

UAMS ADULT SICKLE
CELL CLINICAL
PROGRAM
**ANNUAL
REPORT
2023-24**



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Program Leadership

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DIRECTOR, UAMS ADULT SICKLE CELL
CLINICAL PROGRAM

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IDHI, DIRECTOR

ROSALYN PERKINS, MNSC, WHNP-BC
IDHI, APRN COORDINATOR
HIGH-RISK PREGNANCY PROGRAM DIRECTOR

REBECCA CAMP, MNSC., APRN
UAMS ADULT SICKLE CELL PROGRAM

The University of Arkansas for Medical Sciences (UAMS) Division of Hematology and Oncology, part of the Department of Internal Medicine, has teamed up with the Institute for Digital Health & Innovation (IDHI) to establish a comprehensive support system for sickle cell disease (SCD) patients and their caregivers across the state. By enhancing and standardizing treatment through the Adult Sickle Cell Clinical Program, UAMS aims to significantly improve the quality of life for individuals with SCD statewide.

From the Director

Dear Colleagues and Supporters,

It is with great enthusiasm that I present to you this comprehensive report on the progress and impact of the University of Arkansas for Medical Sciences (UAMS) Adult Sickle Cell Clinical Program. As you will see, our collaboration with the Institute for Digital Health & Innovation (IDHI) has paved the way for a robust support system designed to enhance the lives of sickle cell disease (SCD) patients and their caregivers across Arkansas.

In our ongoing efforts to improve and standardize treatment, the Adult Sickle Cell Clinical Program aims to provide exceptional care through a multidisciplinary approach. This report highlights our achievements, including patient stories, our transition project from pediatric to adult care and the innovative strategies we are implementing to ensure the best outcomes for our patients.

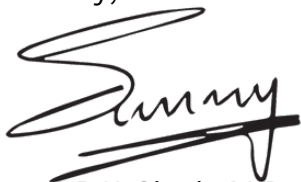
We detail our efforts to provide seamless care transitions, educational initiatives, and community outreach that extend our impact beyond the clinic.

Our commitment to continuous improvement is further reflected in our participation in key events, including the American Society of Hematology workshop and our annual Sickle Cell Symposium. These initiatives not only enhance our clinical practices but also foster collaboration and knowledge sharing within the broader healthcare community.

As we celebrate the 10th anniversary of the UAMS Adult Sickle Cell Program, we reflect on a decade of significant strides and look forward to the future with renewed determination. We remain dedicated to advancing the care and support we provide, driven by the unwavering support of our community and the passion of our team.

Thank you for your continued dedication and support in our shared mission to transform the lives of those affected by sickle cell disease.

Sincerely,



Sunny R.K. Singh, M.D.
Director, UAMS Adult Sickle Cell Clinical Program



Welcoming Daja Green, Licensed Master Social Worker, to the UAMS Adult Sickle Cell Program

We are thrilled to announce that Daja Green, LMSW, has joined the UAMS Adult Sickle Cell Program (ASCP) as of November 2023. Daja brings a wealth of experience and a deep commitment to her role, enhancing our team's ability to provide comprehensive care to individuals with sickle cell disease. Daja Green graduated with a Bachelor's in Social Work in 2018 and obtained her Master's degree in Social Work in 2020, both from the University of Arkansas at Little Rock. Her professional journey began at Youth Home, Inc., where she served as a Qualified Behavioral Health Provider. After obtaining her licensure, she was promoted to a therapist position, delivering school-based health therapy to individuals and families.

Daja's passion for social work is driven by her desire to help others and be an advocate for those in need. "I believe in being an advocate for others," Green said. "To be able to be a voice for others is very important to me."

In addition to her role at ASCP, Daja currently assists with transition preparation at Arkansas Children's Hospital (ACH). Since joining the ASCP, she has embraced the opportunity to expand her knowledge about sickle cell disease and has demonstrated unwavering dedication to her patients, striving to maximize the support available despite limited resources and funding.

Daja attributes her success as a social worker to staying open-minded, empathetic, passionate, and committed to providing healthcare to patients whenever possible.

When she is not working, Daja enjoys playing basketball, listening to music, podcasting, and spending time at home in her own world.

We are confident that Daja Green's expertise and enthusiasm will greatly benefit the ASCP and the patients we serve. Please join us in welcoming her to our team!



DAJA GREEN, LMSW

Transition Project

The transition from pediatric to adult care can be a challenging period for patients with sickle cell disease (SCD). During this time, they often face disruptions in their health care providers and treatment. Pediatric patients can receive management at Arkansas Children's until they turn 21. However, they may start transitioning to the UAMS Adult Sickle Cell Clinic at age 18. To facilitate a smooth transition, planning begins years in advance, with tailored strategies to ensure comprehensive care. A key component of this process is having a social worker who is embedded in both the pediatric sickle cell clinic at Children's and the UAMS sickle cell clinic. This dual role helps build relationships with patients and supports them through the transition to adult care. An educational program has been established, where patients receive both written and verbal information on various aspects of their disease, including psychosocial factors, twice a year. This program ensures patients are well-prepared for the transition. Additionally, the UAMS social worker helps patients find an adult primary care provider in their community, if needed, and schedules their initial appointment at the UAMS clinic. The clinic teams from UAMS and Children's meet biannually to review upcoming transitions and strengthen collaboration, ensuring continuity of care for patients.

100

PATIENTS AT ARKANSAS
CHILDREN'S AGED 16 OR
OLDER THAT CAN
TRANSITION AT THE AGE
OF 21

14

PATIENTS HAVE
TRANSITIONED THEIR
CARE FROM ARKANSAS
CHILDREN'S TO UAMS
DURING FISCAL YEAR
2023-24



UAMS Adult Sickle Cell Program Multidisciplinary Clinic

The UAMS Adult Sickle Cell Clinical Program adopts an interdisciplinary approach to managing adult patients primary with sickle cell disease, offering services throughout Arkansas. The frequency of clinic visits is tailored to each patient's disease severity, ranging from monthly to annually, or more frequently if needed. Comprehensive care is customized to address individual needs, with ongoing communication between the program and each patient's care provider to ensure holistic management.

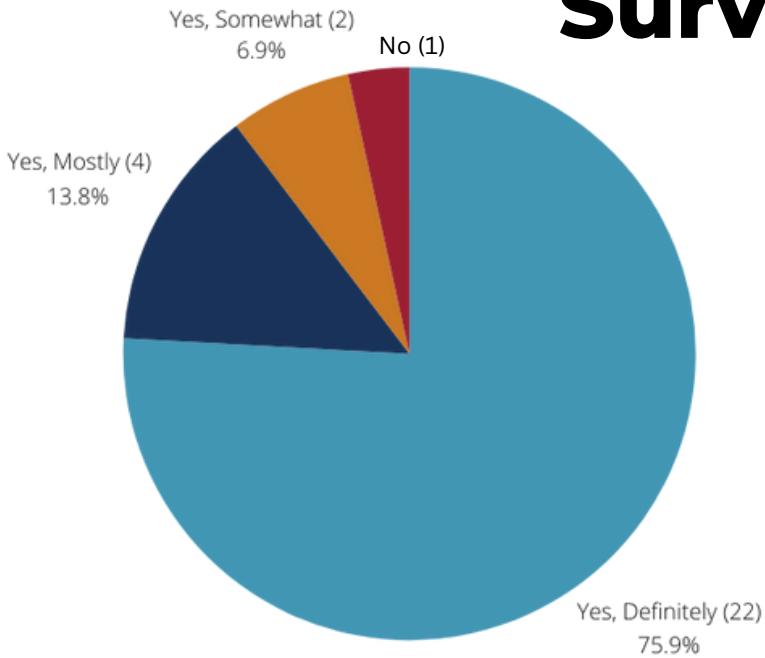
The interdisciplinary team includes hematologists, who specialize in blood disorders, and a nurse practitioner who collaborates with the team to provide thorough care through assessment, treatment planning, maintenance, and follow-up. A licensed clinical social worker supports patients and their families with social and emotional needs, addresses health-related expenses for the underinsured or uninsured, assists with transportation costs, and explores employment options. They also facilitate the transition from pediatric care at Arkansas Children's to the adult clinical setting.

A registered nurse delivers outpatient care and acts as the liaison between the call center, patients and the sickle cell team. Additionally, they coordinate community outreach, fostering relationships between clinical staff, the community and health care providers across Arkansas. A pharmacist manages medication through comprehensive reconciliation and counseling, while evaluating medication efficacy to ensure optimal patient care.

In addition to these core team members, the program coordinates with health care professionals throughout UAMS to ensure our patients receive the very best care and treatments available.



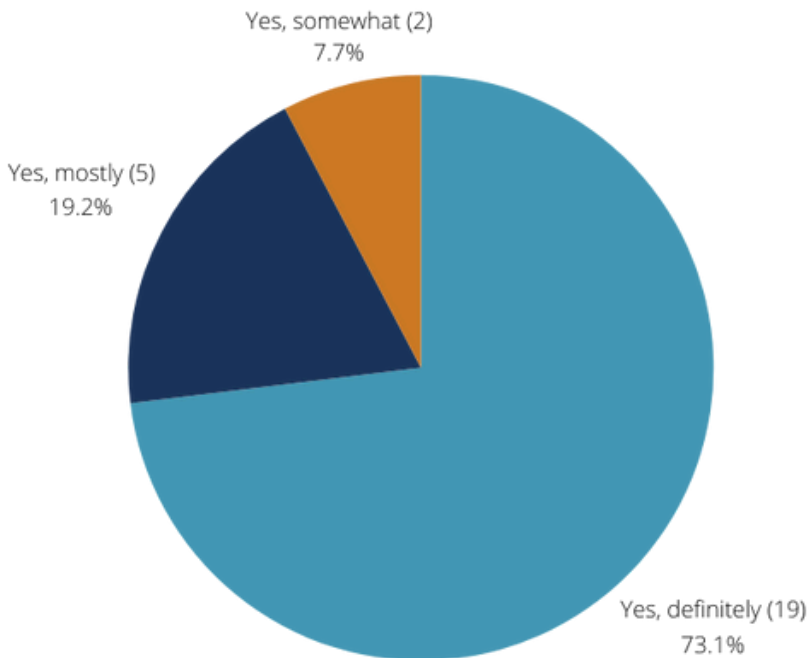
Patient Satisfaction Surveys



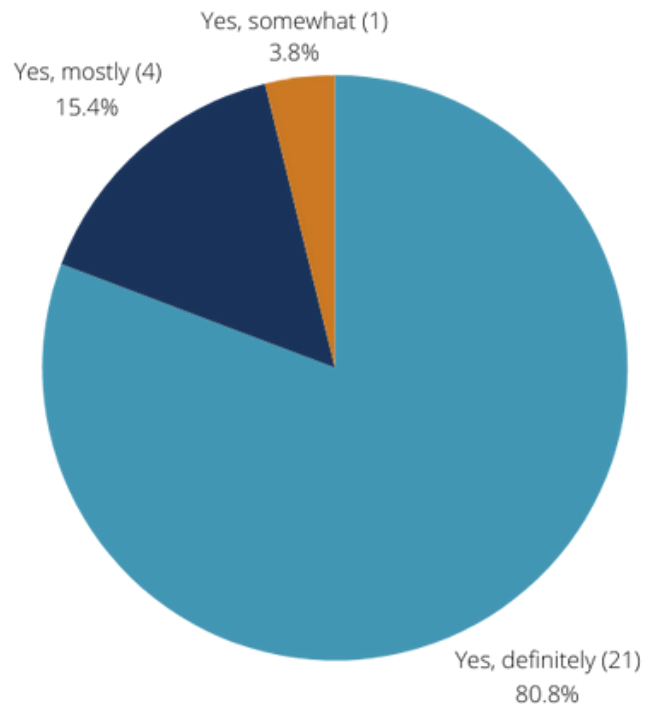
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How likely are you to recommend this provider to your family and friends?

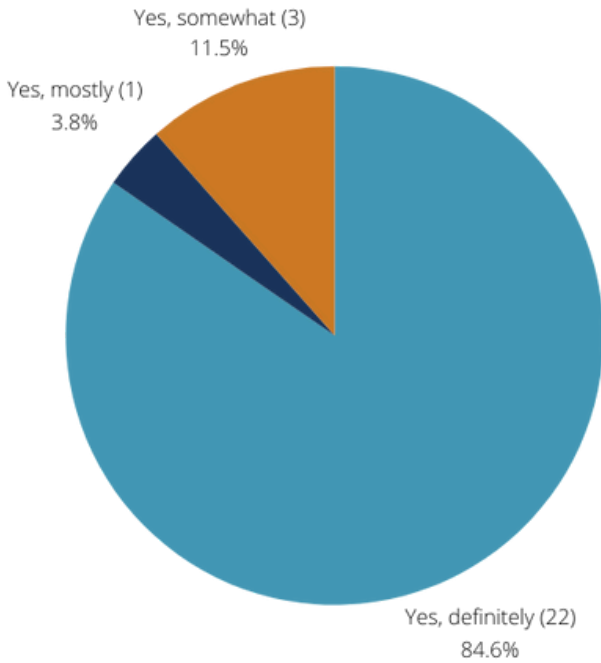


Did nurses explain things in a way you could explain?



Did nurses listen carefully to you?

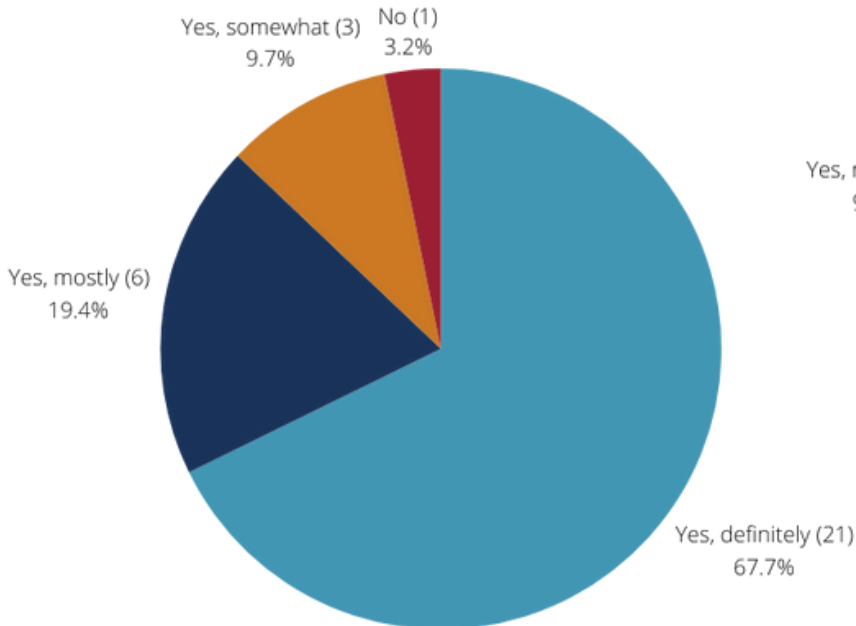
Patient Satisfaction Surveys



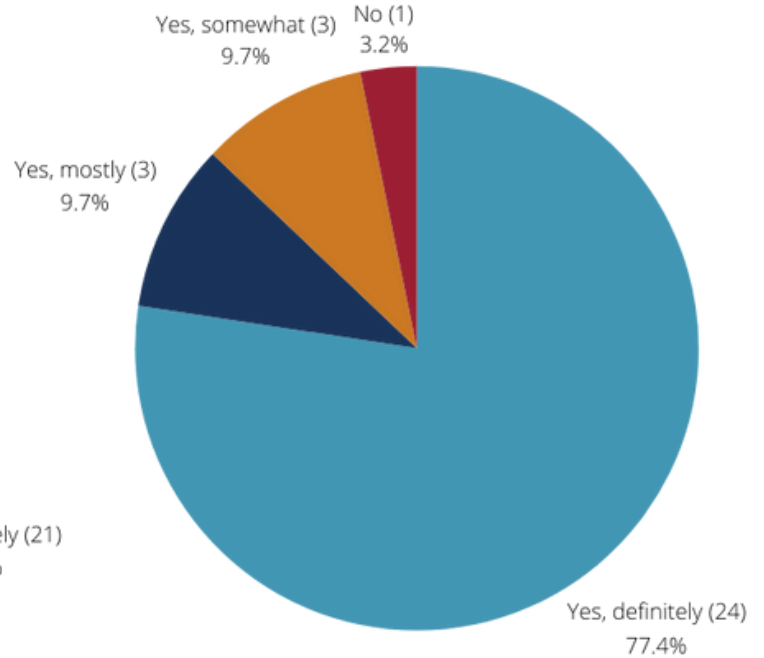
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Did nurses treat you with courtesy and respect?

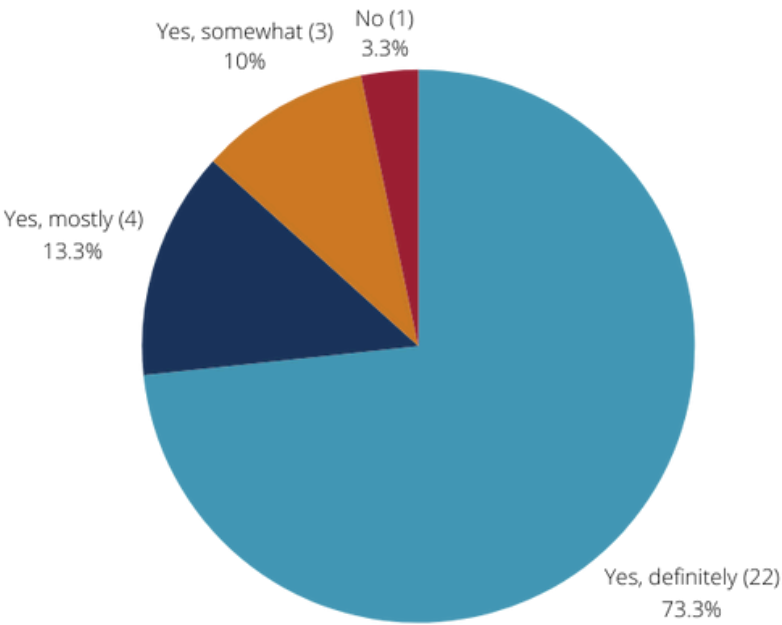


Did this provider give you enough information about your health and treatment?



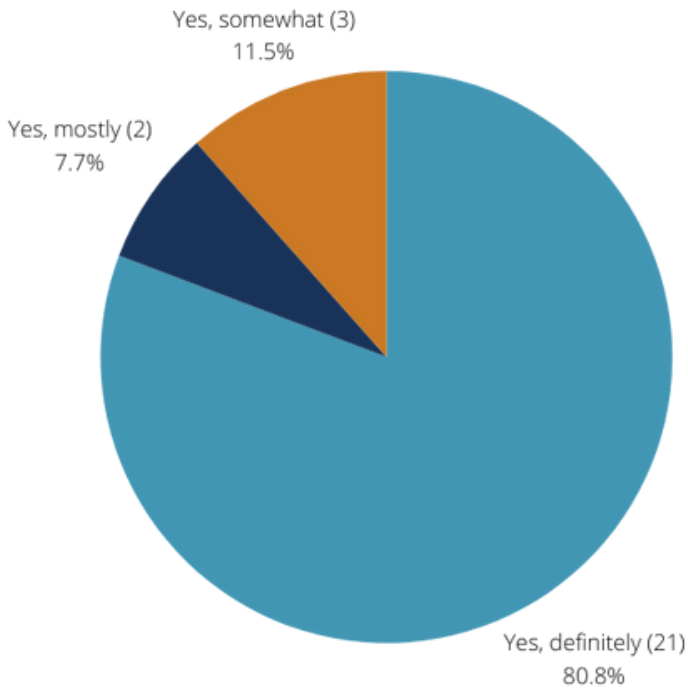
Did this provider listen carefully to you?

Patient Satisfaction Surveys

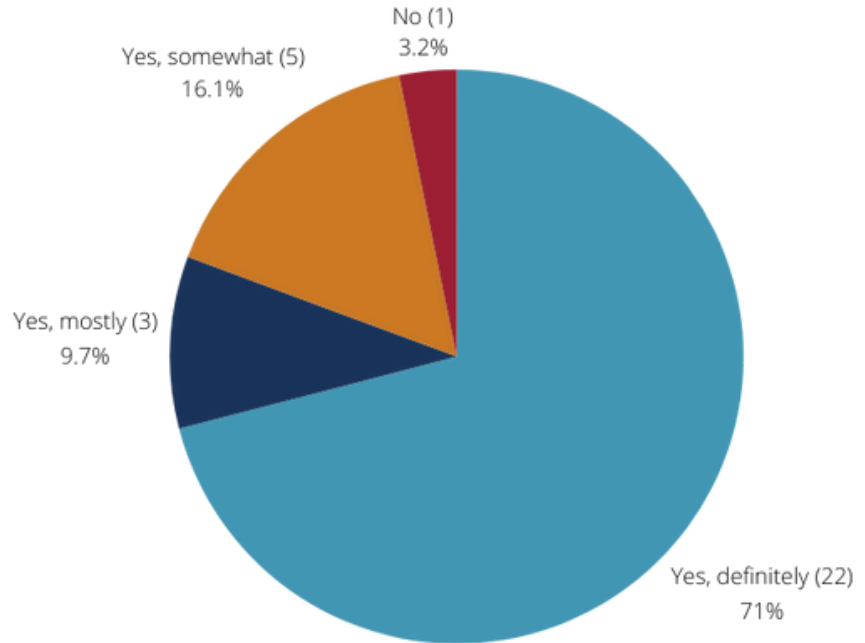


Did this provider seem to know your medical history?

Graph Legend

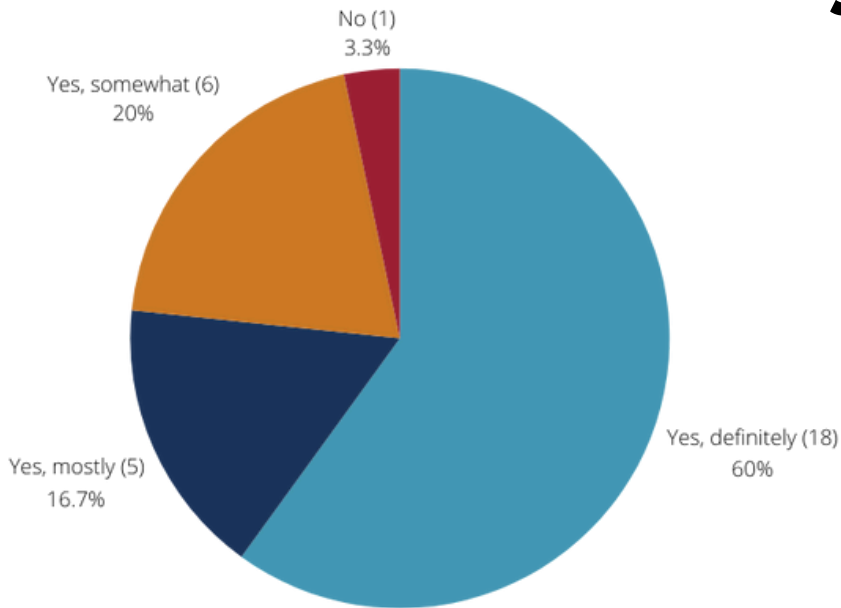


Did you have confidence and trust in the nurses treating you?



Did you trust this provider with your care?

Patient Satisfaction Surveys



Was the front desk staff courteous and helpful?

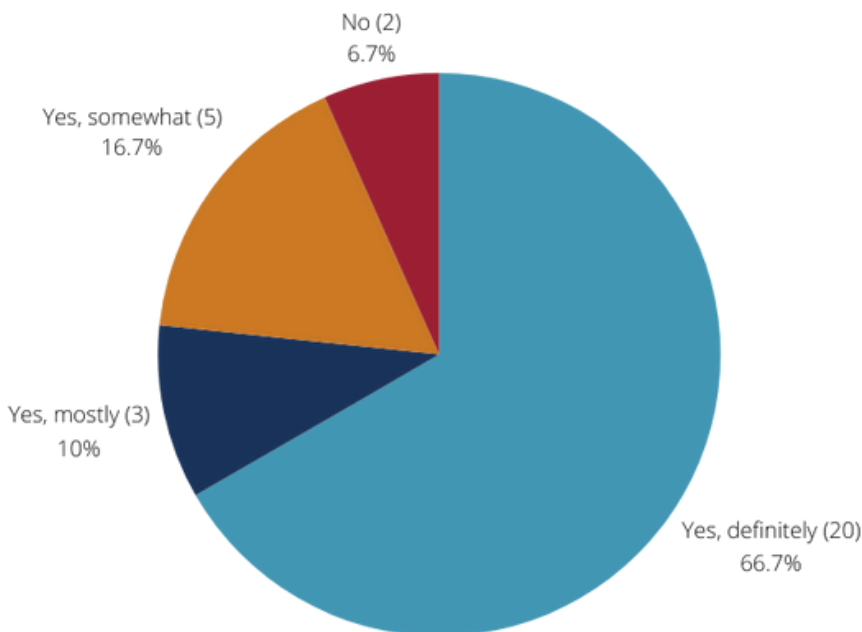
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YES, DEFINITELY

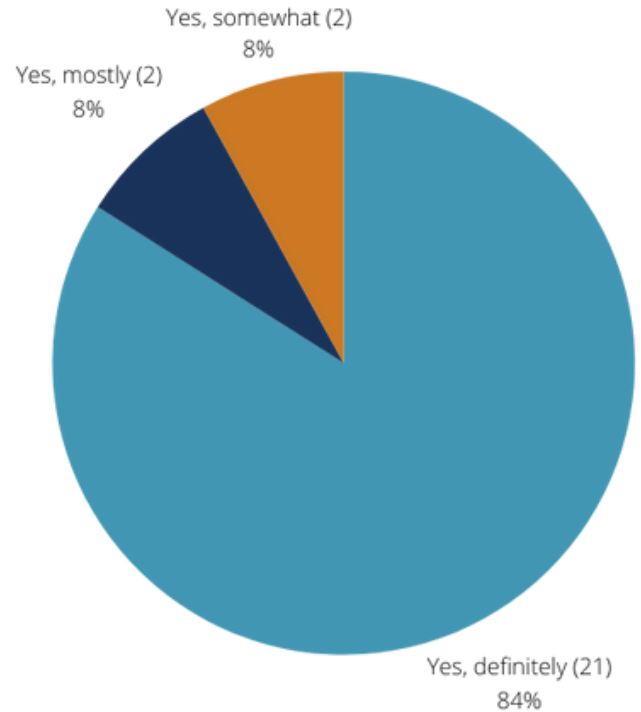
YES, MOSTLY

YES, SOMEWHAT

NO



Were you able to schedule an appointment with this provider as soon as you needed?



Were you comfortable talking with nurses about your worries or concerns?

Digital Health Support

**24/7 CALL CENTER WITH
SICKLE CELL HOT LINE**



Staffed by experienced RNs who can offer:



Education concerning acute and chronic health problems related to sickle cell disease



Doc to doc consults supporting primary care, the Emergency Department (ED), and other providers caring for sickle cell patients across the state



Telephone triage for patients with immediate health concerns:

Emotional support

Assistance with medication refills

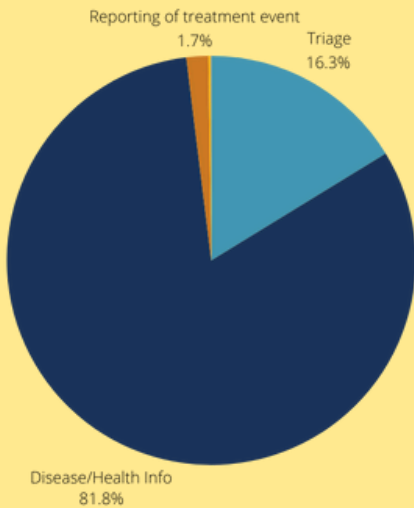
Home care instructions to lessen symptoms

Secondary-level triage (through the Call Center) before sending patients to ED, giving alternatives to ED visit when appropriate

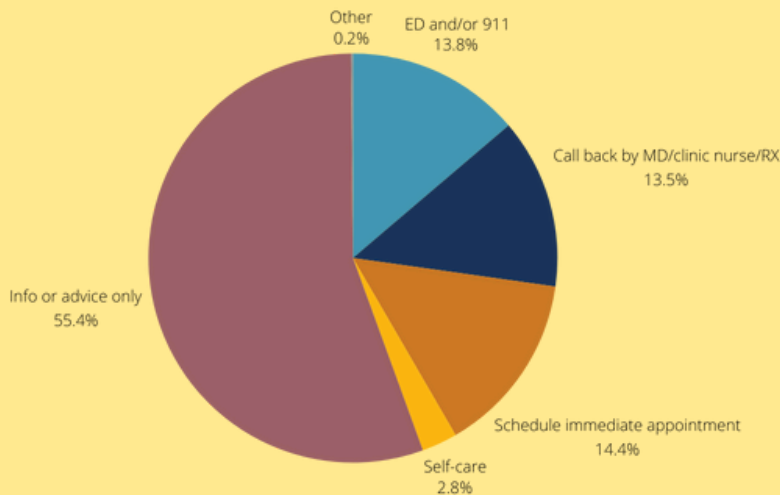
Call Center

Sickle cell patients have 24/7 access to the Call Center, which is operated by the UAMS Institute for Digital Health & Innovation. Patients can reach out with urgent issues, which are initially assessed by a registered nurse. Based on the assessment, the triage nurse may recommend going to the Emergency Department for immediate care, scheduling a clinic appointment, coming in for an outpatient infusion, or receiving guidance for self-care at home. By providing direct access to a triage nurse experienced in sickle cell disease, along with secondary-level support from the Adult Sickle Cell Clinical Program team, the Call Center helps patients navigate their next steps in treatment.

The Call Center serves as a vital resource for patients, physicians, providers and the community, supporting residents of Arkansas, out-of-state individuals and international callers. It assists health care professionals with patient care inquiries and referrals to the program. This resource is crucial to the program's goal of being a statewide asset, offering support to patients, providers and the broader community in Arkansas and beyond. In addition to helping patients and healthcare providers, the Call Center also provides assistance to the general public.



Caller Request



Call Center Triage Outcomes



Education and Outreach

The University of Arkansas Medical Sciences (UAMS) Adult Sickle Cell Program continues to provide education and outreach, which aligns with the mission of the program. The cornerstone of the mission is to educate and provide evidence-based care for patients with sickle cell disease (SCD). This is achieved by visiting health fairs, conferences, schools, churches, and other venues to raise awareness of SCD.

CAP Talks and Telemedicine Advancements

The UAMS Adult Sickle Cell Program continued its commitment to education and outreach through the Connecting across Professions (CAP) talks, a vital resource for informing healthcare providers and workers about the clinic's services and advancements in Sickle Cell Disease (SCD) care.

Key Presentations

December 12, 2023: Sickle Cell Update by Sunny R. K. Singh, M.D.

Dr. Singh delivered a comprehensive update on SCD, sharing the latest research findings and clinical practices. This presentation provided valuable insights into the complexities of SCD management and treatment, enhancing the knowledge base of attending healthcare professionals.

March 5, 2024: Sickle Cell Update by Lindsey Dayer, Pharm.D.

Dr. Dayer presented another crucial update on SCD, focusing on recent advancements in treatment and care strategies. Her expertise and innovative approaches to SCD management offered attendees practical tools and information to improve patient outcomes.

Impact of CAP Talks

The CAP talks, conducted by the entire team, have proven instrumental in raising awareness about the clinic's capabilities and services. By facilitating knowledge exchange and professional development, these talks support the continuous improvement of SCD care within the health care community.

Telemedicine Integration

In addition to CAP talks, the integration of telemedicine has been a significant advancement for the UAMS Adult Sickle Cell Program. Telemedicine has expanded the program's reach, allowing for ongoing education and information dissemination to patients and providers. This technology has enabled the program to maintain high standards of care and support, regardless of geographical barriers.

The combination of CAP talks and telemedicine ensures that the UAMS Adult Sickle Cell Program remains at the forefront of SCD education and patient care, fostering a well-informed and connected healthcare community.

COMPASSIONATELY CONNECTED FOR VETERANS, INC. HOSTS

THE COMPASSION PROJECT **FREE** COMMUNITY RESOURCE FAIR

FOR VETERANS, THE COMMUNITY AND THEIR FAMILIES
PLEASANT VALLEY CHURCH OF CHRIST 10900 N. RODNEY PARHAM ROAD, LITTLE ROCK, AR 72212

“Empowering Communities”

On April 6, 2024, the UAMS Adult Sickle Cell Program participated in the Compassion Project Community Resource Fair. This free community resource event allowed the program to provide valuable information and resources to attendees. The event highlighted the program's ongoing commitment to outreach and education, ensuring that the community has access to the support and knowledge necessary for managing Sickle Cell Disease (SCD). Through participation in such events, the UAMS Adult Sickle Cell Program continues to enhance its impact and support for patients and the broader community.

Community Engagement and Patient-Led Education

This year, a significant event was held at a fair organized by a patient and the Omicron Lambda Lambda (OLL) Chapter of Omega Psi Phi Fraternity, Inc. The OLL Chapter focused on community health, education and service during a multi-service event at Horace Mann Magnet School.

Patient-Driven Outreach

This fair marked a milestone as the first event organized by a patient, who also took an active role in educating attendees at the table. The community responded positively to having a patient as an educator, finding value in learning from someone with lived experience.

Community Impact

The event highlighted the potential of patient-led education, demonstrating that showcasing healthy and thriving patients can significantly enhance community engagement and understanding of SCD. This approach received enthusiastic feedback and may be incorporated into future outreach efforts, further empowering patients and enriching the program's educational initiatives.

The success of this event underscores the importance of innovative and inclusive community outreach, reinforcing the UAMS Adult Sickle Cell Program's commitment to education and patient advocacy.

Health Fair

April 27, 2024
10am -1pm



Horace Mann Middle School
1000 E. Roosevelt Road
Little Rock, AR, 72206



Free Lunch Served

- Free Blood Pressure Check
- Free Cholesterol Check
- Free Glucose Screening
- Free CPR Training
- Learn About Good Eating Habits
- Fitness Demonstration
- Sickle Cell Disease Education
- Organ Donor Registration
- And More!

Sponsored By



Uniting Communities: UAMS Adult Sickle Cell Program Social Worker

The UAMS Adult Sickle Cell Program Social Worker Daja Green, LMSW, embarked on a remarkable community engagement initiative on May 18, 2024 attending the University Plaza of UA-Little Rock for the TRIO Educational Opportunity Center Popup Event. This event was about forging connections and fostering relationships within the community within an atmosphere of educational assistance, free food and live entertainment.

Amid the vibrant atmosphere of the event, Green connected with individuals, providing valuable resources and information about the UAMS Adult Sickle Cell Program. By actively engaging with attendees and sharing insights about SCD care, she not only raised awareness but also built bridges between the program and the community it serves.

This event exemplifies the UAMS Adult Sickle Cell Program's commitment to reaching beyond traditional boundaries, embracing opportunities to connect with diverse audiences and extend its impact.

Through initiatives like these, the program continues to strengthen its ties with the community while advancing its mission to provide comprehensive care and support for individuals living with SCD.

Innovative Educational Initiatives by Lindsey Dayer, Pharm.D.

Lindsey Dayer, Pharm.D., the program's pharmacist, plays a crucial role in the UAMS Adult Sickle Cell Program's outreach efforts. Her commitment to educating new and current pharmacists on the nuances of SCD care has been exemplary.

Interactive Educational Approach

As part of her pain management elective, Dr. Dayer introduced an innovative "sickle cell escape room" for pharmacy students. This interactive learning experience required students to solve cases and answer questions to progress through various stages, encompassing 9-10 parts of the case. This engaging method not only captured students' attention but also reinforced critical concepts in SCD care, enhancing their understanding and preparedness.



LINDSEY DAYER, PHARM.D.

Impact on Pharmacist Training and Health Care Community

Dr. Dayer's creative and engaging educational methods have significantly impacted the training of future pharmacists and the broader healthcare community. By fostering a deeper understanding of SCD and its management, her initiatives ensure that pharmacists are better equipped to provide high-quality care to SCD patients.

Her dedication to improving SCD care through innovative education and outreach aligns perfectly with the mission of the UAMS Adult Sickle Cell Program, which strives to advance patient care and enhance community awareness through continuous education and support.

Advancements from the American Society Hematology (ASH) Sickle Cell Disease Center Workshop

In 2023, the UAMS Sickle Cell Program Team was honored with a grant to attend The American Society of Hematology (ASH) Sickle Cell Disease Center Workshop in Washington, DC. The team participated in the second cohort workshop held from May 6-9, 2024, which focused on training healthcare professionals to establish clinical centers tailored to the needs of adults living with SCD.

Workshop Participation and Learning

The workshop provided comprehensive guidance on various aspects essential for establishing and operating SCD centers. Key areas of focus included:

- **Developing Business Plans:** Training on creating robust business plans to ensure the sustainability and efficiency of SCD centers.
- **Advocating to Stakeholders:** Strategies for effectively communicating the needs and benefits of SCD centers to stakeholders.
- **Managing Operations:** Best practices for the day-to-day management of clinical centers dedicated to SCD care.
- **Measuring Impact:** Approaches for assessing the effectiveness of care provided and implementing continuous improvements to enhance patient outcomes.

Ongoing Support and Application

Monthly meetings with ASH leaders have been instrumental in reinforcing the concepts introduced during the workshop. These sessions have provided the UAMS team with the latest information and specialized training, ensuring that the program remains at the cutting edge of SCD patient care.

Future Directions

The UAMS Sickle Cell Program is committed to utilizing the knowledge and resources gained from the workshop to further develop and enhance the program. By integrating these insights, the team aims to provide optimal care for SCD patients, continually improving the quality and reach of services offered in the clinic. This ongoing education and professional development underscore the program's dedication to excellence in SCD care, positioning the UAMS Adult Sickle Cell Program as a leader in the field.



Advancing the Fight Against Sickle Cell Disease: Insights from UAMS Annual Sickle Symposium

On September 12, 2023, the University of Arkansas for Medical Sciences (UAMS) hosted its Annual Sickle Cell Symposium, uniting renowned researchers, clinicians, patients, and community advocates to share cutting-edge advancements, address challenges, and devise strategies toward a cure.

Symposium Highlights

"Advancements in Sickle Cell Research and Treatment: Paving the Way Towards a Cure"

Presented by Santosh Saraf, M.D., associate professor of medicine and director of translational research at the Sickle Cell Center of the University of Illinois at Chicago. Dr. Saraf illuminated the latest breakthroughs in research and treatment methodologies, offering hope for a future without SCD.

"Gene Therapy for Sickle Cell Disease – An Overview"

Delivered by Shalini Shenoy, M.D., professor of pediatrics at Washington University in St. Louis. Dr. Shenoy provided a comprehensive overview of gene therapy's potential in combating SCD, offering insights into this promising frontier of treatment.

"Moving Forward: UAMS Adult Sickle Cell Program Future Directions"

Presented by Muthu Veera Kumaran, M.D., director of hematology and oncology and clinical program director for stem cell transplantation and cellular therapy at the UAMS Winthrop P. Rockefeller Cancer Institute. Dr. Kumaran outlined the future trajectory of the UAMS Adult Sickle Cell Program, highlighting the institution's commitment to innovation and patient-centric care.

Panel Discussion

Following the presentations, a dynamic panel discussion ensued, moderated by Lindsey Dayer, Pharm.D., associate professor and director of experiential education in the UAMS College of Pharmacy. Panelists, including Dr. Singh and the aforementioned presenters, engaged with the audience, addressing inquiries spanning from emerging gene therapy methodologies to navigating treatment side effects and cost considerations.

The symposium served as a catalyst for collaboration, innovation, and progress in the fight against SCD. With the collective efforts of researchers, clinicians, patients, and advocates, the vision of a world free from the burden of sickle cell disease draws nearer.



DR SINGH ANSWERS A QUESTION DURING PANEL DISCUSSION

Celebrating a Decade of Impact: The 10th Anniversary of the UAMS Adult Sickle Cell Program

The University of Arkansas Medical Sciences (UAMS) Adult Sickle Cell Program launched in 2014 and proudly marks its 10th anniversary this year, celebrating a decade of unwavering dedication to education, outreach and evidence-based care for patients with sickle cell disease (SCD) in Arkansas. Over the past 10 years, the program has made significant strides, yet the journey toward comprehensive care and awareness continues with renewed vigor.

A Decade of Milestones and Achievements

Since its inception, the UAMS Adult Sickle Cell Program has been a beacon of hope and a source of vital support for the SCD community. The program's mission to educate and provide evidence-based care has been realized through numerous initiatives, including health fairs, conferences, school visits, faith outreach and various community events. These efforts have not only raised awareness about SCD but also empowered patients and their families with the knowledge and resources needed to manage the disease effectively.

Looking Forward: The Next Decade

As the UAMS Adult Sickle Cell Program celebrates this milestone, the commitment to education, outreach and patient care is stronger than ever. The program's impact over the past 10 years is evident, but the vision for the future includes even more significant advancements and broader outreach. With continued dedication and community support, the next decade promises to bring transformative changes and improved outcomes for SCD patients in Arkansas.

Here's to 10 years of progress, and to many more years of making a difference in the lives of those affected by sickle cell disease. The UAMS Adult Sickle Cell Program remains steadfast in its mission, driven by the hope and determination to create a brighter future for all.





Institute for Digital
Health & Innovation

For patient services call the 24/7 Call Center
1-855-SIC-CELL (742-2355)

For more information visit
sicklecell.uams.edu