

# Human-Centered Design Report

Opportunity Area 1: SCD care is difficult to access (section 2 of 9)

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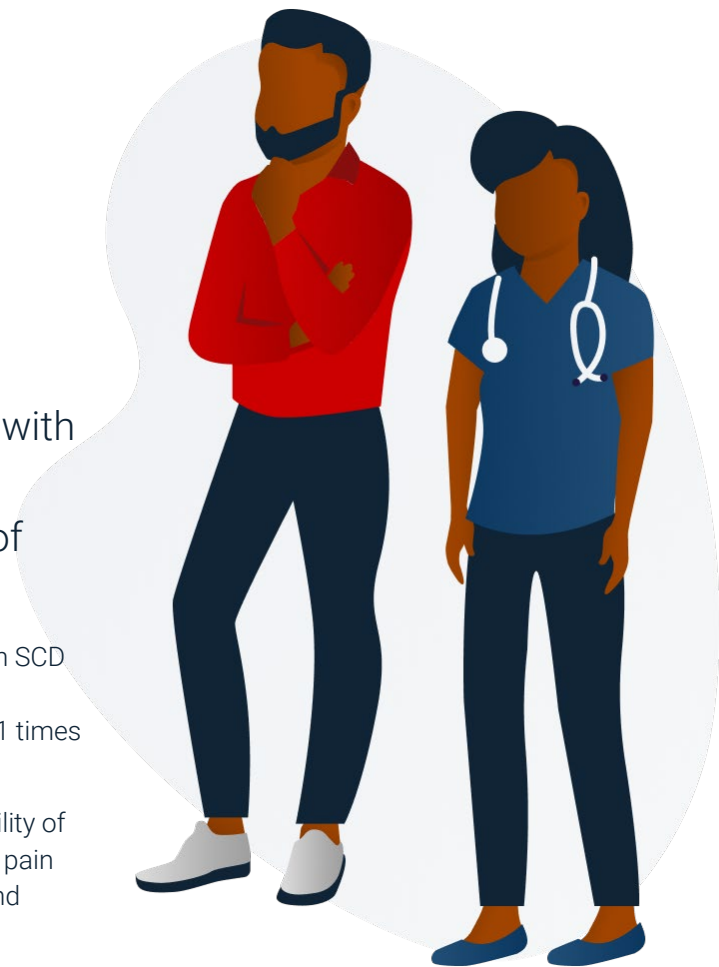


# About Health+ Sickle Cell Disease

Health+ Sickle Cell Disease is a project that aims at providing insights, stories, and journeys around the experience of people with Sickle Cell Disease (SCD) to accelerate the identification and implementation of innovative solutions to increase the quality of life for patients living with SCD.

SCD is the most common inherited blood disorder. About 100,000 Americans currently live with SCD and the disease disproportionately affects African Americans. SCD is costly; expenditures for patients with SCD are estimated to be 6 times higher than non-SCD patients in Medicaid and 11 times higher than non-SCD patients with private insurance.

African Americans disproportionately experience challenges with access, quality, and affordability of care. Patients with SCD may encounter racial discrimination when seeking treatment for acute pain crises, including accusations of “drug seeking”, extended emergency department wait times, and difficulty filling prescriptions.



# Opportunity Areas

## 1 SCD care is difficult to access

- Healthcare lacks proper provider training, specialized clinics, and non-opioid treatments
- Patients are stigmatized as drug seekers in healthcare
- Access to treatment is compromised by barriers to primary care and cost
- Patients are often skeptical of healthcare providers

## 2 ER is a last resort for patients

- Patients fear being accused of drug seeking
- ERs often aren't familiar with SCD protocols
- Adult ERs are busy, with long wait times

## 3 People with SCD struggle with transition to adulthood

- Coordinating care independently is challenging
- Young adults lack understanding on how to secure proper health insurance
- Hand-off from caregiver to young adult patient is insufficient

## 4 "Trial and Error": Patients bear the burden of individualizing their care plan

- Traumatic events are triggers to learn
- Non-prescribed treatments are a common recourse
- Patients develop communication strategies to negotiate with providers
- Patients develop complex financial and health insurance tactics to cover care

## 5 Patients plan their lives around unpredictability of SCD

- Emergencies cause emotional trauma in patients and their loved ones
- Patients anticipate emergencies in all occasions
- "Invisible disease": isolation, stigma, and lack of understanding at work and school
- Patients plan careers and even relocate to maximize access to SCD support

## 6 SCD care requires complex support networks

- Family is preferred support—but it's often not available
- Community-based organizations, social media provide solidarity, education, and services
- Patients wish they could be more independent

# SCD care is difficult to access

SCD care is compromised by lack of treatment options, infrastructure, knowledgeable providers, and empathy in healthcare. This leads to high distrust in healthcare from patients, which can result in poor relationships with providers, poor treatment compliance, and even withdrawal from the system. The disconnect of primary care can result in increased ER visits and hospitalizations, which can be traumatic, costly, and dangerous for the health of the patient.

- Healthcare lacks proper provider training, specialized clinics, and non-opioid treatments
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- Access to treatment is compromised by barriers to primary care and cost
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*“But then you have all these specialties and all these specialists and everything for cancer or they want to do this for HIV, but why not sickle cell. Why is there so much discrimination or stigma tied to sickle cell disease? One of the first blood diseases, why?” -Patient*



## Healthcare lacks proper provider training, specialized clinics, and non-opioid treatments

Multiple factors affect this issue:

- Most adult care isn't equipped to provide proper SCD care due to lack of knowledge—it's considered a rare disease but it affects specific communities disproportionately.
- SCD care requires extensive resources, such as infusion centers and hospital beds, but there aren't enough to service all patients.
- Knowledgeable providers are rare, hard to find, and hard to secure.
- Most treatment options for SCD, especially curative options, are very aggressive, and mostly available only to children and youth.
- SCD treatment requires multiple specialties to collaborate, particularly when there are other health issues in place. But siloed traditional healthcare models and lack of payment for care coordination time stop this collaboration from happening. This creates barriers for medical record-keeping and proper medical plan decision-making.

*"Showing up at the emergency room and telling the different ER physicians, hey I have a sinus infection that's triggering my crisis, it was like telling them that I was the Easter bunny because no one believed that a sinus infection could throw me into crisis." -Patient*

*"With other places and other hospitals [other than Johns Hopkins], especially in predominantly white communities, they don't even know what this disease is. They don't know how to treat it." -Patient*

*"My guess is, a general hematologist/oncology practice in a private practice setting probably wouldn't know about these things. I know about the drugs, either my center's been involved [...]. To get physicians to prescribe their drug, the physicians have to know about the drug. [Pharma companies] know that there's a market out there, so they're promoting summits on access to care for Sickle Cell Disease and promoting the model that you should be cared for in a specialty center because it's a rare disease. They're making sure that the physicians who deliver this type of specialty care know about their drug and that more patients will come to see us because their bottom line is, they want to sell the drug. And that is also \$10,000 a month." -Provider from SCD program*



## Patients are stigmatized as drug seekers in healthcare

The most common and recommended pain management for SCD relies on opioids, which patients often have to use for many years on a regular basis. This extended use builds tolerance in patients, who need them at higher dosage over time to be able to properly control their pain crises. Many providers are not aware of this aspect of SCD, especially in ER and adult care, and confuse appropriate opioid usage for SCD pain management with opioid addiction.

A race bias often affects providers' perception of SCD patients, causing them to not believe the patient's pain levels and intention. This suspicion can result in patients distrusting providers and avoiding the healthcare system altogether unless there's an emergency.

In addition, providers often fear prescribing opioids due to strict regulations meant to address the opioid crisis, and are not aware that patients with SCD are exempt from those regulations. This causes patients to have insufficient access to life-saving pain management.

*“There are so many providers that are hesitant to administer pain medication, but especially to members of the black community because the automatic stigma that we’re drug addicts or drug users, just here to get your fix, which is a terrible thing. But even outside of sickle cell, you got a black woman dying in childbirth because they’re not taking their issues as seriously. So that’s always been a thing.” -Patient*

*“I think she was going to give me morphine, I was like, no don’t give me that. Morphine does not work at all. It has to be dilaudid, at the time, they were giving me and she made a comment like you’re carrying on like you’re a junkie, like you’re a fiend.” -Patient*

*“Patients have a hard time in the emergency department for a variety of reasons including there can be really long wait times, there’s no objective measurement that you can to prove that they’re in a vaso-occlusive crisis, so people don’t believe them often and think that they’re just interested in drug seeking and that’s why they’re in the emergency department and there are a lot of negative stereotypes around these patients who are predominately patients of color, obviously. And so they’ve just had really bad experiences with ED providers in the past and have a lot of mistrust. [...] Providers are worried about providing opioids pain medications in the context of the opioids crisis, but they understand that patient need it, but then they’re never sure which patients need it or if there’s a possibility that there’s diversion.” -Nurse*



## Access to treatment is compromised by barriers to primary care and cost

Primary care is hard to access in the United States, as it commonly requires patients to provide proof of insurance or ability to pay. Because of this, patients with SCD are forced to skip it and end up going to the ER often, where providers are mandated to provide care to all regardless of payment (Emergency Medical Treatment and Labor Act, also known as EMTALA). ER care doesn't provide preventative treatment, which could improve these patients' conditions.

When patients do access primary care, most treatment options are new and costly. They're often not covered by insurance. Some pharmaceutical options can cost up to \$100k/year.

Underemployed patients ineligible to Medicaid (often the case outside of Medicaid expansion states) are especially affected. Paired with their lack of financial and support resources, quickly snowballs health crises into life crises.

*"DC Medicaid follows about 600 adult sickle cell patients and they spend \$71 million a year, at least I think those were the numbers from 2016 or 17. [...] Of those 600 patients only 15% are on hydroxyurea. So that works out to about \$120,000 per patient, but most of that cost is ER visits and hospitalizations. I'm cheap to see and nobody wants to reimburse me very much, but when you're dealing with numbers like that, I think even at that price, it's probably cost effective or at least cost neutral and if you want to go a step further, I think that the human cost of Sickle Cell Disease is even greater and I think that's not easy to quantify. [...] I would argue for other diseases we're spending that money all the time. For equally severe diseases. I don't want to prioritize diseases, but this is just one we left behind and we're spending the money in the wrong places." - Provider from SCD program*



## Patients are often skeptical of healthcare providers

Patients trust in healthcare may be compromised:

- When providers express lack of trust in the patient and/or stigmatize them
- When providers ignore the patient's input when designing their care plan
- When providers express lack of knowledge based on what the patient knows about SCD
- When they try treatments that fail or that have side effects, and the provider fails to offer more alternatives

This can compromise their engagement with healthcare, which can lead to more ER visits and hospitalizations as SCD is left untreated.

*"He was yelling at my while I was in crisis, if you do not start the hydroxyurea I will not prescribe you any more pain medications." -Patient*

*"Here they really don't know what to do. So I be there and they have to figure out what to do and then they get you medicines that don't work and admit me to the hospital and then when I'm in the hospital they don't know how to treat me when I'm in the hospital, so it's basically real different down here. So that's why I feel that I really need a hematologist down here." -Patient*

*"I refuse to go there, I call it the intern hospital because all the interns, all the fresh out of the medical school, that's where they go and get their hours and they intern, so you have all these young kids that don't know shit, but they don't know shit about the disease and they're experimenting." -Patient*

*"I'm not against a transplant, but at the end of the day, it may not work for everyone. I have friends that it did not work for. So, I just want to be at a hospital and have doctors that care about me and my feelings and are not just trying to push treatments and everything on me if that's not what I want to do." -Patient*



## Recommendations for Healthcare

- SCD clinician-to-patient education programs (e.g. diabetes, cystic fibrosis, hemophilia, other chronic diseases)
- More integrated care:
  - Community health workers and social workers to help with outreach and connect patients to resources
  - Patient-centered medical home
  - Reimbursement for care coordination
  - Increased collaboration between providers who specialize in SCD and other providers (for inspiration: Vermont's Hub and Spoke model)
  - Easy sharing of individualized care plans between PCPs and ER
  - SCD status registry (similar to Prescription Drug Monitoring Programs (PMDPs))
  - Improved ways of concisely capturing pain management plans, care plans and continuity of care plans across Health IT systems, healthcare facilities and organizations, geographic locations and states
- Reminders and suggestions for appointments, immunizations, etc.
- Health insurance options education and assistance



## Recommendations for Healthcare (cont.)

- Increased patient access to SCD community
- Increased clinician education:
  - Increase numbers of hematologists who specialize in benign (non-cancerous) conditions
  - Patient-to-clinician working sessions to increase clinician empathy
  - Educational credits and financial incentives for clinicians specializing in SCD
  - Sensitivity training for providers around communicating challenging news, particularly to caregivers around children with SCD
  - Specialized SCD training for adult primary care providers
  - SCD residency for nurse practitioners and physician assistants
  - More education to providers who care for older patients
  - Provider-to-provider mentorship, case conferences program for SCD
  - Financial incentives for providers caring for SCD patients



## Recommendations for Healthcare (cont.)

- Increased access and education on clinical trials for SCD
- Quality measures for SCD, with consistent data standards across facilities
- More widespread access to research findings, including in accessible language for patients



## Recommendations for Healthcare Finance and Policy

- Development of SCD payment model
- Reimbursement for telehealth, informal virtual consultations, phone calls, care coordination, connecting patients to external resources
- Value-based incentive payments for SCD care
- Medicaid reform to include adults with SCD along with children
- Increased coverage of new therapies
- Simplify and increase access to specialist referrals
- SCD surveillance: increased monitoring of costs of ER visits vs. preventative treatment
- National SCD registry for verification of SCD status – linked to newborn screening database
- SCD surveillance: Funding to support CDC SCD data collection program across all U.S. states
- National open registry of SCD treatment centers and programs
- Partner with other countries to support international efforts
- Programs to increase access to new and expensive therapies
- Add SCD to 340B payment models



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