle cell patients require chronic opiate therapy (COT) for their chronic pain. While there are no randomized trials proving the superiority of COT for chronic SCD pain, and while multimodal pain regimens that are less dependent on opioids may better improve pain outcomes, this has not yet been demonstrated for SCD. At the same time, the team takes the philosophy that there are dangers in COT even for sickle cell patients, though recent literature has shown the dangers are lower in sickle cell than for many other chronic diseases.

So, to enhance safe prescribing and demonstrate compliance with federal prescribing requirements, we continued to conduct frequent urine drug screen monitoring in the outpatient setting. 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. Though in-person visits were limited in 2020 due to COVID-19, routine urine drug screens were still performed, either during in-person visit or during separate trip to the lab if the visit occurred over the phone.

CLINICIAN TEAM

Safe Prescribing and More Selective Chronic Opioid Management con't

Further, we have attempted to categorize patients that may be less safe, or less appropriate for COT, or more appropriate for closer monitoring, by grouping patients based on hospital/emergency room utilization, behavioral screening results, opioid utilization, appropriateness of opioid monitoring, and cues to diversion. This categorization is still being perfected but helps in determining what behavioral health or clinical interventions are necessary, whether restrictive prescribing agreements need to be in place, or whether COT has failed and the patient needs to be slowly tapered off opioids.

Individualized Treatment Plans

Individualized treatment plans, especially for Vaso-occlusive crises, continue to be the national standard of care to assist Emergency Department providers and other team members with pain care. Plans contain dosing suggestions and schedules for opioid for pain management.They contain (sometimes restrictive) guidelines to promote appropriate admission and to avoid inappropriate admission to the hospital. These opioid doses are adjusted based on recent inpatient nurse practitioner evaluations of the efficacy of analgesia either in the emergency department or inpatient setting. Specific intravenous and oral dosing is calculated by the inpatient nurse practitioner, and frequent dialong is conducted with inpatient team members and with the patient to ensure adequate analgesia, safe prescribing, and as rapid a hospital discharge as feasible.

Specifically, individualized 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

Tiered Oral Therapy Protocol

The clinical team continues to used a new hybrid approach to inpatient sickle cell analgesia during a vaso-occlusive crisis that has caught on nationwide. Called Tiered Oral Therapy Protocol (TOTP), the plan relies on incorporating home oral opioid management into inpatient management, such that smoother transitions occur between outpatient and inpatient regimens.

CLINICIAN TEAM

Tiered Oral Therapy Protocol con't

Components of TOTP include:

1. Inpatient management relies on the use of intravenous and oral opioid doses
2. Upward dose titrations seek to achieve rapid and adequate analgesia (Phase I, goal <24-36 hours), followed by a holding pattern (Phase II), to allow for rest and recovery and a dual phase process to down titrate medications in preparation for discharge (Phases III and IV)
3. 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)
4. Oral doses are typically derived from the outpatient prescription (may be adjusted based on patient reports of actual use pattern)

TOTP aims to be effective, efficient, and safe for patients. TOTP can also serve as a guideline to make management of vaso-occlusive pain a little easier for novice pain management clinicians.

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.

New Clinic Space

The Adult Sickle Cell clinic now occupies a sickle-cell-only, sickle cell-branded hall and suite of rooms on the 13th floor of the new 19-story, 615,000 square foot VCU Ambulatory Outpatient Pavilion, completed in December 2021. The AOP houses a variety of outpatient clinics formerly at the Ambulatory Care Center, North Hospital and Nelson Clinic. The AOP includes a 425,000-square-foot parking deck with more than 1,000 spaces, increasing patient and visitor parking options at the point of service.

CLINICIAN TEAM

New Clinic Space con't

AOP features include:

- Plentiful and convenient parking, with easy elevator access direct to patients' destination
- A wide array of outpatient clinics, including women services, all in the building
- Co-located services to ensure efficiency and collaboration between specialties
- Convenient diagnostic testing, with on-site laboratory and medical imaging services
- Healing and welcoming spaces to comfort patients and families

BEHAVIORAL HEALTH TEAM

After a slow start in 2018-19 due to staffing issues and establishing evaluation processes, the Behavioral Health Team (BHT) started in earnest in 2020, with an ambitious agenda to advance program processes and metrics.

Goals of the Team

The overarching goal of the BHT is to offer emotional and behavioral health support to our adult SCD patients, especially those most vulnerable. We aim to enhance each patient's distress tolerance. SCD is clearly a distressing disease. One definition of distress tolerance is "perceived capacity to withstand negative emotional and/or other aversive states (e.g. physical discomfort), and the behavioral act of withstanding distressing internal states elicited by some type of stressor."[1] We also want to help patients with emotional regulation and self-care, with the intention of alleviating life stressors so that each patient can manage their unique disease manifestations with treatments prescribed by our providers. Therefore, each member of our BHT acts as navigator, educator, advocate, case manager and counselor, while still working within their respective scope of practice. Further, the full Medical Home team meets daily in order to share patient interactions and to jointly, continually discern patient need and delineate tasks to help meet those needs, and the BHT meets weekly to assess newer patients and review progress on needier patients.

The team was developed based on the concept of patient navigation in 2018 during the inception of the medical home. Many have used the title of patient navigator, it may refer to nurses, social workers, lay health workers or other community health workers. We refer to our case management staff as Patient Navigators. At minimum they must be trained as Community Health Workers, but may also be social workers. These workers are the backbone of the entire medical home.

However, as the program evolved, we have added to the BHT the positions of Licensed Clinical Social Worker (LCSW), Transition Coordinator (a specially trained patient navigator for adolescents and young adults). We have also supported BSW and MSW interns each year from the VCU School of Social Work for the past six years.

Our trained PNs offer case management and community support. They act as a lifeline for the patients who are considered high-risk, offering direct access to their Sickle Cell provider team. We consider a high-risk patient as one who is most at risk for co-morbidities, frequent hospitalizations, homelessness, and/or death. Since 2015, PN staff and other team members have been provided intense training. The curriculum is now mature, and is delivered in the form of a four day in-person and/or virtual conference known as SCCAPE, led by VCU team leaders (discussed in another section). At SCCAPE, PNs are provided key knowledge, skills, and modelling of attitudes to help them address all patient needs.

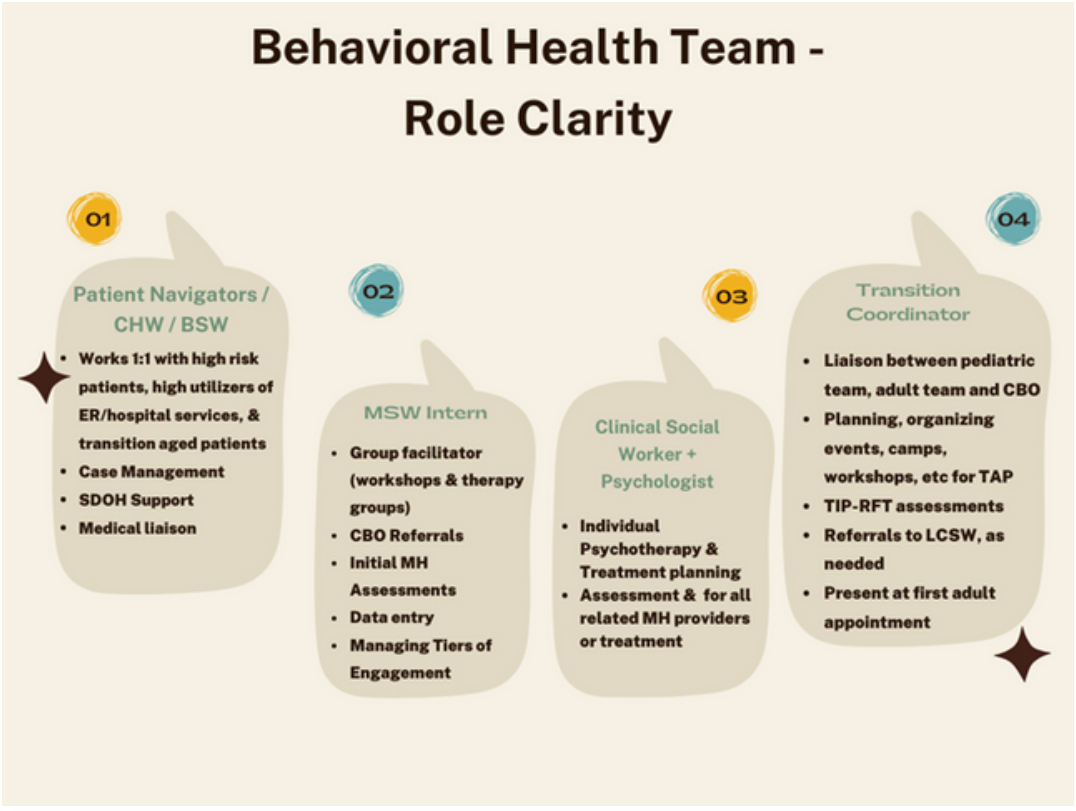
BEHAVIORAL HEALTH TEAM

All members of our BHT are accessible to patients via text, phone, or through MyChart. In fact, a hazard of our now mature program now is that some impatient patients contact multiple team members with the same need, hoping to get quicker service.

Formal emotional and behavioral health support is offered to identified patients by our Licensed Clinical Social Worker (LCSW, described in detail below), in the forms of individual and/or group therapy. Our LCSW handles internal team referrals, usually from MDs or APPs, for patients who need talk therapy, and helps refer out patients who need psychiatric services. This is voluntary on the part of the patient of course, but it may be offered to any Sickle Cell patient. Of course, patients are also encouraged to continue any psychotherapy they may already be engaged in.

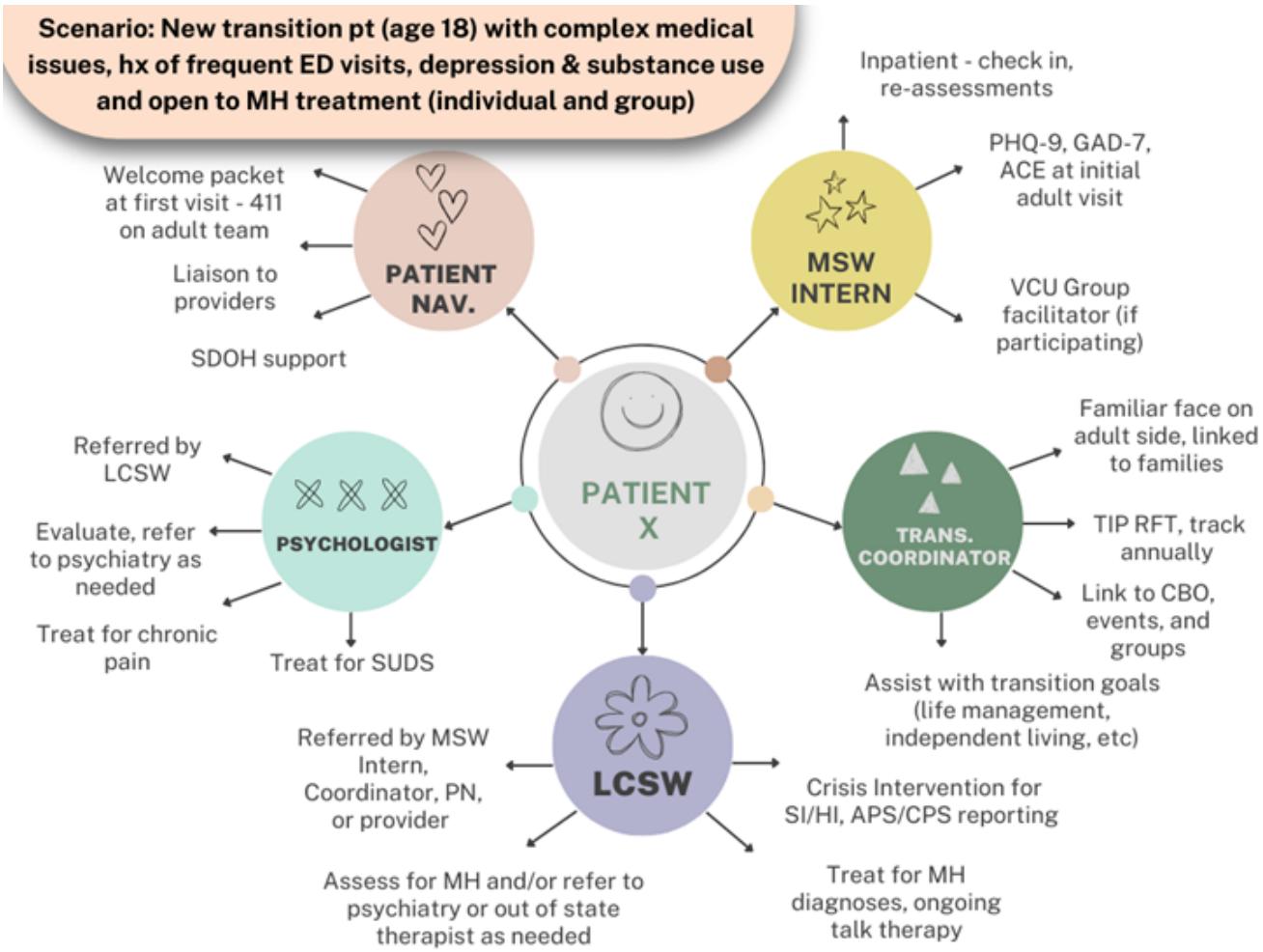
Optional support groups are currently led by our team Master's of Social Work (MSW) Intern. We have a closed women's only support group. In the past during the height of the pandemic, there were groups led for transition age patients that focused on life skill areas. For example, one group attended by 10 patients in 2022 took a trip to the VCU Health Hub grocery store for a healthy eating shopping trip. Support groups are created and conducted based on the identified need of each participant. Current plans include a men's health group.

Our team uses a strengths-based and patient-centered approach to assess overall needs that are impacted by patients' social determinants of health (SDoH), with the goal to improve quality of life. Adding the BHT has let us provide comprehensive clinical and emotional support for patients, using a multi-disciplinary team approach (see diagram below).



BEHAVIORAL HEALTH TEAM

Further, below is a case example that describes how each member of the BHT may work together to support a given patient.



COVID-19 Pandemic - Impediments to Team Enhancement

Prior to the COVID-19 pandemic, we planned to replace our departing social worker, to hire a physician focused on biopsychosocial research, and to hire a dedicated psychologist focused on behavioral health therapy and research.

However due to the impact of the pandemic, VCU Health initiated a hiring freeze which lasted over two years. All non-essential staff were asked to work from home. Members of our team that were considered essential, were the providers who were still holding clinic. Therefore, we could no longer pursue the physician or psychologist hires that were on our agenda in January 2020. The BHT was asked to manage with the resources available and attempt to continue quality behavioral health care through telecommunications. Through 2020 and then 2021, we learned to re-engage in a process of patient care that was safe for the patient and staff, and continuing the supportive work of the program. The staff engaged via in-person, telephonic and on-line visual/virtual care to ensure patients needs were met. We also drastically enhanced inter-team communication, described below.

BEHAVIORAL HEALTH TEAM

Changes in Team Communication

To accomplish behavioral health care during the pandemic, in early 2020 we instituted a daily virtual case management huddle held Monday-Friday on Zoom, which continues presently. We review patients' needs, discuss requests from patients who contacted the team the previous day or weekend, or if any team member has case considerations or challenges to discuss. Huddles were employed to help the team stay connected to patients and to each other as telework began. Our multi-disciplinary team is required to attend these huddles to discuss patient care or follow up on patient needs—clinical, behavioral, or psychosocial. All needs and strategies to employ are discussed alongside one another. Patients are presented, a clinician voiced recommendations on care of their clinical requirements, followed by recommendations of other staff and medications needs, including prior authorizations.

Additionally, the BHT meets weekly to address any upcoming assessment needs for patients who are scheduled to be seen in our outpatient clinic. The BHT also meets monthly to review outcome measures, discuss processes and to make any changes as needed.

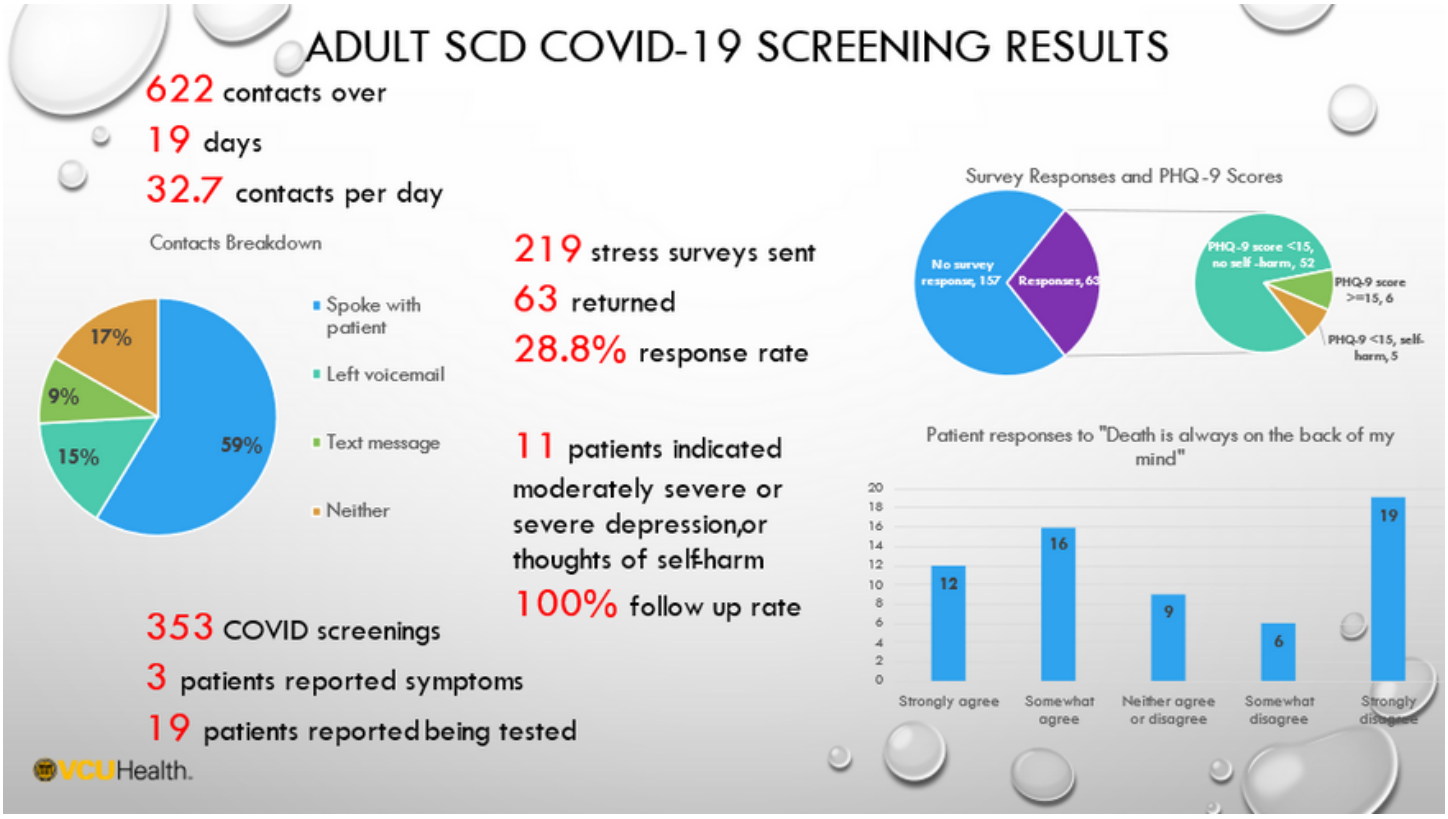
As a result of establishing daily huddles, as well as the team's group chat (described elsewhere), we find enhanced continuity between inpatient/outpatient care, connection among team members, and maintaining continuity of care for patients. Because the huddles involve the behavioral health team, clinicians, analysts, our prior authorization specialist, and managers, they included more holistic care discussions that affected clinical care. Unexpectedly, these huddles provided insight, and the holistic discussions enhanced the case work of the Patient Navigators as well as treatment decisions of clinical staff.

Patient Communication and Contact Methods

From prior surveys, we learned that our SCD patients appropriately viewed their Patient Navigator (PN) as their connection to the team and outside providers or services. One concern for the BHT during the pandemic, was the potential for an increase in unsafe patient behavior and isolation. The BHT raised concerns about patients losing connection to medical care, community resources, and other needs. Formerly, PNs met with patients while they were in the clinic or hospital. We sought to preserve bonding and rapport of those PN-patient relationships (see Patient Navigators).

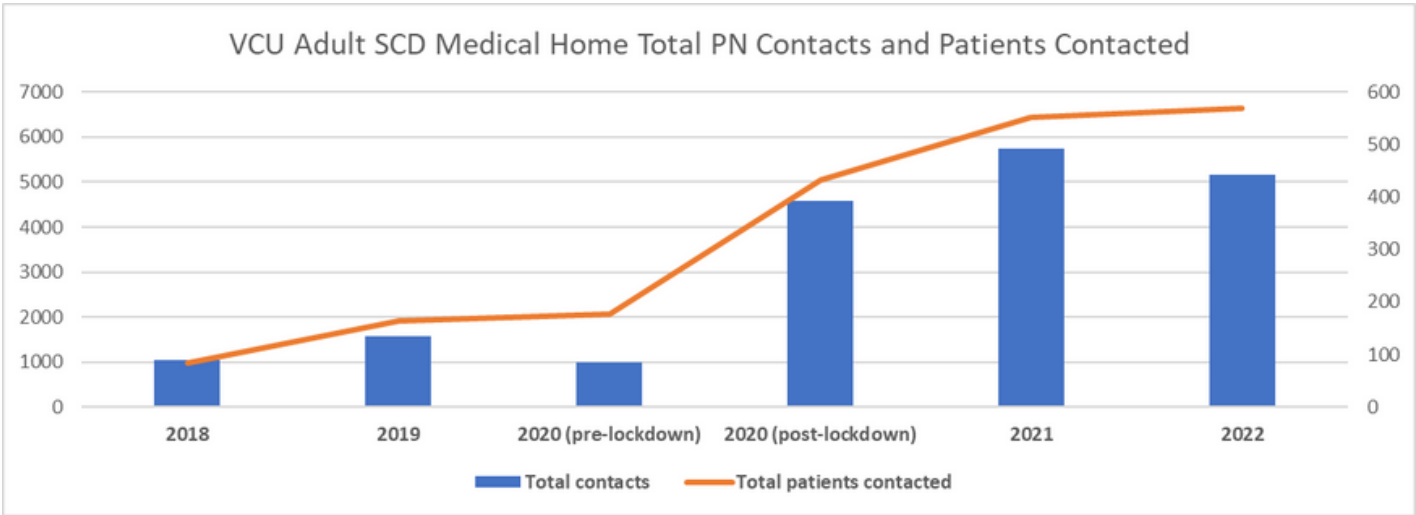
When the pandemic began, there was a great deal of concern for the isolation of our patients and a decision was made to reach out to each patient and assess their mental and physical health needs for safety. A list of patients was divided up between 14 staff and over a two-week time period an attempt to reach all patients was made. Below are the results of the surveys conducted on the patients we were able to reach. On patients that were displaying signs of severe depression or medical issues, follow-up via phone or video was handled by clinical providers until patient was stable.

BEHAVIORAL HEALTH TEAM



To preserve this bonding and continuity of care for patients as their needs arose, we dramatically ramped up tele-contact and tele-navigation. We encouraged PNs to text and/or call patients, and tracked activity of those contacts. This method of meeting patients where they are and addressing their needs, became one of the focal points throughout 2020 and the pandemic. The PNs corresponded with patients, assessed their needs, and notified staff of these needs during daily huddles, or through the group chat, to communicate any developments, requests, problems or emergencies.

The below graph shows the dramatic increase in the number of PN contacts made in 2020 through 2022, compared to 2018 and 2019.



BEHAVIORAL HEALTH TEAM

Emergence from COVID-19

The end of 2021 marked a substantial new changes in our physical clinic space. We moved into brand new clinic space and at the same time moved from our old electronic health records system (Cerner) and adopted a brand new electronic medical record (Epic). Our clinic re-opened in January 2022. Slowly we have increased the pace of ambulatory medical visits nearly back to pre-COVID levels, and with it, have advanced the pace of BHT activities.

Enhancements to Team Structure

Just before the hiring freeze, we were able to hire and onboard a new LCSW, which we determined was desired to provide the therapeutic interventions to our patients within our medical home. Our new LCSW, Rachel Walls was able to begin work in Fall 2020. Rachel has been licensed to provide psychotherapy for eight years and has worked extensively with individuals living with chronic disease. Rachel is a board-certified Clinical Supervisor in the Commonwealth of Virginia and is an EMDR Practitioner. She received her Master's in Social Work (MSW) from Tulane University with a concentration in Disaster Mental Health.

The Behavioral Health team continues to work on expanding its mission to assist sickle cell patients in improving their medical care and overall quality of life. As part of our program, each year, we onboard at least one master's of social work (MSW) intern who is supervised, mentored and taught by our LCSW. Our MSW interns conduct assessments, screenings, contribute to research, and create & implement a support group.

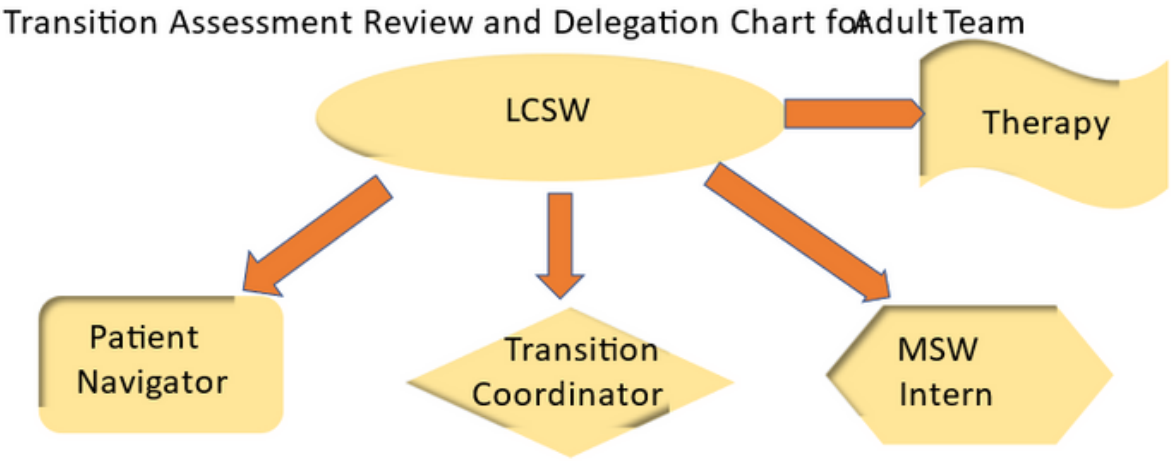
Pediatric to Adult Transition

Transition-age patients have special needs, stressors, and fears. We strongly encourage them to see the LCSW, who is also responsible for overseeing or administering the initial behavioral assessment of all transition age patients coming over from pediatrics. The LCSW makes judgments about behavioral health needs based on these assessments. The LCSW meets with the BHT, as well as with providers who need to prescribe psychotropics, to oversee team member interventions and interactions and assure we are meeting the behavioral health needs of transition patients (see diagram below).

In detail, we conduct an overall mental health assessment process completed during their initial appointment into the adult clinic. These assessments are critical in developing a baseline of any depression, anxiety or trauma for a patient, an adult education/vocational plan is also developed and therapeutic recommendations are discussed and assignments of the behavioral health team are documented for follow-up with all team members acknowledging the needs of the patient and ensuring that these needs are met.

BEHAVIORAL HEALTH TEAM

Since there are also existing transition patients in the adult program- since a transition patient is identified as such until age 26- we also provide this same evaluation on each of those patients to provide the same program support now that our program is complete. Below is a diagram of how a weekly meeting by the BHT is held a determination of role assignments and follow through is determined and overseen by the program manager.



Assessments completed at first adult appointment visit by either LCSW or MSW intern. Each week LCSW reviews assessment outcomes with all behavioral health team members above in a meeting and team determines roles and responsibilities for that patients based on assessment outcomes. Please also review pediatric Tiers of Engagement and Educational Plan with adult team

A dot note is completed by LCSW in EPIC outlying the meeting as follows:

LCSW: therapy appointment scheduled ___yes___ No_____ date
MSW Intern follow-up___ yes___ no___ assignment
Transition Coordinator follow-up:___ yes___ no
Educational Plan in EPIC:____ yes___ no
Patient Navigator follow-up:___ yes___ no___ assignment

Transition Coordinator will update team members weekly during morning meeting after this is completed.

Another component of our transition program, team-based patient engagement assessment using implicitly determined Tiers of Engagement was developed out of a quality improvement project and is now used weekly. Our team uses the criteria below to identify patients who may need more engagement or attention from the team. Based on where a transition aged patient falls in this criterion, the team works to address those areas that may need attention.

Our goal is that supportive behavioral health and case management support, career development and continuity of care, will impact the comorbidity rate of the transition age population.

BEHAVIORAL HEALTH TEAM

Tiers of Engagement in Patient with Sickle Cell Disease

Tier 1

Medical:

- medication adherent
- consistent refill history
- attends scheduled appointments with sickle cell provider and other specialists
- has active insurance
- no ED visits or infrequent ED visits

Educational/Vocational:

- regularly attends school/work
- maintains good grades/employment status
- has a long term plan for school/work fulfillment

Mental:

- no history of mental health concerns or has stable management of mental health symptoms,
- maintains appropriate behavior for chronological age
- appropriately advocates for their needs and utilizes natural support system

Social

- has hobbies and other interests that are practiced regularly
- engages in social activities through school or the community
- enrolled with CBO and has attended monthly groups
- strong social support system
- permanent housing, no safety concerns

Tier 2

Medical:

- takes medications at least 50% of the time
- mostly consistent refill history with some short gaps
- has some cancellations for appointments but calls to reschedule
- has had problems with insurance coverage but they are easily resolved
- occasional ED visits

Educational/Vocational:

- misses less than 12 days of school/work per year
- struggles in some classes but maintains average grades (C's)
- has thoughts about after graduation
- employment status reduced by employer

Mental:

- minor mental health concerns (anxiety, adjustment issues, etc)
- has some symptoms that impact daily life, but overall functions normally
- needs help with advocating for needs and utilizing additional supports
- referred for therapy and regularly attends therapy appointments

Social:

- has interests in hobbies but is not connected with school or the community
- enrolled with CBO but has not engaged with them
- limited social support system
- stable housing but unsafe conditions

Tier 3

Medical:

- poor medication adherence, inconsistent refill history
- constant no-shows or cancellations with sickle cell providers and other specialists
- does not have active insurance
- frequent, sometimes unnecessary ED visits

Educational/Vocational:

- misses over 12 days of school/work per year
- failing some or all classes, does not have a plan in place
- no after graduation plans
- lost employment (laid off, fired, furloughed)

Mental:

- significant mental health concerns (hx of psychiatric hospitalizations,
- psychotropic medications have been prescribed
- behaviors impact daily life, relationships
- does not advocate for needs independently
- not consistent with therapy appointments

Social:

- does not present with any interests in activities
- not connected with any resources through school or in the community
- has not enrolled with CBO
- at risk of homelessness
- no social support system

In 2022, we were awarded a five-year grant from the Virginia Department of Health for adult sickle cell and pediatric-to-adult transition of care, which was the first time in history funding was provided by the General Assembly for Adults living with Sickle Cell Disease. Nationally, it is recognized that the most vulnerable age group in sickle cell disease is the transition age cohort. Many programs do not have adult providers to which to send patients. Even if there is an adult provider, the resources to support transition-aged patients is limited. Thus, over the past 5-10 years there has been a huge national focus placed on SCD transition of care by the American Society of Hematology (ASH), Sickle Cell Disease of America (SCDAA), Pharmaceutical companies, National Alliance of Sickle Cell Centers (NASCC), and several states, including Virginia, which already had state-funded pediatric sickle cell programs.

Virginia thus allocated funds to four regions of the state for this purpose, and VCU was awarded funds for the central region. With these funds, we continue the work we began twelve years earlier to enhance the transition from pediatric to adult SCD care. We used allocated funds to hire a dedicated Transition Coordinator, Raven Hines (see **Transition Team**), who in October 2022 began to work with both pediatric and adult programs to better serve the 15-26 age group of young adults who need additional support.

BEHAVIORAL HEALTH TEAM

Raven comes to the team from Virginia Department of Health with over ten years of experience in the public health field; where her focus and passion has been helping vulnerable populations, especially at-risk youth. Raven is a graduate of Virginia Commonwealth University where she received her Bachelors of Science in Community Health Education. She also holds a Certified Health Education Specialist certification.

The long-term goal is providing a life span program at VCU for sickle cell patients and this role will assist in the development of that program.

Housing Program

Adults with SCD often face more challenging life situations than just managing their chronic illness. There is a plethora of adverse social determinants of health (SDoH), and we recognize that attending to SDoH often curbs high SCD health care utilization. One often-overlooked SDoH in adults is housing insecurity. Interventions to stabilize housing have been shown to lower utilization in veterans, substance misusers, and other vulnerable adults.

The VCU Adult Sickle Cell Medical Home was fortunate enough to get an opportunity to partner with Virginia Supportive Housing(VSH) in a pilot program to eliminate housing instability, and thereby lower healthcare utilization among our high-utilizing SCD adults. The pilot housing program began in 2018-19 for five selected SCD adult recipients enrolled in the Medical Home. Each recipient had already been assigned a Patient Navigator, each had unstable housing, high healthcare utilization, and possibly high opioid use or suspicion of opioid misuse or diversion. To be invited, recipients either: 1) had been deemed homeless by Federal guidelines; 2) had reported that they were living temporarily with others and moving repeatedly (aka sofa surfing); 3) lived in a rooming house that could make it challenging to sustain medical adherence or safe storage of their opioids; 4) had been recently released from jail but had no support system or housing, or; 5) underwent medical or cognitive assessment leading to the conclusion that their current housing posed a physical or medical threat.

We followed patients for over a year and maintained contact with them as long as they remined in the program and even after they left. Medical care continued with the same providers during this period. Patient Navigators met with and supported patients throughout their entry into and throughout their stay in the housing unit. Recipients were the subject of weekly case management and care coordination meetings, visits from the Patient Navigators in their homes, and assistance with other community services. During the pandemic, virtual visits, meetings with the VSH staff and others, continued to support these patients. Virginia Supportive Housing staff were tasked with developing individualized self-improvement, care transition, and housing transition plans for each patient, though VCU did not co-develop or monitor these. Reported utilization, most of which occurred within the VCU health system, was tracked. Utilization data was collected for 5 months pre-program and post-program for each patient.

BEHAVIORAL HEALTH TEAM

Results of the program were stunning and encouraging. Nine patients were invited to enter the housing program. Five patients, including three men and two women, agreed. For these five patients, compared to FY 2017-18, total FY 2018-19 hospital charges decreased by 44%, and 3-day ED return rates decreased by 13%. Thirty-day readmission rates decreased by 74%. Inpatient average length of stay decreased by 25 %. Inpatient visits decreased by 34%. In contrast, ED visit return rates increased by 5.4 %. Total 2018 hospital days were 448 days, and total charges were $843,498.44. These decreased to 107 days and $319,257, respectively in 2019 after placement, for a savings of $524,241. Anecdotally, patients self-reported increased wellness days, decreased opioid utilization and dependence, increased safety, and increased engagement in seeking or obtaining employment.

The behavioral health team reported these results nationally. For example, the abstract was one of the highest rated abstracts at the Foundation for Sickle Cell Disease Research (FSCDR) national conference in 2020, where a virtual presentation was held and presented by the program manager.

Trauma-Informed Care

Our LCSW was able to identify key concepts and approaches that needed to be implemented to offer best practices from a behavioral health standpoint. She approaches therapy through a trauma-informed lens and has dedicated time to educating our entire team on the benefits of operating as a trauma-informed practice. In implementing this new approach, our LCSW began assessing patients using the Adverse Childhood Experience survey (ACEs) to provide a wider base of knowledge about the trauma that patients may be bringing with them into the exam rooms and hospitals. Our LCSW has also been able to contribute and conduct research on this childhood trauma survey. Our team collaborated on this project and we were able to conduct research on whether or not the ACE could be an accurate predictor to several important identifiers among Sickle Cell patients.

BEHAVIORAL HEALTH TEAM

	All	Mood Disorder	No Mood Disorder	Anxiety Disorder	No Anxiety Disorder
Total Contacts	3532	1450	1910	1314	1731
Total patients	409	98	311	95	1731
Avg time of contact (min)	16.44	17.26	15.81	18.13	15.36
Contacts per patient	8.6	14.8	6.1	13.8	5.5
		ACE Score			
	0	**1-2**	**3+**		
Total Contacts	64	181	709		
Total patients	8	16	33		
Avg time of contact (min)	18.86	16.1	18.2		
Contacts per patient	8	11.3	21.5		

Other Assessments

In honoring a patient-first approach, viewing each patient holistically is essential when understanding patient behavior. Just as past trauma is an internal barrier, also identifying the Social Determinants of Health (SDoH) for each patient will assist in identifying external barriers to achieving patient health. Currently, we use the following assessments to assist our team in understanding patient behavior and supporting behavioral change as needed.

- ACE (Adverse Childhood Experience)
- AUDIT-C (Alcohol Use)
- C-SSRS (Columbia Suicide Severity Rating Scale)
- DAST-10 (Drug Abuse)
- DSM-5 Criteria for PTSD
- GAD-7 (Anxiety)
- PHQ-9 (Depression)

For transition aged patients (AYAs age 18-25), the assessment algorithm also includes a transition psychosocial battery administered at transfer and the initial adult intake, then annually thereafter. On their first or second visit, all patients undergo a biopsychosocial assessment. Physicians conduct the history and physical. At the same visit staff administer assessments covering a wide variety of behavioral health, substance use, and social determinants of health-related issues.

BEHAVIORAL HEALTH TEAM

Recognizing that our transition aged patients are at the most risk for co-morbidities and death, we use the following to assess transition attitudes, stressors, coping, and readiness for transition (*indicates a scale developed and validated at VCU and now used nationally):

- Biopsychosocial Assessment (including physical exam, implicit evaluation, interview by LCSW)
- Habitat Inquiry
- Sickle Cell Stress Scale, Adult (long, 10-item version)*
- TIP-RFT (Transitions Intervention Program- Readiness for Transition)*

Towards an Anticipated Behavioral Health Resiliency Predictor

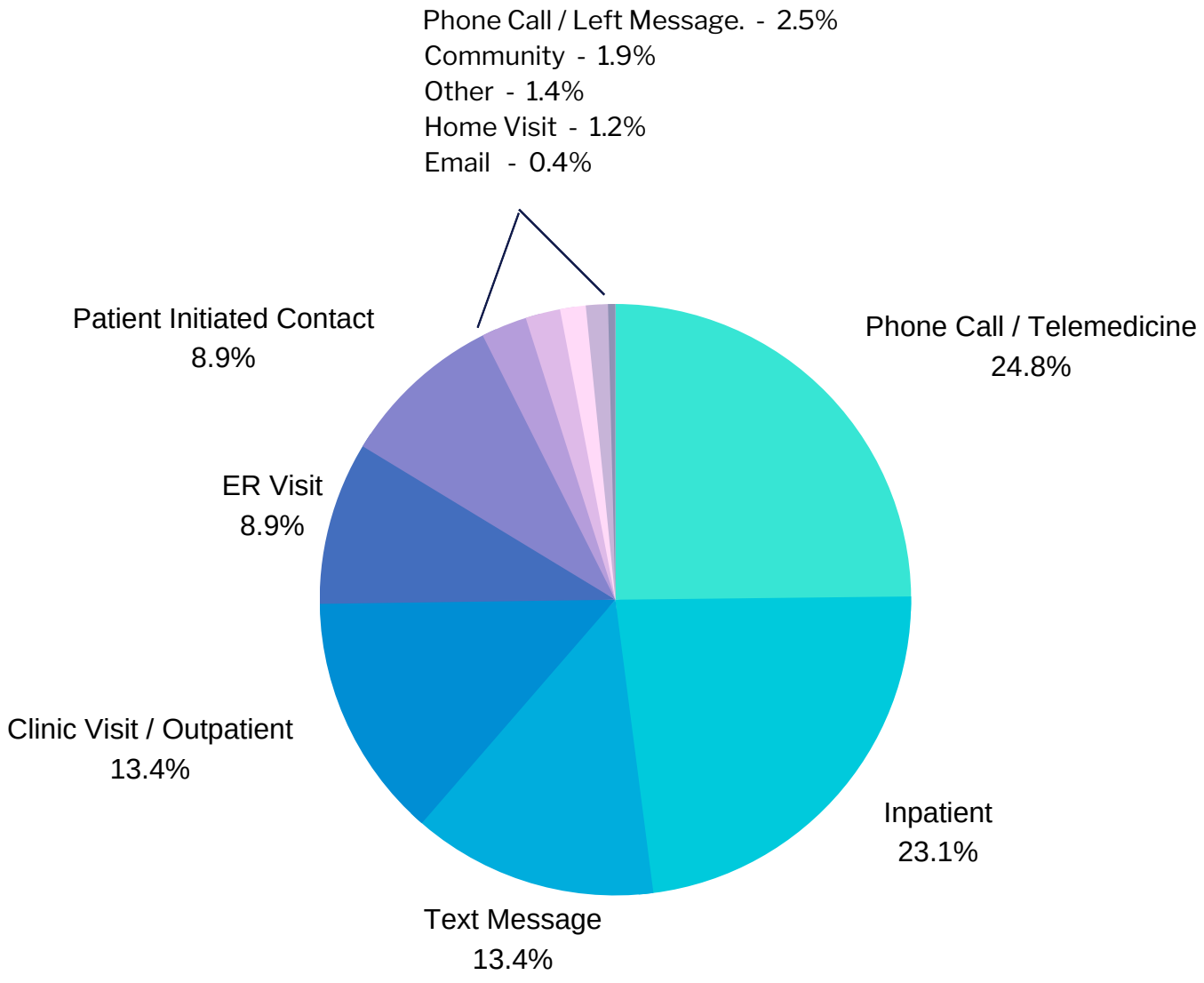
To align with the principles of a strengths-based approach to care, the BHT discovered a need to examine each patients' individual level of resilience, or their most strengths. Health care too often approaches patients, seeking problems to solve or address. Our Sickle Cell population faces life-long problems including but not limited to: medial trauma, chronic pain, loss of functioning, co-morbidities, challenges in relationships, identity crises, substance misuse, depression, anxiety, food insecurities, housing insecurities, racism and bullying.

In order to address these barriers and burdens, we feel that it is important to acknowledge a patient's inherent and learned resilience as well as their areas of growth. Currently, there are no such resiliency scales specific to patients living with SCD. This is a multi-year analysis project which aims to highlight the resiliency of SCD patients compared to the rest of the world.

All of the assessments that our BHT uses is to enhance our understanding of each patient so that we can advocate for and deploy center behavioral health resources. If we can identify resiliency factors alongside a patient's history of trauma, mental health, and other barriers, we can more accurately identify high risk patients as well as offer more detailed treatment plans and support. As the program continues to expand, we are now in the position to once again look to add the Biopsychosocial Scientists to our faculty and will be recruiting in 2023. We continue to collaborate within Virginia Commonwealth University with colleagues and are nationally recognized for the work the BHT accomplishes. In December 2022, an oral abstract was presented at the American Society of Hematology conference in New Orleans, by program manager, Shirley Johnson on "Intensive Case Management in an Adult Sickle Cell Medical Home: Annual Effects on Utilization Efficiency Using Community Health Workers".

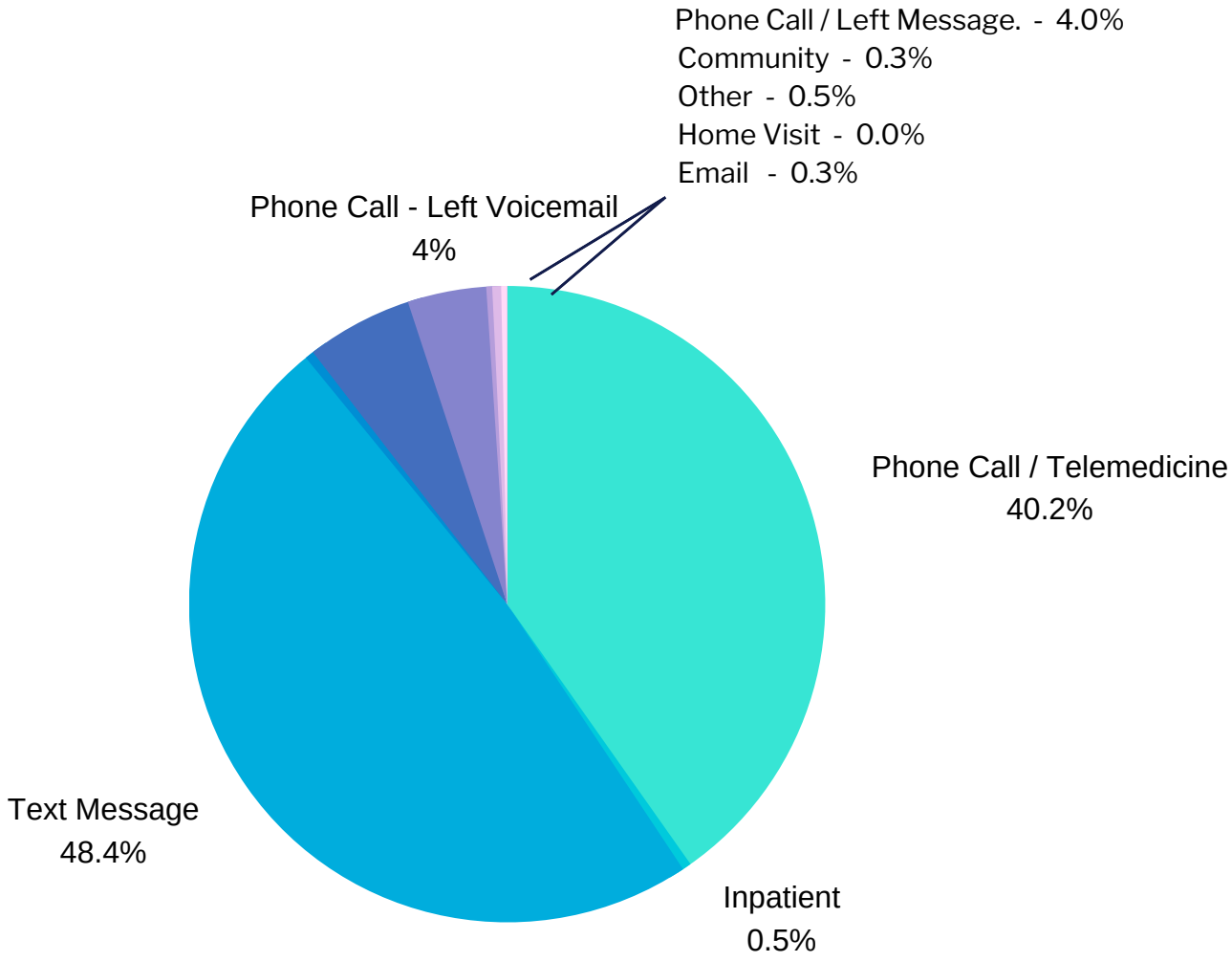
PATIENT NAVIGATORS

A Month in the Life of a Patient Navigator: Before COVID



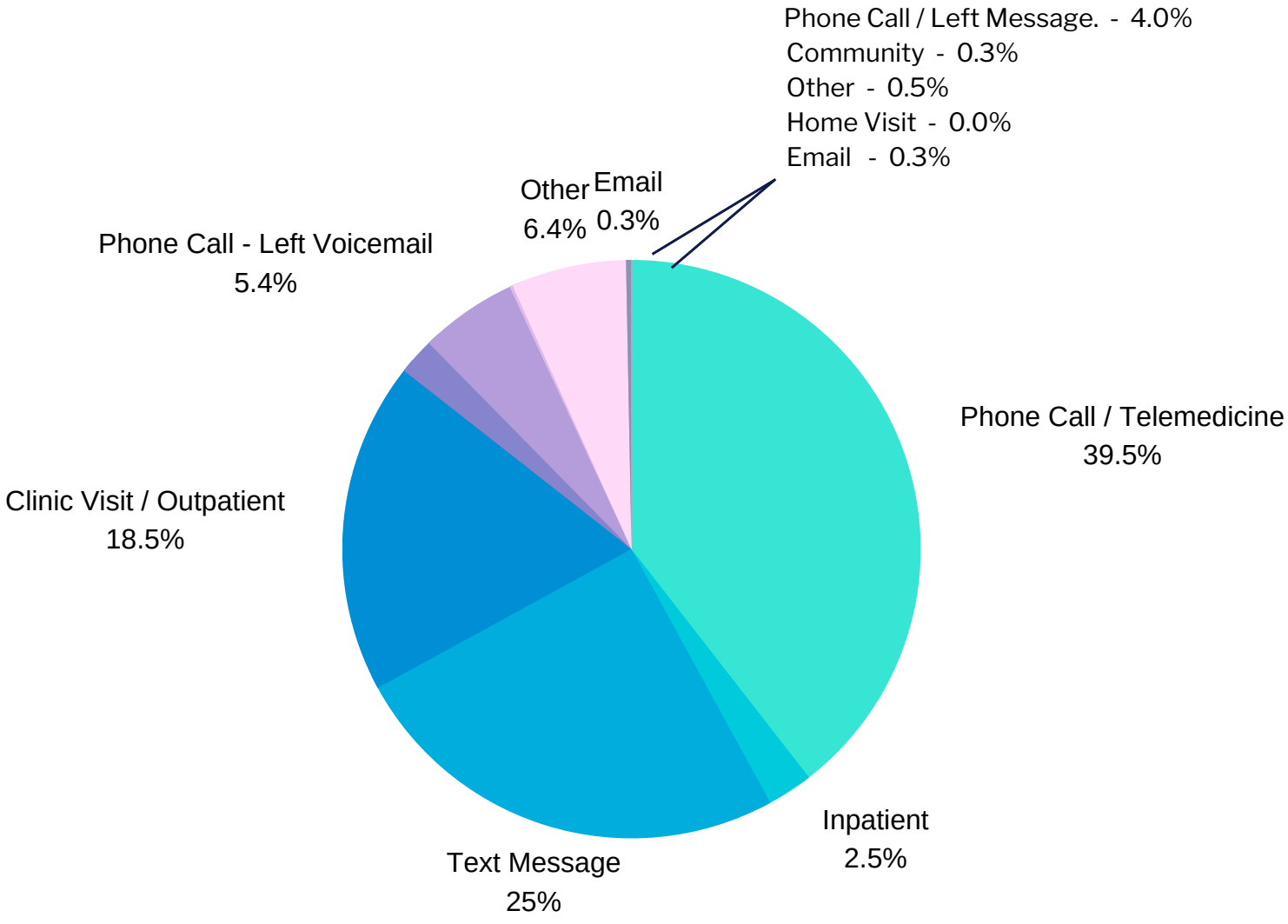
PATIENT NAVIGATORS

A Month in the Life of a Patient Navigator: During COVID



PATIENT NAVIGATORS

A Month in the Life of a Patient Navigator: After COVID



PRIOR AUTHORIZATION

Typical Effort for a Prior Authorization Specialist

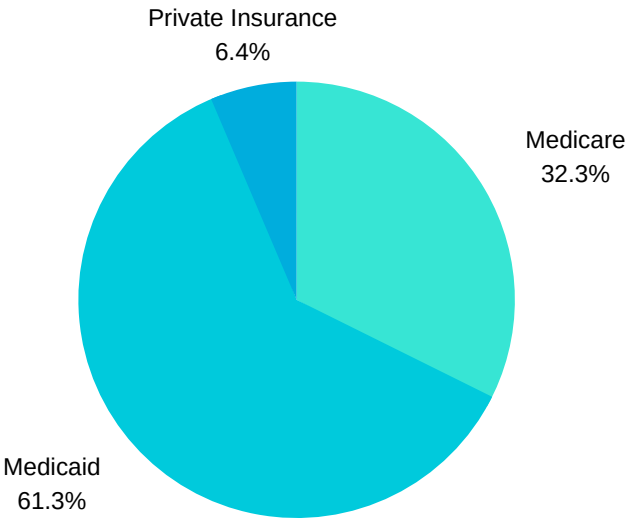
Having patients obtain their medications in a timely manner is significant to unnecessary trips to the emergency department and being admitted to the hospital. In 2018, the medical home team determined that a person dedicated to handling the enormous amounts of prior authorizations for sickle cell patients was necessary to assist with the success of the program. This position has been invaluable to the clinical team and over many of our patients, as well as contributing to the avoidance of unnecessary trips to the ED.

In addition, a partnership with managed care organizations that serve many of our patients have been established to handle issues that may arise, thus avoiding again unnecessary trips to the ED.

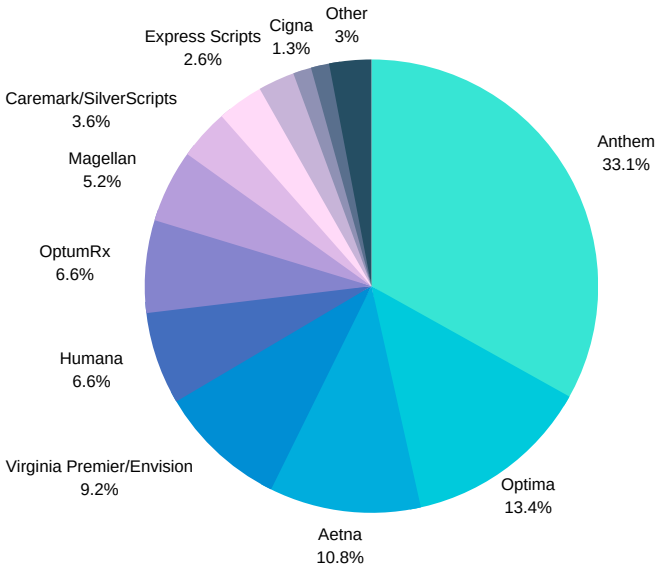
PRIOR AUTHORIZATION

Typical Effort for a Prior Authorization Specialist

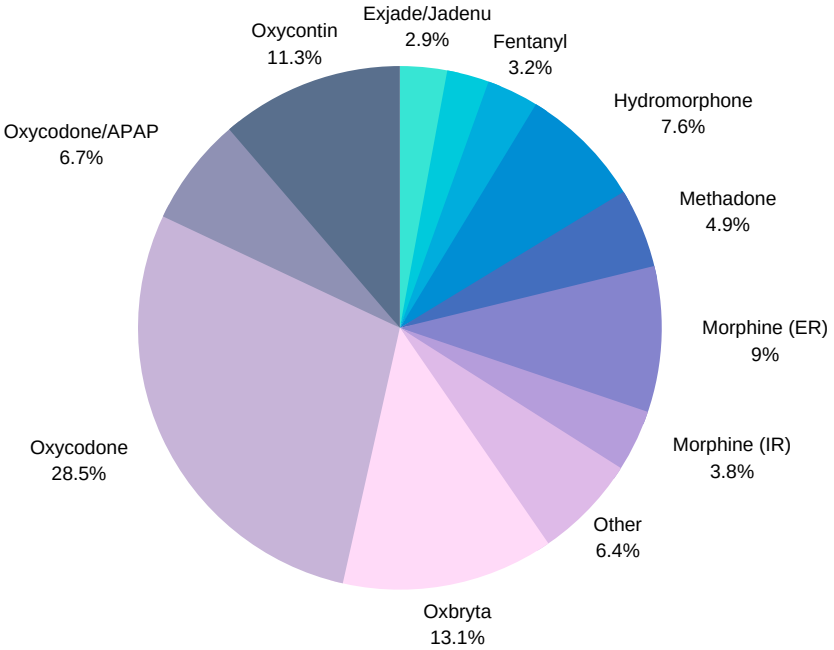
Prior Authorization Primary Payers



Prior Authorization MCOs

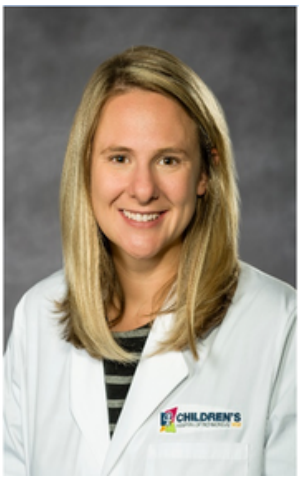


Prior Authorization Medications



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

Raven Hines
Transitions Coordinator
Adult SCD Medical Home

Alesha R. Lieser
Licensed Clinical Social Worker
Pediatric Hematology Oncology

TRANSITION TEAM

The Transition Program is a collaborative effort between the Pediatric and Adult Programs with a focus of care on young adults ages 15-25. These patients have been cared for in the pediatric clinic since birth, using a pediatric model of care. The transition program aims to slowly adjust patients to an adult model of care, with the adolescent taking a more active role in health care decision making and planning. The goal is to prepare the patient for care in the in the adult clinic, by promoting medical maturity and teaching self-advocacy and self-empowerment. Under the leadership of Dr. India Sisler, Director of the CHoR's sickle cell program, the pediatric team has developed a robust transition program for high school students in the pediatric clinic. Other key members of the pediatric team include Dr. Nadirah El-Amin, Physician Assistant Jennifer Newlin, Social worker Alesha Lieser, Nurse Navigator Jill Farrar, and Educational Consultant Alma Morgan. While in the transition program, youth engage in transition planning and individual goal setting at each clinic visit. They are invited to participate in weekend retreats to meet other patients and build community. They have access to educational and vocational resources to ensure post-high success, as well as psychology and mental health services that can support them as they develop attitudes around their chronic illness.

Additionally, our transition program includes an overall assessment of the patients' readiness for transition which involves meeting with the clinical social worker to identify needs in transition readiness, depression and anxiety. These assessments helped to identify areas of growth to set goals for patients to work on following transition.

TRANSITION TEAM

Dr. El-Amin now sees patients <25 years of age in the adult clinic space. When patients prefer, they get to know Dr. El-Amin in the pediatric clinic and form a relationship prior to transfer of care. When they transfer to the adult clinic, Dr. El-Amin is a familiar face who can provide continuity while the young adult gets to know other members of the adult health care team.

Our goal for 2023 is to continue to build on our transition program to ultimately create a more robust and expansive transition program that fully supports the needs of this complex population. In support of that endeavor, we have applied for grant funding that will allow us to help fund a transition coordinator position, to revamp our current curriculum and to recruit a patient navigator specifically for the transition aged population.
Lastly, as part of a transition project funded by PCORI, the pediatric and adult health care teams are actively engaged in quality improvement work around transition. The teams meet monthly, with representatives from community-based organizations (CBO) and patients to address the specifics of transition. A major focus of this work has been increasing patient and CBO engagement in the process of transition.

QUALITY IMPROVEMENT TEAM

Meet Our Quality Improvement Champions

Shirley Johnson
Program Manager

Ben Jaworowski
Business Analyst

Throughout 2021 and 2022, the staff at the SCD Medical Home staff took steps to improve the quality and efficiency or services offered to adult SCD patients.

To support this work and to identify opportunities for improvement, a suite of standardized reporting was built to support all aspects of medical home operations. Clinical reports showing patient hospital utilization, emergency department use, outpatient appointment adherence, and clinical Relative Value Units (RVU). Reports have also been developed to track patient navigator contacts, prior authorizations, and LCSW work. These reports helped to form the foundation of the quality improvement (QI) work over the past couple years.

The QI specialist also interviewed various staff members, diagrammed workflows, and observed various team observations to help identify opportunities and learn about staff concerns and priorities. QI projects throughout 2021 and 2022 include:

Opioid Prescription Monitoring

In cooperation with VCU Health's Enterprise Analytics department, the SCD Medical Home was able to have Epic dashboards built to help monitor opioid prescriptions and use by SCD patients. This will help to improve patient safety and ensure that SCD Medical Home .

QUALITY IMPROVEMENT TEAM

Patient Surveys

In cooperation with VCU Health's Patient Experience department, the QI specialist built surveys to ask patients about their experiences with the medical home's patient navigator, prior authorization department, and counseling services. These surveys are being administered in person throughout the early part of 2022. It is expected that these surveys will provide our staff with additional insights into patient's opinions and help us to identify potential gaps.

Patient Behavioral Outcomes

Using a DMAIC process, the QI specialist was able to recommend and begin implementation of processes to measure patient behavioral outcomes as a result of patient navigator and LSCW interventions. This project is still being implemented as of 2023.

Infusion Center Outcomes

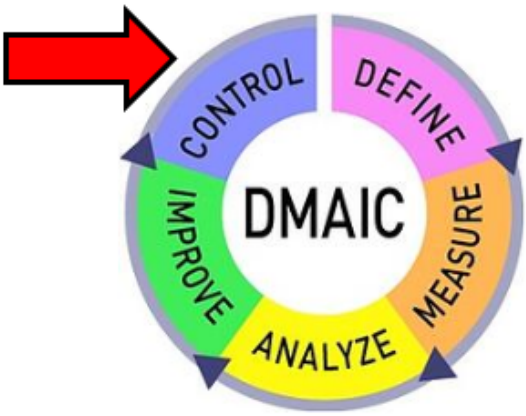
In order to determine the efficacy and results of the SCD infusion program, the QI specialist has created reports to determine the influence of the infusion center on ED and inpatient utilization.

Manual of Operations

The QI Specialist is writing and editing a manual of operations for the entire SCD Medical Home. This document will cover organizational processes, procedures, and best practices. This manual will provide all medical home staff- as well as administration- information to help them reliably and consistently achieve results for our patients and team.

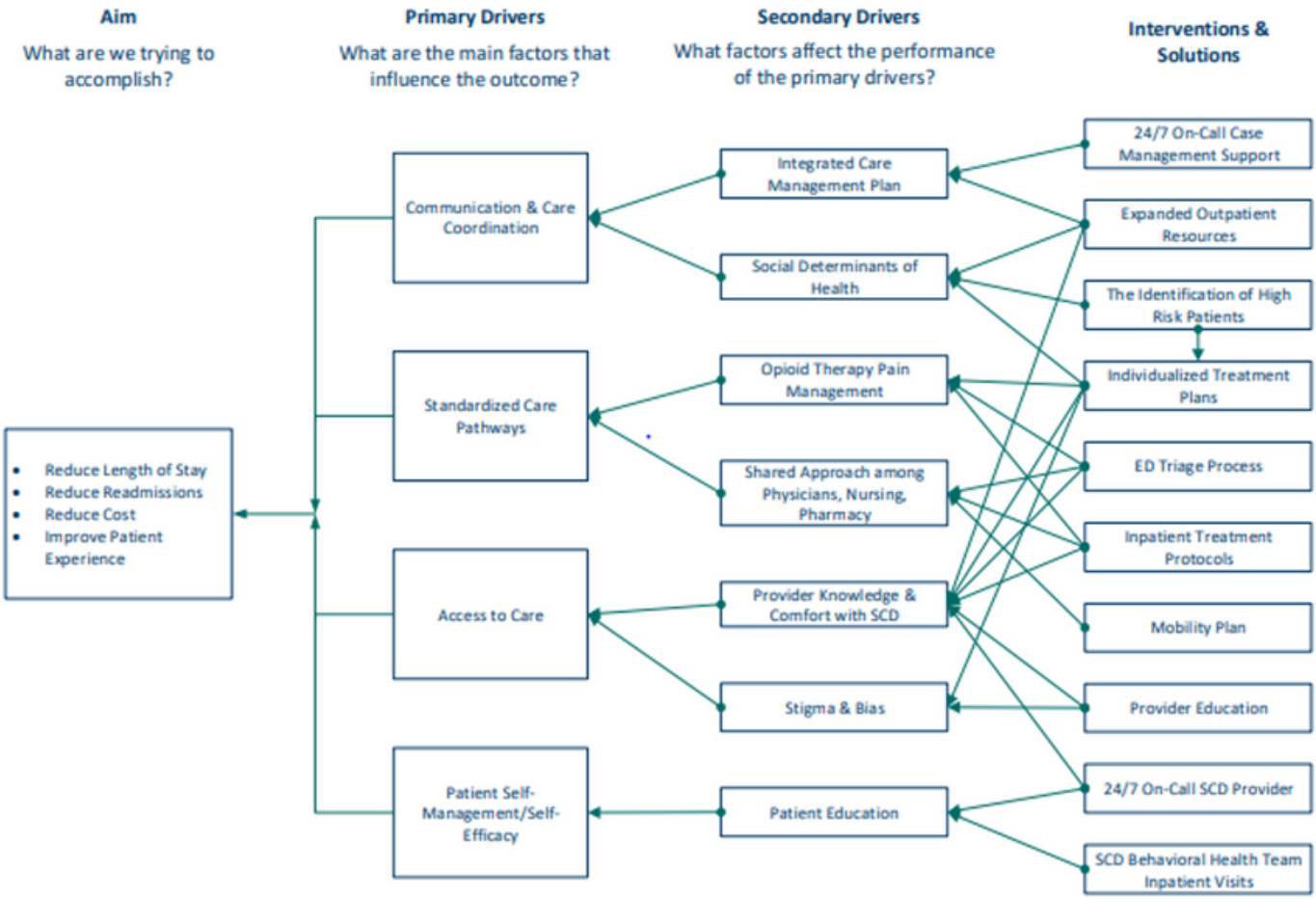
QUALITY IMPROVEMENT TEAM
Processes

DMAIC Process



The medical home staff has been using DMAIC processes to achieve results since before the full implementation of the medical home. This process is still used to guide projects.

Key Drivers



EDUCATION AND OUTREACH

Project ECHO

Project ECHO, launched in February 2019, and is a 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 continues to run monthly where nearly a dozen academic centers from around the country and Canada join us and share didactic presentations and de-identified patient cases for professional expertise opinions on care

2022 ECHO At a Glance

10	CLINICS	107	TOTAL PARTICIPANTS
15	HOURS	48	UNIQUE PARTICIPANTS
17	CASES	26	SPOKE INSTITUTIONS

EDUCATION AND OUTREACH

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

VCUHealth
SCCAPE
www.sccape.org

In March 2021 and March 2022, the 2nd and 3rd annual SCCAPE (Sickle Cell Coordination for Achieving Patient Empowerment Conference) were once again held- virtually this time due to COVID. This four-day event has continued to evolve 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 continues to be supported each year by pharmaceutical companies recognizing the importance of education and support for those professionals caring for sickle cell patients. Attendees included nurses, social workers, community-based organizations, patient navigators, patients, advocates and other staff from all over the country. This conference has become one of the key training programs for sickle cell care in the country and in 2023, will become a hybrid model of training as we are coming out of COVID.

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 (Senior Research Analyst) and Dr. Wally Smith (Medical Director). Please visit our website at https://www.sccape.org/

ADULT SCD POPULATION AT VCU

604 TOTAL PATIENTS

GENDER

56.5%
FEMALES

43.5%
MALES

AGE

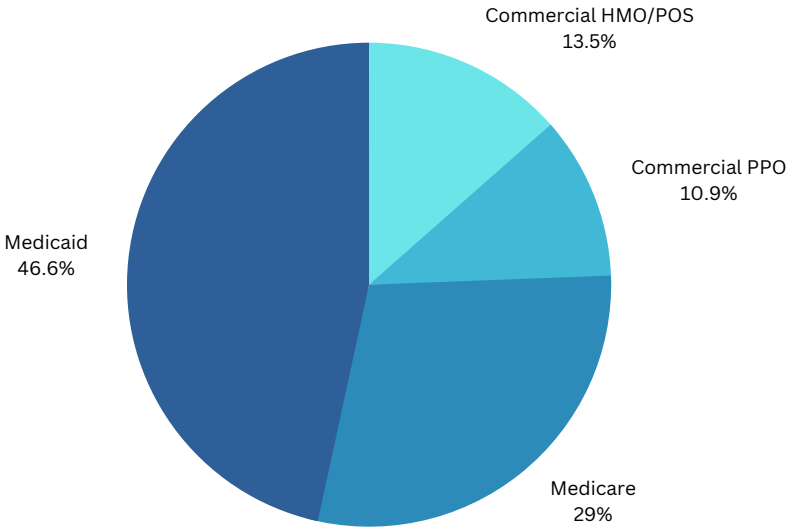
18-25 22.9%

40-64 31.9%

26-39 42.1%

65+ 3.1%

TYPE OF INSURANCE



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.

Nadirah El-Amin, DO

Dr. El-Amin is a pediatric hematologist/oncologist who began seeing young transition age patients in the clinic in late 2019. Our goal is develop a smooth transition of care from pediatrics to adult care and maintain a lifespan approach to care for sickle cell patients. Dr. El-Amin provides this crucial medical support for these patients.

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.

Mica Ferlis, ACNP

Mica is a nurse practitioner that works in collaboration with the inpatient and emergency room providers to deliver health care services to patients with SCD in the inpatient and emergency room setting as well as provide remote consultation to our sickle cell patients at state-wide outside institutions.

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.

Chelsea Snead, MSN, ANCC

Chelsea is a nurse practitioner in our outpatient clinic. Chelsea has ten years of experience as an RN working in the hospital setting, urgent care/primary care and radiology.

Emmanuel Ofosu-Agyei, NP

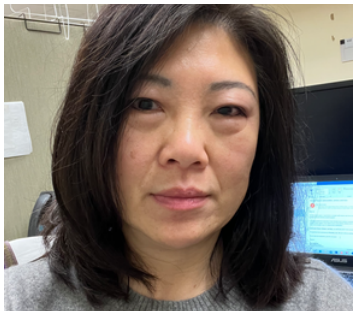
Emmanel Ofosu-Agyei is a nurse practitioner in our outpatient clinic and has been with us since November 2022. He is an alumnus of the VCU School of Nursing and has been in the US Navy Reserves for the past ten years.

Kate Osborne, BS, RN

Kate is a 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.

Yue May Zhang, MS

May is a research assistant here at the adult SCD program. She has a master's in biostatistics from the University of Alabama at Birmingham and several years of experience working in bioresearch labs.



Raven Hines, BS, CHES

Raven Hines recently joined the VCU Sickle Cell Adult Home in the role of Transition Coordinator. Raven comes to the team from Virginia Department of Health with over ten years' experience in the public health field; where her focus and passion has been helping vulnerable populations, especially at-risk youth.

Ben 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, Marla Brannon, BSW & Katrina Dalton, BA

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.

SCHOLARSHIP
Publications

Inpatient Reliance Ratio Versus Emergency Department Reliance Ratio in a Sickle Cell Disease Medical Home

Daniel M Sop, Yue May Zhang, Shirley Johnson, Benjamin Jaworowski, Wally R Smith
Blood 2022

Sickle Cell Disease May Qualify As an Ambulatory Care Sensitive Condition

Wally R Smith, Yue May Zhang, Shirley Johnson, Daniel M Sop
Blood 2022

Expansion of Content in the Phenx Toolkit for Sickle Cell Disease Pain

Stephanie H Guarino, Mark D Nelms, David Williams, Amanda M. Brandow, C. Patrick Carroll, Nitya Bakshi, Claudia M Campbell, Deepika S. Darbari, Martha Kenney, Wally R Smith, Jennifer Stinson, William Zempsky, Wayne Huggins, Deborah Maiese, Tabitha Hendershot, Carol Hamilton
Blood 2022

Screening for Adverse Childhood Experiences (ACEs) As a Way to Predict Overdose Risk in Adult Sickle Cell Patients

Rachel Walls, Daniel M Sop, Yue May Zhang, Benjamin Jaworowski, Shirley Johnson, Wally R Smith

Blood 2022

Oxycodone Produces Antinociception, but Worsens Functional Behaviors, in Humanized Sickle Cell Disease Mice

Kennedy N Goldsborough, Molly Sonenklar, Kalpna Gupta, M Imad Damaj, Wally R Smith, Joyce Lloyd, Aron Lichtman
Blood 2022

Intensive Case Management in an Adult Sickle Cell Medical Home: Annual Effects on Utilization Efficiency Using Community Health Workers

Shirley Johnson, Daniel M Sop, Yue May Zhang, Benjamin Jaworowski, Wally R Smith
Blood 2022

SCHOLARSHIP
Publications

Monoacylglycerol Lipase Inhibition: A Strategy to Treat Chronic Pain in a Humanized Sickle Cell Mouse Model

Kennedy N Goldsborough, Karan Mucchala, Kalpna Gupta, Joyce Lloyd, Hamid Akbarali, Wally R Smith, Aron Lichtman
Blood 2021

Early Initiation of Treatment with Rivipansel for Acute Vaso-Occlusive Crisis in Sickle Cell Disease (SCD) Achieves Earlier Discontinuation of IV Opioids and Shorter Hospital Stay: Reset Clinical Trial Analysis

Carlton D. Dampier, Marilyn J. Telen, Ted Wun, Wally R Smith, R. Clark Brown, Payal Desai, Fuad A El Rassi, Julie Kanter, Beng R. Fuh, Yves D. Pastore, Jennifer A. Rothman, James G. Taylor, David Readett, Jay N Lozier, John L. Magnani, Helen M Thackray, Kathryn L. Hassell
Blood 2020

The Effect of Crizanlizumab on the Number of Days Requiring Opioid Use for Management of Pain Associated with Vaso-Occlusive Crises in Patients with Sickle Cell Disease: Results from the Sustain Trial

Wally R Smith, Kenneth I. Ataga, Santosh L. Saraf, Olufolake A. Adisa, Miranda Bailey, Nicholas Ramscar, Ashley Bonner, Stephen Brown, Laura Pastor
Blood 2020

Improvement in the Clinical Global Impression of Change with Voxelotor in Patients with Sickle Cell Disease in the Phase 3 HOPE Trial

Wally R Smith, Jane S. Hankins, Miguel R Abboud, Ze Cong, Jonathan Sorof, Sarah Gray, Carolyn Hoppe, Paul Telfer
Blood 2020

COVID Symptoms and COVID Anxiety in Sickle Cell Disease

Wally R Smith, Benjamin Jaworowski, Shirley Johnson, Thokozeni Lipato, Daniel M Sop
Blood 2020

SCHOLARSHIP
Publications

Improved Utilization Amongst Adult Sickle Cell Disease Patients: A Multi-Disciplinary Medical Home Approach

Daniel Sop, Shirley Johnson, Benjamin Jaworowski, Wally R Smith
Blood 2020

A Multi-Intervention Approach to Managing Sickle Cell Disease in the Emergency Department

Peter Moffett, MD, Daniel Sop, MS, Tammy Nguyen, PharmD, Shirley Johnson, LSW, Emily Holt, BS, Chantal McHenry, BS, Wally Smith, MD

A Pilot Program of Stabilization of Housing and Case Management Reduces Healthcare Utilization for High-Utilizing Adults with Sickle Cell Disease

Shirley Johnson, BA,LSW; Ryan Raisig, MHA,FACHE; Byron Hunter, MPH,FACHE; Marla Brannon, BS; Stefani Vaughan-Sams; Nakeyia Williams, BS; Brian Artis ,MBA; Sean P Murphy,BS; Daniel Sop, MS; Thokozeni Lipato, MD; Mica Ferlis, MSN,ACNPBC; Caitlin McManus, MSN,AGPCNP-B; Benjamin Jaworowski, BS; Wally R. Smith, MD

Multidisciplinary Quality Improvement Intervention to Decrease Length of Stay for Adults with Sickle Cell Disease

Justin West, BSN, RN; Dale Wright, MS, RN; Daniel Sop, MS, Wally Smith, MD

Structural Racism and Impact on Sickle Cell Disease: Sickle Cell Lives Matter.

Smith WR, Valrie C, Sisler I.

Hematol Oncol Clin North Am. 2022 Dec;36(6):1063-1076. doi: 10.1016/j.hoc.2022.08.008. PMID: 36400531 Review.

Development and validation of the sickle cell stress scale-adult.

Smith WR, McClish DK, Bovbjerg VE, Singh HK.

Eur J Haematol. 2022 Sep;109(3):215-225. doi: 10.1111/ejh.13789. Epub 2022 Jun 3

SCHOLARSHIP
Publications

Moving Toward a Multimodal Analgesic Regimen for Acute Sickle Cell Pain with Non-Opioid Analgesic Adjuncts: A Narrative Review

Kenney MO, Smith WR.
J Pain Res. 2022 Mar 31;15:879-894. doi: 10.2147/JPR.S343069. eCollection 2022

Long-term biological effects in sickle cell disease: insights from a post-crizanlizumab study.

Liles DK, Shah NR, Scullin B, Gordeuk VR, Smith WR, Kanter J, Achebe MM, Boccia R, Crary SE, Kraft WK, Archer N, Cataldo V, Hardesty BM, Idowu M, Desai PC, Ikeda A, Puthenveetil G, Hassell KL, Sarnaik S, Kutlar A.

Br J Haematol. 2021 Nov;195(4):e150-e153. doi: 10.1111/bjh.17739. Epub 2021 Oct 5.

Long-term biological effects in sickle cell disease: insights from a post-crizanlizumab study.
Liles DK, Shah NR, Scullin B, Gordeuk VR, Smith WR, Kanter J, Achebe MM, Boccia R, Crary SE, Kraft WK, Archer N, Cataldo V, Hardesty BM, Idowu M, Desai PC, Ikeda A, Puthenveetil G, Hassell KL, Sarnaik S, Kutlar A.

Br J Haematol. 2021 Nov;195(4):e150-e153. doi: 10.1111/bjh.17739. Epub 2021 Oct 5

Targeting TRPV1 activity via high-dose capsaicin in patients with sickle cell disease.
Glaros AK, Callaghan MU, Smith WR, Zaidi AU.
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How Would You Treat This Patient With Acute and Chronic Pain From Sickle Cell Disease? : Grand Rounds Discussion From Beth Israel Deaconess Medical Center.

Kanjee Z, Achebe MO, Smith WR, Burns RB.

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Urgent use of voxelotor in sickle cell disease when immediate transfusion is not safe.

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SCHOLARSHIP
Publications

Intraindividual pain variability and phenotypes of pain in sickle cell disease: a secondary analysis from the Pain in Sickle Cell Epidemiology Study.

Bakshi N, Gillespie S, McClish D, McCracken C, Smith WR, Krishnamurti L.

Pain. 2022 Jun 1;163(6):1102-1113. doi: 10.1097/j.pain.0000000000002479. Epub 2021 Sep 17

Satisfaction and access to care for adults and adolescents with sickle cell disease: ASCQ-Me quality of care and the SHIP-HU study.

Sisler I, McClish DK, Valrie C, Villella A, Smith WR.

Pediatr Blood Cancer. 2022 Dec;69(12):e29948. doi: 10.1002/pbc.29948. Epub 2022 Sep 24. PMID: 36151945 Clinical Trial.

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Kenney MO, Becerra B, Beatty SA, Smith WR.

J Opioid Manag. 2021 Nov-Dec;17(6):489-497. doi: 10.5055/jom.2021.0683. PMID: 34904697

Early Initiation of Sub-Anesthetic Ketamine Infusion in Adults with Vaso-Occlusive Crises Is Associated with Greater Reduction in Sickle Cell Pain Intensity: A Single Center's Experience.

Kenney MO, Becerra B, Mallikarjunan A, Shah N, Smith WR.

Pain Med. 2022 Dec 1;23(12):2042-2049. doi: 10.1093/pm/pnac094.

SCHOLARSHIP
Manuscripts

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SCHOLARSHIP
Presentations

ORAL PRESENTATIONS

Intensive Case Management in an Adult Sickle Cell Medical Home: Annual Effects on Utilization Efficiency Using Community Health Workers
Shirley Johnson, Daniel M Sop, Yue May Zhang, Benjamin Jaworowski, Wally R Smith

Perils And Progress of Managing an Adult Sickle Cell Medical Home
Shirley Johnson

A Pilot Program of Stabilization of Housing and Case Management Reduces Healthcare Utilization for High-Utilizing Adults with Sickle Cell Disease
Shirley Johnson, Daniel Sop, Byron Hunter

The Success and Barriers of Staff Turnover, Financial Support and Administrative Interest long-Term for a Sickle Cell Medical Home
Shirley Johnson

Time Allocation Among Patient Navigators in an Adult Medical Home
Shirley Johnson

Association of Adverse Childhood Experiences (ACE) & Other Behavioral Risk Factors with High Utilization of Adult Sickle Cell Disease Case Management
Benjamin Jaworowski, BS, Rachel walls, MSW, Shirley Johnson, LSW, Taylor Crouch, PhD, Wally R. Smith, MD

Characteristics of High Utilizers VS. High Case Management Utilizers in Adults with Sickle Cell Disease
Shirley Johnson, LSW; Benjamin Jawoworski, BS; Daniel Sop, MS; Wally R Smith, MD

Impact of Sickle Cell Disease on Cerebral Blood Flow, Neuropathic Pain and Fluid Cognition: A Pilot Study
Daniel Sop, MS, Joel L. Steinberg, MD, Wally Smith, MD, John Wilson, MD PhD

NEWS

- Quality Is the Key: An Interview With Drs. Obiageli Nnodu and Wally Smith on ASH's Sickle Cell Disease Programs
- ASH Podcasts: Bringing Sickle Cell Disease to Life – Wally R Smith, MD
- ASH Panel: The Role of Race in Biomedical Research – Wally Smith, MD

COMING IN 2023

While the infusion, transition, and behavioral health teams have expanded and are fully staffed, the care models in each place are still in evolution, and undergoing quality testing. We also plan expansions and improvement of team functions as below.

We expect to:

- Expand our now-reinstated infusion program
- Further integrate care coordination for transition patients and all patients
- More tightly integrate results of standardized testing and surveys of our patients into formulation of individualized biopsychosocial care plans:
    - Pediatric to adult transition of care plans
    - Pain action plans
    - Behavioral care plans
    - Preventive care plans for patients
    - Remittive care plans for patients and providers
    - For selected patients, curative care plans

- Use PDCA cycles to monitor and improve:
    - Processes of care
    - Achievement of quality indicators
    - Biopsychosocial care outcomes

- Use national collaboratives to contribute data and compare ourselves to best practices at other adult sickle cell programs in the country
- Lead in innovation of the use of community health workers
- Grow our alliances with community-based organizations
- Continue and expand our training initiatives:
    - American Society of Hematology –co-leadership and faculty of the annual sickle cell centers workshop
    - National Alliance of Sickle Cell Centers(NASCC)- co-leadership and faculty part of the national landscape of defining sickle cell centers
    - VCU SCCAPE program, which trains health care workers and community workers in the sickle cell space using a biopsychosocial model:
        - SCCAPE online curriculum
        - Deeper scope of training for SCCAPE annual live/virtual conference

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/