

2017
ANNUAL REPORT



Adult Sickle Cell Program



The **University of Arkansas for Medical Sciences Division of Hematology and Oncology in the Department of Internal Medicine** has partnered with the **Center for Distance Health** to create a statewide system of support for patients with sickle cell disease, and for the physicians who care for them. As UAMS improves and standardizes the treatment of patients with sickle cell disease through the **Adult Sickle Cell Clinical Program**, patients throughout the state with SCD will experience an improved wellbeing.



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From the Co-Director

When I started as co-director of the UAMS Adult Sickle Cell Disease Clinical Program, I found an infrastructure of care and a system of clinicians that was excellent. Any changes to it that I've had a part in have been small ones rather than fundamental shifts. Still, 2016 was a year of growth and notable achievements.

Dr. Pooja Motwani is co-director with me. She and I have seized on several opportunities for community outreach. I spoke earlier this year at an annual conference of osteopathic doctors in Rogers. Dr. Motwani spoke at an annual conference for family medicine. Many physicians realize they are working with a gap in their knowledge of sickle cell disease and are eager to fill it. Stella Bowers, R.N., also stays constantly engaged in outreach efforts.

Toward our goal of educating the public about sickle cell disease and our program, for the first time we were the organizers of the annual Sickle Cell Symposium. In October, an evening session and a day session of speakers addressed audiences of clinicians, patients and patient families.

Our Sickle Cell Disease Registry continues to grow, and we are starting to look for research opportunities with other institutions. Together with new institutional partners, we want to share databases and be able to mine that data for research purposes. Combining our small registry with the registries of other institutions will make a statistical sample of all of them stronger and more diverse.

Pharmacist Lindsey Dayer, Pharm.D., has joined the clinical care team along with Collin Montgomery, an advanced practice registered nurse.

Being trained in internal medicine and pediatrics, I am prepared to provide care from birth to death. The transfer from pediatric care at ACH to adult care at UAMS can occur beginning at age 18, with some patients transferring care earlier than others. Not a lot of internists care for many adolescents, but I'm well positioned to take care of those patients and help with the transition.

Day to day, I'm working in the clinical areas of pain and symptom management or palliative care. I review outpatient medications for pain and symptoms, supervise in the infusion clinic where we manage pain, and perform inpatient consults.

Historically, trust between sickle cell patients and the medical community has been an issue. Having that trust in the relationship between patient and physician is critical to a positive health outcome. I've really enjoyed building those relationships of trust on the patient side. I look forward in the year ahead to deepening and strengthening that bond with our patients.

Megan Davis, M.D.
*Co-Director, Adult Sickle
Cell Program*



Transition Project

Patients are treated at Arkansas Children's Hospital (ACH) until age 21. On turning 21, they are transitioned to an adult health care provider. UAMS works with ACH to ensure that transition to adult health care is a smooth and organized process.

One way we work toward that goal is by having the social worker from the Adult Sickle Cell Clinical Program work in the ACH sickle cell clinic, meeting each patient that is nearing transition. During those encounters with each patient at ACH, the social worker assesses the level of disease-specific education needed. It is important that patients entering adulthood are knowledgeable about their disease and how to be their own advocates.

The UAMS social worker and the pediatric team have implemented an educational program specifically to help patients prepare for the transition. The program makes certain every patient receives an education on all aspects of

12 patients

have transitioned their care from ACH to UAMS during this fiscal year.

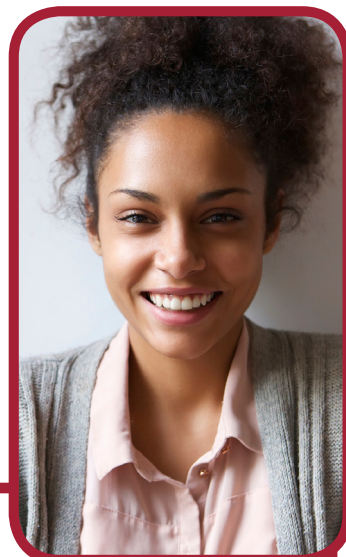
86 patients are

age 16 or older

and interact with the UAMS social worker during ACH clinic appointments.

their disease. There also have been web-based patient education modules developed by the UAMS Sickle Cell team for this purpose. The social worker assists patients with establishing an adult primary care provider in their community, as well as making their initial appointment at UAMS Sickle Cell Clinic.

Another way we work toward the goal of a smooth transition from pediatric to adult care is conducting a biannual transition meeting in which the UAMS social worker, clinic nurse, advanced practice registered nurse (APRN) and co-director Megan Davis, M.D., meet with the pediatric sickle cell team at ACH to review patients who will make the transition to UAMS within the next six months. The meetings help establish the continuity of care for patients during that time.



1 patient

did not successfully transition at age 21 but through continued follow up from the UAMS social worker, has established care at the UAMS Adult Sickle Cell Clinical Program.

Adult Sickle Cell Multidisciplinary Clinic

The UAMS Adult Sickle Cell Clinical Program provides a Multidisciplinary Clinic for adult patients with sickle cell anemia from all over the state. Patients are scheduled for annual appointments unless they have more severe complications that require more frequent visits. On the basis of each comprehensive visit, a care plan for that patient is created to serve as a blueprint for the patient's medical care throughout the year and is communicated to each patient's primary care provider.

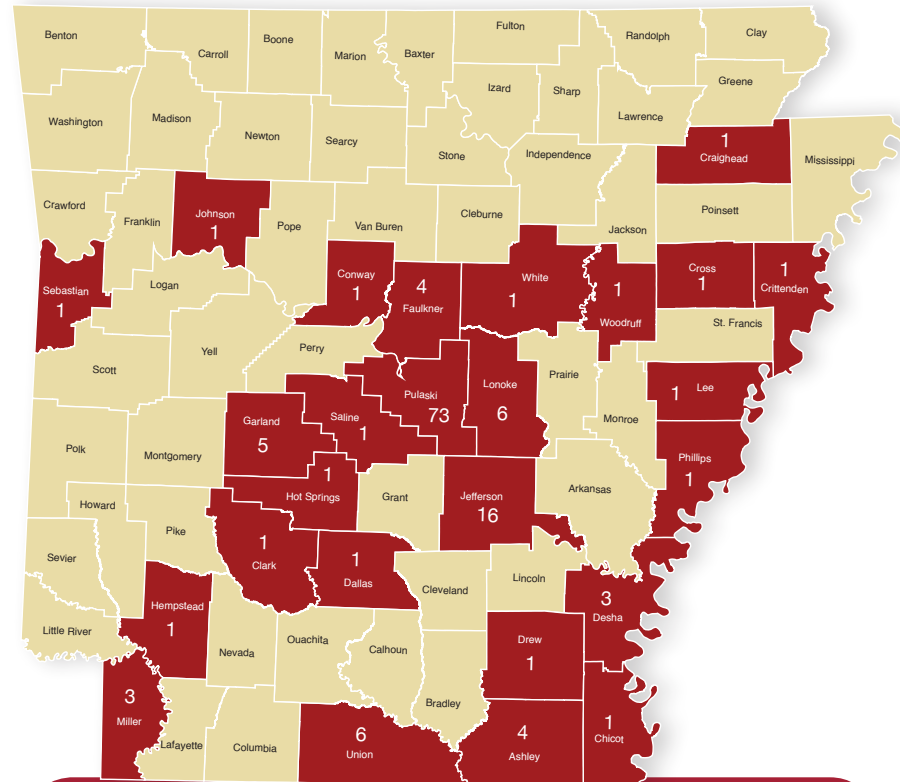
The Multidisciplinary Clinic of the Adult Sickle Cell Clinical Program at UAMS includes:

A primary physician, Megan Davis, M.D., specializes in internal medicine, pain management and care of the adult sickle cell patient.

A physician of hematology, Pooja Motwani, M.D., specializes in blood disorders and diseases, and treatment of sickle cell disease. Motwani and a team of hematology physicians work together to see the patients during their clinic visits and as inpatients as needed.

A nurse practitioner, Collin Montgomery works in collaboration with the physicians and the other team members to deliver health care services to patients with sickle cell disease in the outpatient and inpatient setting.

UAMS Adult Sickle Cell Clinical Program
Clinic Patients-Counties of Residence



157 Current Active Clinic Patients

Adult Sickle Cell Multidisciplinary Clinic

A licensed clinical social worker, Leigh Ann Wilson is in the clinic every week to assist patients and their families regarding social and emotional support, health-related expenses not covered by insurance, transportation costs, and employment options. She also is essential in facilitating transition of care from Arkansas Children's Hospital to the adult setting.

A registered nurse, Stella Bowers, assists with providing care to patients in an outpatient setting. She serves as community outreach coordinator connecting the clinic to the community and health care providers around the state. She also serves as the liaison between the call center staff and the sickle cell team, ensuring that the sickle cell team responds to the caller's needs.

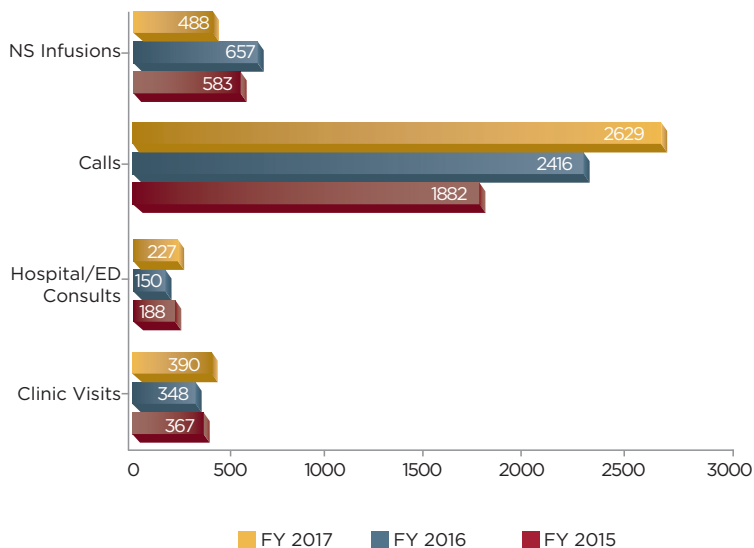
In November 2016, the UAMS Adult Sickle Cell Clinic added pharmacist Lindsey Dayer, Pharm.D. She assists the providers in delivering comprehensive medication management through medication reconciliation, counseling and assessing medication effectiveness.

We also refer patients for annual ophthalmological assessments and for mental wellness evaluations as needed.

About 900 adult sickle cell patients are living in Arkansas, so there is still work to do to reach each one. We are providing a better state of health for the sickle cell patients in Arkansas.

214 Patients scheduled in program since **Jan. 1, 2014.**

14 are deceased, **27** are no longer in the program and **16** have been scheduled but not yet seen.



From Pediatric to
**ADULT CARE,
BIG MOVE**

Facilitated By Program

By Ben Boulden

In the summer of 2016, Shacole Cooksey, 21, made two big changes in her life: Moving to her own place in Maumelle from her family's home in El Dorado and moving to the **UAMS Adult Sickle Cell Clinical Program** from the Arkansas Children's Hospital (ACH) program.





Her father, Darrid Cooksey, has sickle cell disease, so Shacole was tested at birth and found to have it, too. Also like her father decades before, Shacole had received care at ACH. Both of the Cookseys had aged out of the sickle cell program at the children's hospital, Shacole a few months before she turned 21.

Sickle cell disease is a lifelong illness marked by episodes of severe pain. It can affect every organ of the body, causing complications and requiring ongoing medical care.

As young patients grow into adulthood, they are transferred to the adult program gradually and in an organized fashion. The UAMS adult team meets with the pediatric sickle cell team at ACH to identify patients who are nearing adulthood. The social worker meets with these patients to prepare them for the adult program and to facilitate scheduling and records transfers.

"It was a real adjustment at first," Shacole said. "You have to make a decision about where you want to be treated. I like the doctors who ask, 'What's the best treatment for you? What works for you?' and that's what I found."

Despite having sickle cell disease and hospitalizations two or three times a year, Shacole works two part-time jobs — one at a retail store and another as a patient care technician at a regional hospital. The UAMS program helps her do that.

"The program has been great," Shacole said. "I call and Stella Bowers answers my questions, concerns, comments. She gives me answers to things like 'When can I get a refill for my prescription?' or 'Should I come in?' She's great. I'm comfortable there now."

Bowers is a registered nurse who works closely with the clinic's patients.

Shacole has about 10 pain crises in a year, so she relies on Bowers and services like the infusion center. At the infusion center, sickle cell patients can receive intravenous hydration and

intravenous pain medication to minimize symptoms and avoid hospitalizations when they can.

“No one can teach you how to manage your pain,” she said. “What works for one doesn’t work for another person in a pain crisis. What works is staying hydrated and trying not to panic. If there’s anything I need, they’ve told me to call the clinic first before going to the Emergency Department. The infusion center helps with that is unclear. Please restate ‘They can often get me an appointment at the infusion center to avoid me having to go to the Emergency Department’”

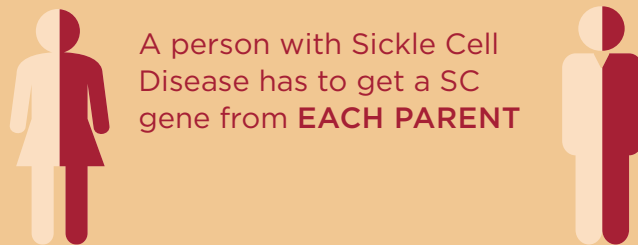
Darrid Cooksey still lives in El Dorado and receives regular treatment there for sickle cell disease, but every six months he also makes a visit to the UAMS sickle cell clinic for lab work and a general assessment of how he is doing with the disease. UAMS also in years past has treated Darrid for pneumonia and performed a kidney transplant related to his sickle cell disease.

He said his case is less severe than his daughter’s, and he experiences pain crises about two or three times a year.

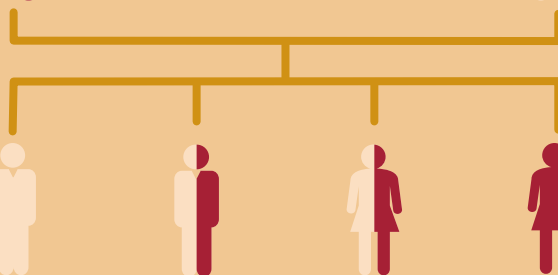
Although her sickle cell causes her pain more frequently, and she is now living in Maumelle, it gives him peace of mind to know that Shacole is receiving good care from the UAMS program.

As for Shacole, she plans one day soon to start studying to become a registered nurse so she can make an even bigger move from patient to health care provider. The UAMS Adult Sickle Cell Clinical Program clinicians and staff want to keep her healthy so she can achieve that dream.

GENETIC of Sickle Cell Disease



A person with Sickle Cell Disease has to get a SC gene from **EACH PARENT**



A person has the SC trait can pass the trait (gene) for Sickle Cell on to their child and if both parents have the SC trait, their child has **A 1 IN 4 CHANCE OF BEING BORN WITH THE DISEASE**

Unlike Sickle Cell Disease a person with Sickle Cell Trait **CARRY ONLY ONE DEFECTIVE GENE**



Adult Sickle Cell Multidisciplinary Clinic

PHARMACIST'S ROLE in the SICKLE CELL CLINIC

Pharmacy services include seeing the patient to optimize the patient's medication therapy. Lindsey Dayer, Pharm.D., is the program's board-certified ambulatory care pharmacist who graduated from the UAMS College of Pharmacy in 2009. She is currently offering clinical pharmacy services within the Adult Sickle Cell Clinic. Clinical pharmacy services were initiated in November 2016. She works with the other providers to deliver comprehensive medication management and to act as part of the interdisciplinary team to offer the best care plan for each individual patient. Dayer assesses whether various medications are working appropriately, determines if medications are being taken appropriately and reconciles medications for the patients. She is available to help answer medication-related questions and provide counseling. Dayer also educates patients about their medications, especially new prescriptions, changes and drug interactions.

NEW FACES



Collin Montgomery, an advanced practice registered nurse, joined the Sickle Cell Clinical Program this year. Already, she has proven herself to be a key member of the care team.

In 2009 she began her nursing career at UAMS. She has extensive clinical experience in renal dialysis, hematology, and oncology.

In 2016, Montgomery earned her master's degree in nursing from UAMS, following on bachelor's and associate degrees in nursing from the University of Arkansas at Little Rock.

Montgomery has many years of experience working as a member of an interdisciplinary team using a patient-centered approach to care. She's passionate about the management of the chronic disease in adult patients across the life span ranging from in late adolescence and of older adults.

PATIENT SATISFACTION SURVEYS

In March 2017, the ANGELS Call Center by telephone conducted a patient satisfaction survey. The patients surveyed were randomly selected patients of the UAMS Adult Sickle Cell Clinical Program. The survey was specifically about the outpatient clinic experience with the UAMS Adult Sickle Cell Team.

Patient Satisfaction Surveys



Lindsey Dayer, Pharm.D., started work as a pharmacist in the program in 2016.

She received her Doctor of Pharmacy degree in 2009 from the UAMS College of Pharmacy and completed a residency at UAMS Medical Center in 2010. Dayer also is an assistant professor in the College of Pharmacy's Department of Pharmacy Practice.

From 2011-2015, Dayer worked as a clinical pharmacist in the Palliative Care Clinic of the UAMS Winthrop P. Rockefeller Cancer Institute, and from 2010-2013 also served in a similar position in the institute's Medical Oncology Clinic.

Working with the clinical team, Dayer adds an extra layer of support and education by keeping an accurate medication history on each patient. She helps with medication orders and has further improved efficiency in drug therapy. She also counsels patients on medication use, drug side effects and drug interactions. Having a pharmacist on the team provides valuable assistance to clinicians, too, providing prompt, knowledgeable answers to questions they have.

Twenty percent of clinic patients were surveyed using a total of ten questions. To ensure the patients understood clearly the purpose of the survey, they were read this statement before starting the survey and then asked if they had any questions:

"I know that you have met many health care providers, but I want you to focus on the sickle cell team when answering the following questions. For questions that address how well you think the sickle cell team did, please respond with excellent, good, fair, or poor. Please let me know if the question doesn't apply to you."

Eight of the ten questions received positive responses that totaled 90 percent or greater.

In comparison with the survey done in spring of 2016, we also noticed many questions with a significant increase in the response of 'excellent'.

Areas where the greatest improvement was reported by our patients were: educating patients regarding their illness, involving the patient and family in health care decisions, and respecting cultural traditions.

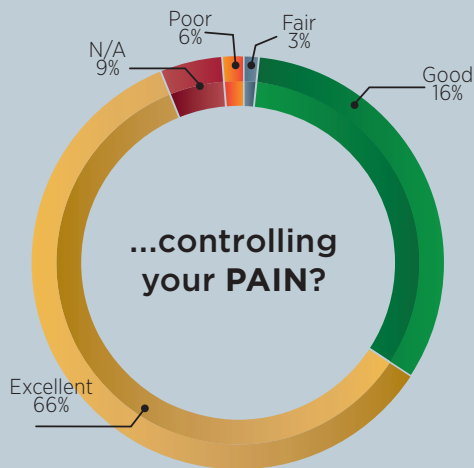
Areas with lower total positive scores this year were: controlling pain, and responding to social needs. Although these two areas displayed a decrease in total positive responses the 'excellent' responses showed increases of 16 percent and 14 percent respectively.

We are very pleased with the overall rate of positive responses on all questions. The team will continue to make efforts toward improvement.

The following graphs are the results from the multidisciplinary clinic survey.

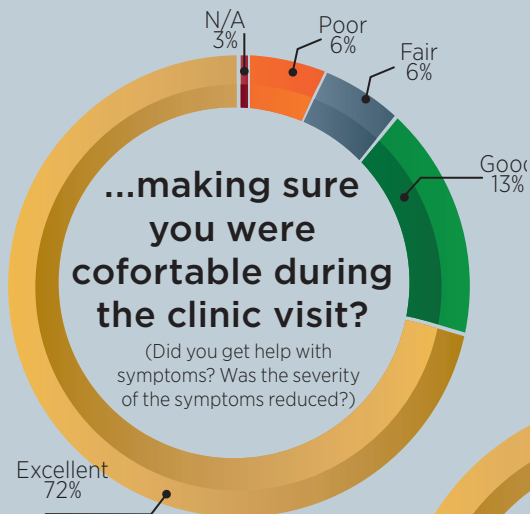
Patient Satisfaction Surveys

How well did the sickle cell team do in...

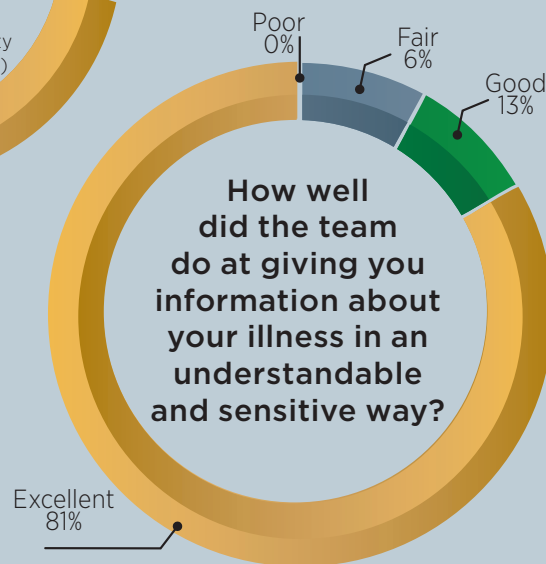


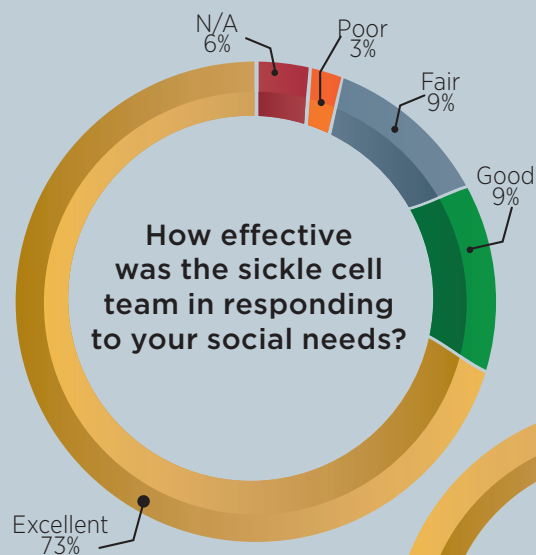
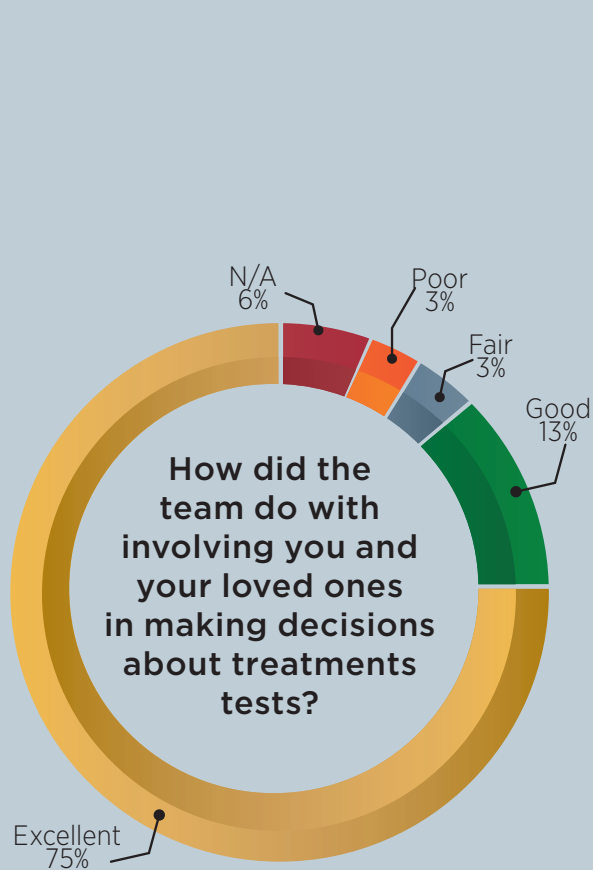
...making sure you were comfortable during the clinic visit?

(Did you get help with symptoms? Was the severity of the symptoms reduced?)

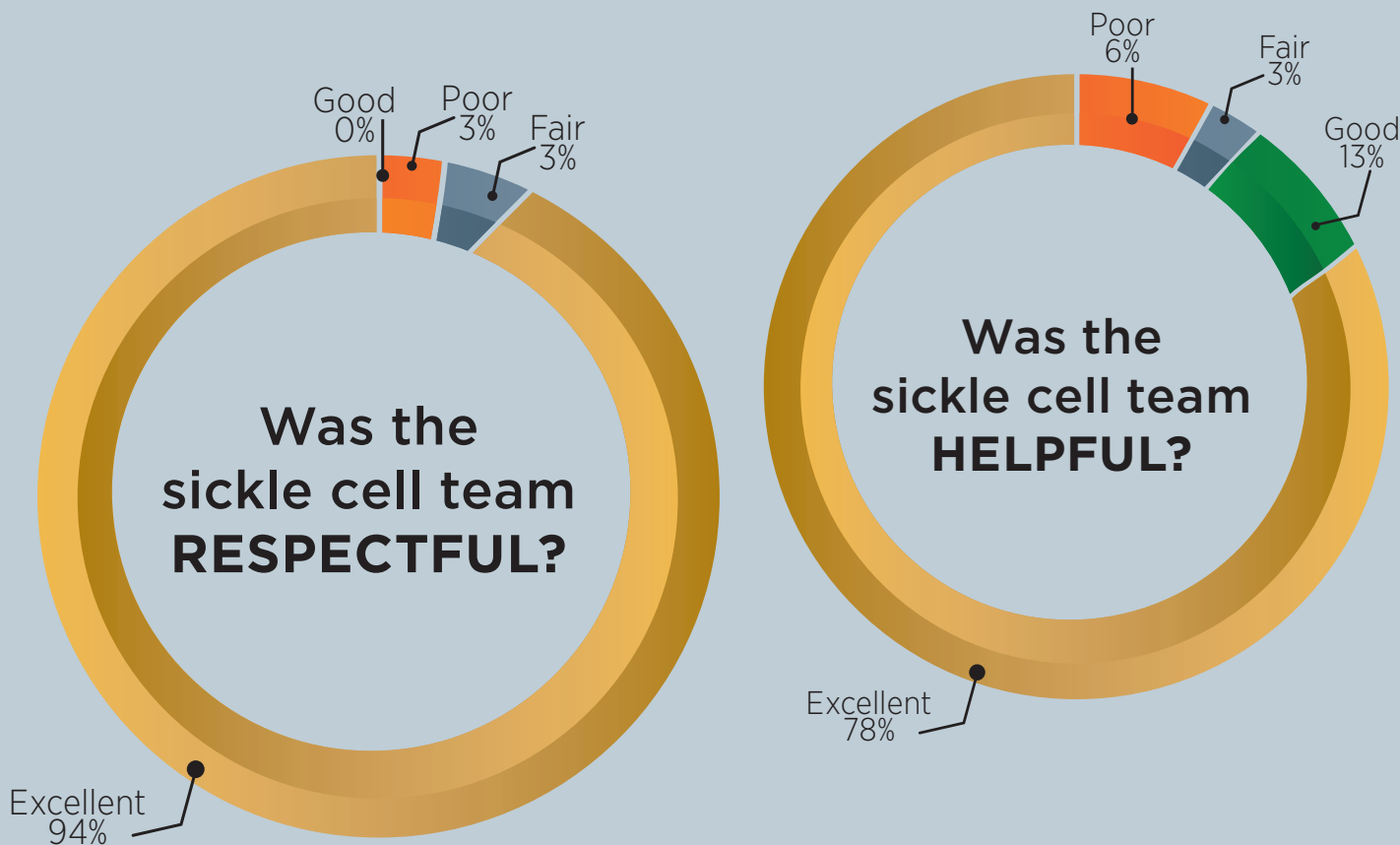


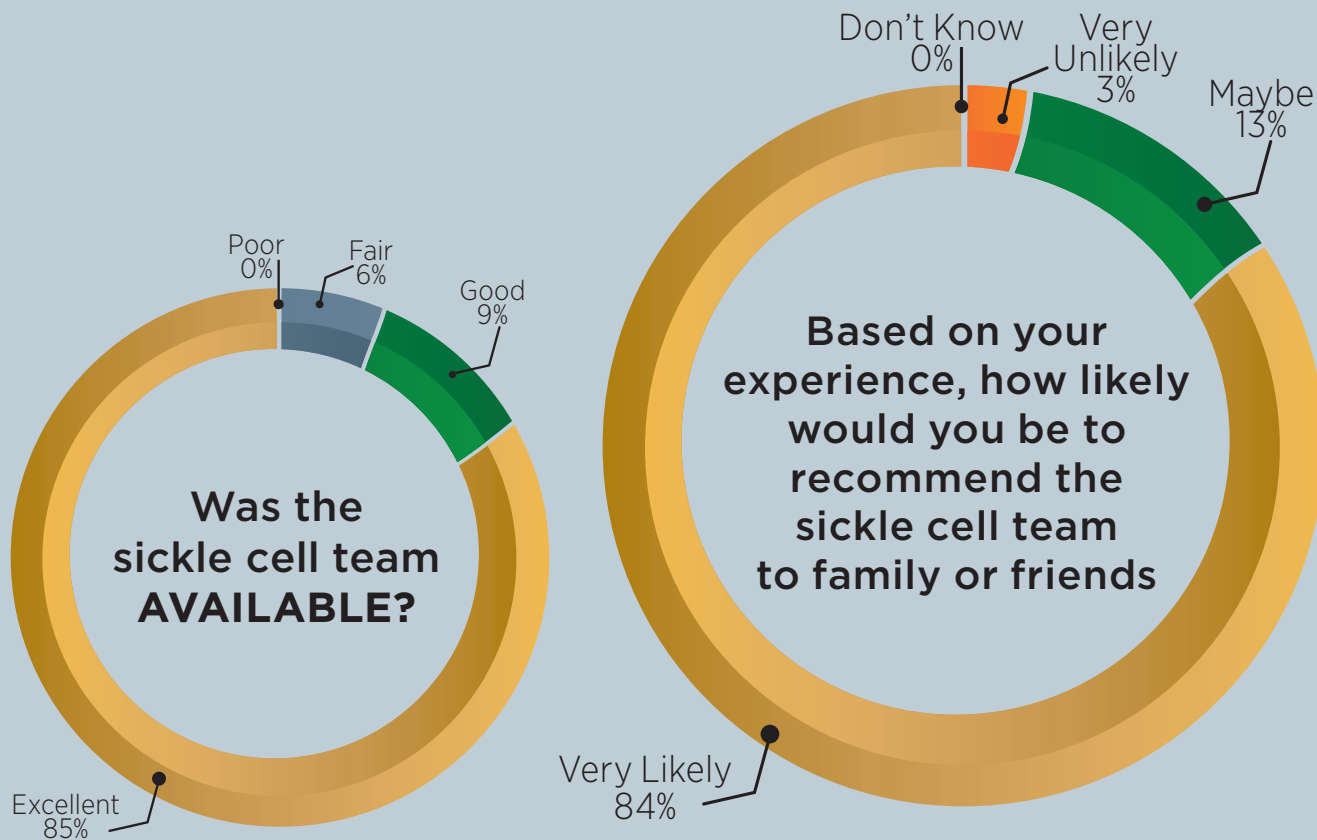
How well did the team do at giving you information about your illness in an understandable and sensitive way?





Patient Satisfaction Surveys



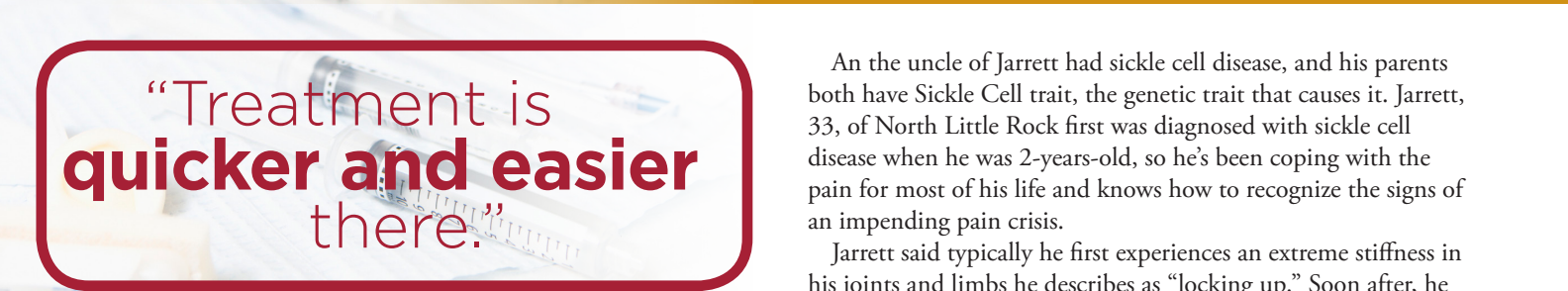




INFUSION CLINIC

Helps Patients Avoid Hospital Stays, Disruptions

By Ben Boulden



“Treatment is quicker and easier there.”

For patients like Michael Jarrett, choosing two or three hours of treatment in the infusion clinic of the UAMS Adult Sickle Cell Clinical Program can mean avoiding a hospital stay.

Successful use of infusion treatment in which the patient receives intravenous hydration and intravenous pain medication can result in less pain, a briefer pain crisis and less disruption in their everyday life that a two- or three-day hospitalization would cause.

An the uncle of Jarrett had sickle cell disease, and his parents both have Sickle Cell trait, the genetic trait that causes it. Jarrett, 33, of North Little Rock first was diagnosed with sickle cell disease when he was 2-years-old, so he’s been coping with the pain for most of his life and knows how to recognize the signs of an impending pain crisis.

Jarrett said typically he first experiences an extreme stiffness in his joints and limbs he describes as “locking up.” Soon after, he starts hurting all over. Dehydration is often the cause of a pain crisis.

Collin Montgomery, an advanced practice registered nurse in the Adult Sickle Cell Program, said like many patients, Jarrett’s first line of defense with a pain crisis is to start the ‘pain treatment plan’ that Dr. Davis and I developed with him. This includes taking his ‘home pain medication’ and drinking lots of water to hydrate on his own. If that isn’t effective in reducing the pain, then he calls the program’s hotline 1-866-Sic-Cell to speak

Infusion Center



to a triage nurse. Most times a visit to the Infusion Center can be scheduled for the same day.

Montgomery said that usually means a shorter stay than he would have if he was treated in the UAMS Medical Center's Emergency Department. The intravenous pain medicine helps Jarrett and other sickle cell patients experience less severe and shorter periods of pain. Intravenous hydration means the water that sickle cell patients need enters the blood vessels faster and more effectively.

Pain crises in sickle cell patients are brought on because the sickle shapes of many of their blood cells can cause them to clump and crowd a vein or artery, which prevents blood flow, which in turn prevents oxygen from getting to tissues around it. Better hydration means less clumping, less pain and less stress on a patient's body, Montgomery explained.

About two or three times a year, Jarrett said he has a pain crisis so severe and persistent that treatment requires a hospital stay; but without infusion, he would be hospitalized twice as often.

"The Sickle Cell program has helped keep me from going into the hospital as much," Jarrett said. "It's helped me in all kinds of ways. The staff is cool, and we always have conversations about how to deal with the pain. I recommend it. Treatment is quicker and easier there."

Statistically speaking, patients with fewer hospitalizations live longer because they have fewer severe episodes and put less stress on their bodies and personal health, Montgomery said.

Sickle cell patients also can have blood drawn and assessed when they visit the clinic.

Although Jarrett hasn't yet needed it, some sickle cell patients go to the infusion clinic for blood transfusion when they are experiencing sickle cell anemia. Their blood work is analyzed and the decision made of whether the patient would best be helped by hydration or blood transfusion. Transfusions should not be used routinely to treat pain crises, but if the patient's blood counts are significantly lower than their baseline, then a blood transfusion could help put oxygen back into the blood and therefore improve symptoms.

Receiving blood at the infusion center usually is a quicker process than in the outpatient clinic or Emergency Department, Montgomery said.

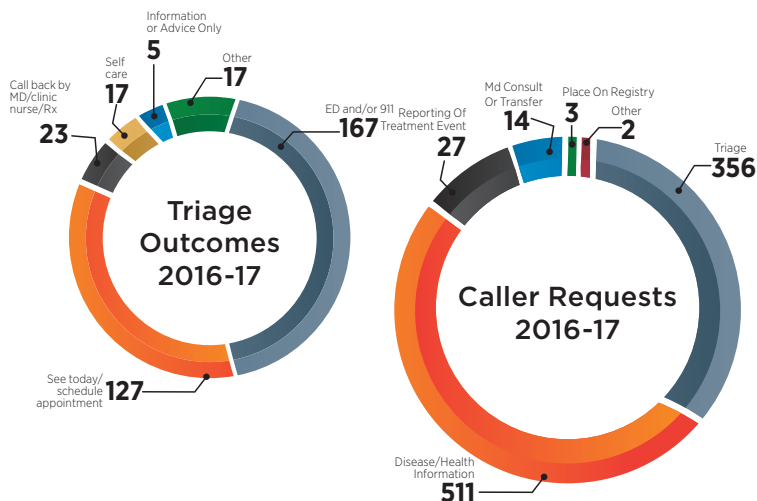
In treating people with sickle cell disease, timely treatment can mean lessening the severity and length of a pain crisis and giving patients like Michael Jarrett back time they would otherwise lose.

Call Center



The Sickle Cell hotline is hosted by the 24/7 Center for Distance Health Call Center at UAMS. The Call Center provides assistance to health care providers requesting advice on patient management, patients needing assistance with appointments or questions on disease process or complications. Acute medical issues are triaged by the Call Center registered nurse and advice is given regarding the level of care needed.

The triage nurses are familiar with this disease and have been equipped with nationally recognized triage guidelines that were written especially for this high-risk population of patients. At times, it is necessary to instruct patients to go to the emergency department (ED) for urgent or severe illness. The Sickle Cell Clinical Team also provides a second level of triage, assisting the call center nurse when an alternative to the ED is appropriate.



Advice may include sending the patient to the infusion center that day for fluids and medication, scheduling a sooner appointment, or providing instruction for self-care at home.

Having direct access to the hotline allows patients to receive the most appropriate level of care and reduces ED visits in this population.

Another aspect of the call center is to assist primary care physicians in Arkansas. Physicians can call for a 'Doc to Doc' consult to get advice on patient management, for patients needing assistance with appointments or can give their patients the hotline number to call with any disease related question or concern. One goal of the Adult Sickle Cell Clinical Program is to become a resource to all health care providers in the state, and the call center is a major asset in providing that service.

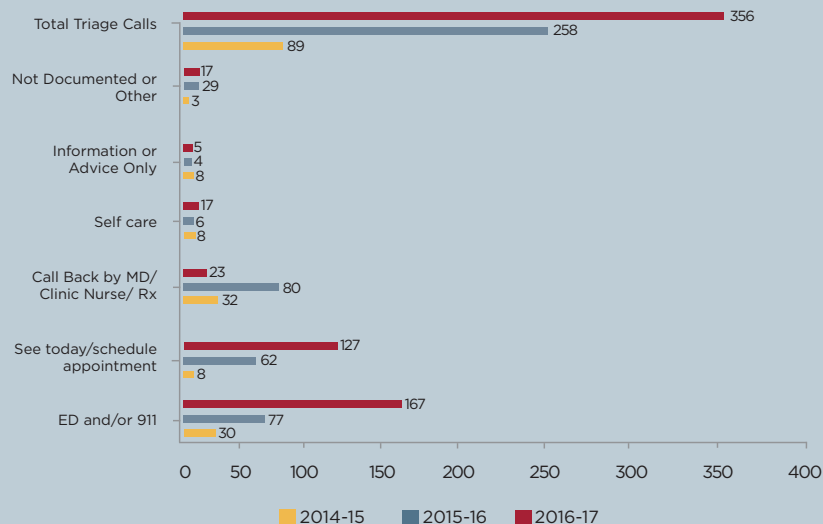
Telehealth Support

24/7 Call Center with Sickle Cell hotline

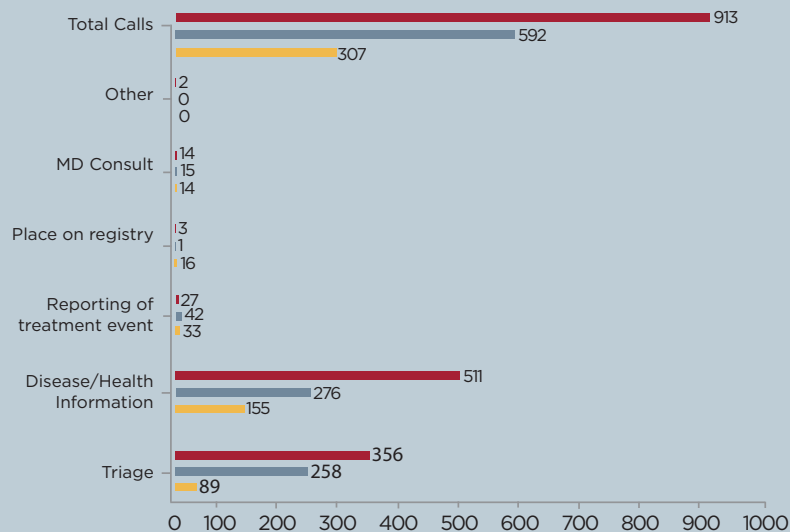
Staffed by experienced RNs that can offer:

- ≡ Patients, families education concerning acute and chronic health problems related to sickle cell disease
- ≡ Telephone triage for patients with immediate health concerns
 - Emotional Support, assistance with medication refills
 - Home Care instructions to lessen symptoms, prevent crisis
 - Second level triage (calling Sickle Cell Team Member) before sending patient to ED → giving alternatives to ED visit when appropriate
- ≡ Doc to Doc consults - supporting PCPs and ED physicians that are caring for SC patients across the state

Triage outcomes--3 Year Comparison



Caller Request--3 Year Comparison



Education and Outreach

Part of the mission of the Adult Sickle Cell Clinical Program is to ensure adult Arkansans with sickle cell disease receive standardized, comprehensive health care services. To meet that objective, primary care physicians in Arkansas caring for adult patients with sickle cell disease are offered education and support through:

- ⇒ Collaboration and education regarding best care practices and provider support to keep the patients in their community for care whenever appropriate.
- ⇒ Telephone consults available 24/7 where the physician can call the Sickle Cell hotline at 1-855-Sic-Cell, and the nurse in the call center will connect them with a physician on the Sickle Cell team. The Call Center nurse will then facilitate any recommendations that a physician needs assistance, hospital transfer, appointment in the sickle cell clinic, or assistance with a copy of the treatment guidelines.
- ⇒ Evidence-based treatment guidelines on best practices to assist providers in their efforts to care for their patients in their local health care facilities. These treatment guidelines are made available by request and at <http://sicklecell.uams.edu/>. Treatment guideline for the management of the perinatal patient with sickle cell disease is available by request on the website, and on the ANGELS guidelines website <http://angelsguidelines.com>.
- ⇒ Educational presentations, including case presentations, difficult cases and lectures on demand are given to increase awareness regarding best case practices for medical management of these patients. The UAMS
- ⇒ Center for Distance Health provides the opportunity for participation in Connecting Across Professions (CAP), a statewide means of provider teleconferencing. The CAP teleconferences are given quarterly regarding various aspects of sickle cell disease and treatment. These presentations are available to providers across the state for live viewing and on-demand viewing. Providers can earn CEUs for education provided at these teleconferences.
- ⇒ The team provides educational lectures to groups at UAMS, including medical residents in emergency and family medicine. The team attends and presents at professional meetings and conferences. The team continues to reach out to health care providers around the state through professional conferences providing disease-specific education and working to identify a core group of providers across the state to engage in collaborative primary care for this population. Outreach is also provided through exhibit booths at statewide conferences.

Patient Education Modules

The Sickle Cell team, with instructional development specialists at the Center for Distance Health, has developed a set of interactive learning modules for our sickle cell patients. These, found at uamspatientslearn.org, provide the patient with information about their disease and appropriate ways to manage their illness. To encourage use of the education modules, patients are assisted in using tablets to access the modules during their clinic wait time.

The patient education modules include the following titles:

- ⇒ Genetics of Sickle Cell Disease
- ⇒ Nutrition to Fight Sickle Cell Disease
- ⇒ Respect for Opiates Used to Treat Sickle Cell Disease
- ⇒ Response to Painful Crises in Sickle Cell Disease
- ⇒ Medications used in Sickle Cell Disease
- ⇒ Organs Affected by Sickle Cell Disease
- ⇒ Coping with Sickle Cell Disease
- ⇒ Procedures & Treatments in Sickle Cell Disease
- ⇒ Pregnancy and Sickle Cell Disease
- ⇒ Transition from Pediatric to Adult Care with Sickle Cell Disease
- ⇒ Preventive Health for Sickle Cell Disease



Outreach at Health Fairs and Community Events

This past year the program staff continued to spread awareness through visiting health fairs, schools, churches and other venues raising awareness of Sickle Disease and the Adult Sickle Cell Clinical Program. We continued to partner with Sickle Cell Support Services (SCSS) to provide awareness through the annual Sickle Cell Walk held in April 2017 and other events within the city. September is National Sickle Cell Awareness Month. As part of that wider effort, we organized and participated in several media and community events that provided outreach in the community.

Those events were:

- ⇒ The Victory Radio Show with Stella Bowers, B.S.N., R.N.
- ⇒ KUAR Radio Show Yesterday, Today and Tomorrow with clinic patient William Cooney and clinic co-directors Megan Davis, M.D., and Pooja Motwani, M.D.
- ⇒ KATV 7 Live Interview with Pooja Motwani
- ⇒ SCSS Blood Drive Health Fair/Sickle Cell Awareness Day at which Bowers was a speaker
- ⇒ 102.5 Praise Radio Show with Bowers and Lakisha Johnson, CEO of SCSS; American Medical Technologists Meeting at which Bowers was a guest speaker and ended in SCSS Candlelight Vigil at the State Capitol.



Support Group for Patients and Family

In the fall of 2016, a new platform for the Sickie Cell Support Group began. The support group is now patient led and is an open group with a relaxed format. The group members are free to discuss any topics and can share with the group about their life, family and health issues. The members decide the date/time/location that works best for the group, the topic of interest and schedule of events. The group has created a format of three meetings per quarter—open group discussion of common disease-related issues, with one meeting per quarter having a guest speaker on a disease-related topic.

A patient advocate, LaKisha Johnson of Sickie Cell Support Services, who is not a member of the clinic staff, is the liaison between the patient support group and the clinic. The patient facilitator is a volunteer and is being trained by the liaison in leading the group. The UAMS Sickie Cell Clinical Program encourages participation in the group through distributing flyers in clinic, when attending outreach events, and on the program website.

ADVOCACY, EXPERTISE

on Display at UAMS' Sickle Cell Symposium

After attending the Sickie Cell Symposium at UAMS, Dalissa Robinson didn't feel as alone in coping with her sickie cell disease as she sometimes does.

"I was impressed by what strong advocates the symposium speakers are," Robinson said. "We don't have enough advocates for sickie cell disease. I like how they are standing up for us. I don't want to feel as confrontational as I feel I have to be sometimes because of my health care. I get very frustrated."

The Sickie Cell Symposium was presented by Future Builders Inc. in collaboration with the UAMS Adult Sickie Cell Clinical Program.

Robinson and her mother, Nicole Smith, both live in Malvern. Both wore T-shirts emblazoned with big letters. Smith's shirt read, "Her Mama," and Robinson's shirt read, "I Get It From My Mama."

Smith carries the sickie cell genetic trait for sickie cell disease, a severe hereditary form of anemia in which blood hemoglobin becomes distorted



Smith said she was impressed by the leadership she saw on display at the symposium, and she came away with some new knowledge, too.

At the opening evening session Oct. 6, Barbie Brunner, UAMS director of Patient- and Family-Centered Care, discussed “Engaging Patients and Families for Quality and Safety.” At 7 p.m. LaKisha Johnson, executive director of Sickle Cell Support Services in Little Rock, presented “Advocating for Yourself: Patient Practices for Successful Health.”



Cell Rapid Evaluation & Acute Management (SCREAM) for Acute Pain Crisis Patients in the E.D. — A Safe and Standardized Approach,” she explained the history of the Johns Hopkins

“We turned it into advocacy,” Figueroa said. “We’re going to SCREAM for those patients in a pain crisis. We know they’re hurting and we want to get them care in a faster fashion that’s appropriate and focused on their needs. This is where SCREAM came from and now it has become a verb in our department. When we ‘scream’ a patient, it means they have gone through the protocol we developed.”

The ED there is able to accomplish that for more than 70 percent of its sickle cell pain patients. In 2000 before the SCREAM protocols and plan were in place, wait times averaged three hours and could be as long as 12.

After Figueroa spoke, Elizabeth Storm, M.D., an attending physician in the ED at Arkansas Children's Hospital presented "Sickle Cell Disease — A Pediatric Emergency Department Perspective." Storm joined Figueroa, Johnson, and Pooja Motwani, M.D., and Megan Davis, M.D., in a panel discussion of issues related to pain medication, dependence and addiction. Motwani and Davis are co-directors of the UAMS Adult Sickle Cell Clinical Program.



Sickle Cell **DISEASE REGISTRY** in Arkansas

The state of Arkansas did not have a way of tracking patients with sickle cell disease after screening newborns. It is unclear the number of people living in Arkansas with sickle cell disease as well as any information about them. The Arkansas Department of Health has been conducting newborn screenings of all Arkansas births since 1988 that include screening for sickle cell disease. Through this, we know that about 25 babies are born every year in Arkansas with sickle cell disease. Given the life expectancy of those with the most severe form of the disease is in the mid-forties, a rough estimate of the total number of people with the disease in Arkansas is 1,300.

A Sickle Cell Disease Registry was established to learn more about the adults living in Arkansas. Where do they live? Where do they receive care? How long are they living? The purpose of the registry is to help health care providers learn more about the adult population and to improve the care they are providing.

Patients are eligible for participation if they are over age

18, live in Arkansas, and have sickle cell disease. Patients are identified for participation by the sickle cell care team. Patients have the option to participate in the data collection as well as provide a one-time blood and urine sample. At the time consent is completed, patients provide information about their past health care utilization, complications, demographic information, sickle cell diagnosis, and complete a quality-of-life assessment. Patient's health care utilization, labs, medications and complications are monitored by the sickle cell team through medical chart review and updated yearly. A patient's tissue sample is collected at the time of their next lab appointment, if the patient agreed to blood and urine collection. Their sample is then stored for future research. Collection of data in the registry began in March 2015 and as of March 2017 there were 106 patients enrolled. Reports from the data have been completed with all 106 patients and are represented in the following graphs.

GENDER:

61 FEMALES



45 MALES



TYPE OF INSURANCE:

61
MEDICAID

26
MEDICARE

17
PRIVATE
INSURANCE

2
WITHOUT INSURANCE

STATE OF BIRTH:

82
BORN IN
ARKANSAS

24
BORN OUTSIDE
OF ARKANSAS

EMPLOYMENT:

10
Employed
part time

18
Employed
full time

14 Unemployed

17 STUDENTS 47 DISABLED

EDUCATION LEVEL:



48
Some College

5
Post Graduate

16
Less than
high school
education

25
High School
Diploma

12
College
Graduate

REPRODUCTIVE:

68
Have Children

38
DO NOT
Have
Children



82

Patients with a family
member with sickle
cell disease

98
Patients received
prescriptions
for Hydroxyurea

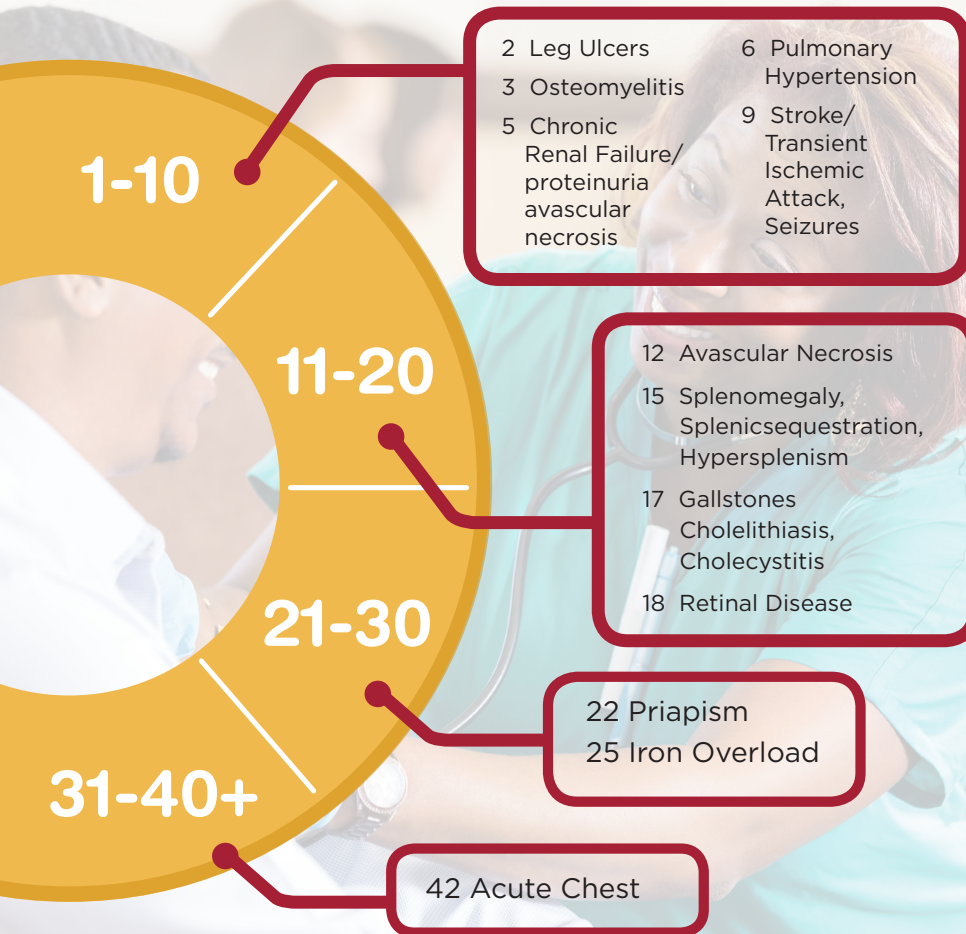


90 Patients that
consented to
blood and urine collection

27 Patients received prescriptions for Exjade

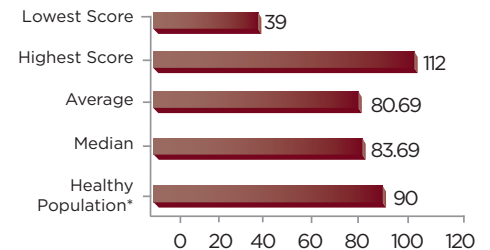
Disease Registry

106 Patients had the following Complications of Sickle Cell Disease



Participants of the Sickle Cell Registry are asked to rate their quality of life. Quality of life (QOL) is defined as an overall assessment of a person's well-being, which may include physical, emotional and social dimensions as well as stress level, sexual function and self-perceived health status. The QOL ranges from 16 (worst possible) to 112 (best possible). In the first graph, the ranges of score results are shown in comparison with the average score of the "Healthy Population without Sickle Cell Disease". The second graph shows the average QOL scores of patients with other significant medical conditions to see how the average Sickle Cell QOL score compares.

Quality of Life Scale in Sickle Cell



* Average score of Healthy Population without Sickle Cell Disease

From the Co-Director

During my first year as co-director of the UAMS Adult Sickle Cell Clinical Program along with Megan Davis, M.D., we began several innovative initiatives to improve the care and health of the program's patients. We are fully committed to expanding those efforts in the next 12 months.

The program seeks to include the standards of care for the newest therapies that are proven to be safe and effective so patients receive the most up-to-date therapies and best health outcomes.

We are incorporating into patient care the findings from new clinical trials that have shown vitamin D deficiencies are linked to sickle cell crises. With that in mind, we are striving to optimize vitamin D levels in all our patients. We are doing the same with certain proteins identified by recent studies to be beneficial to sickle cell patients in reducing severity, frequency and duration of pain crises as well as the hospitalizations sometimes associated with them.

Pain medication and hydration remain effective, but we're actively searching for ways to benefit sickle cell patients that go beyond symptoms management. In the next couple of years and contingent on finding the research funding, we would like to use our disease registry and the patient tissue bank to do some projects and clinical trials in sickle cell disease. We want to research and look into what interventions we can do with the drugs we have right now to reduce patients' pain crises – both their severity and frequency.

We really care about the long-term health of our patients, and iron chelation is one example of how we do that. Iron chelation therapy is the removal of excess iron from the body with special drugs. Many sickle cell patients have iron overload

from blood transfusions. The clinic's infusion center is where we do intravenous iron chelation to improve iron levels quickly, benefitting liver health. We will continue doing that in the next year with even greater energy and focus.

To educate clinicians about these aspects of sickle cell care as well as the basics of the disease, I'm planning to address about 150 family medicine residents at a conference and another large group shortly after. For the second time in October the program again will organize and host the Sickle Cell Disease Symposium at UAMS for the public and health care providers.

Finally, in terms of my own day-to-day areas of responsibility in the program, Dr. Davis and I will keep seeing patients. Together, we monitor the side effects of drug therapies and follow the patients undergoing them. Managing their medications and annual health screenings, evaluating the heart health of patients and closely watching their transfusions will remain core responsibilities of mine. All of us in the program are committed to maintaining the high standards of care set in the last year and are passionately engaged in raising them even higher in the coming year.

Pooja Motwani, M.D.
*Co-Director, Adult Sickle
Cell Program*





| Adult Sickle Cell Clinic

To utilize the service of this program
call the 24/7 Call Center
@ 1-855-Sic-Cell (742-2355)
For more information visit
<http://sicklecell.uams.edu>