health+ Sickle Cell Disease | CTO Office of the CHIEF TECHNOLOGY OFFICER | OMH U.S. Department of Health and Human Services Office of Minority Health

Human-Centered Design Report

Executive Summary (section 1 of 9)

&partners | June 2020

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

The ER Journey

Crisis Onset

Patient feels pain crisis symptoms
Tries to manage crisis at home
Crisis isn't getting better over time
Decides it's time to go to the ER

♥ Avoids and fears ER

Preparing for the ER

Patient identifies "familiar" ER
Plans for long absence
Solicits advocates
Goes to the ER

♥ Anticipates bias and lack of knowledge at ER

Needs support in case of hospitalization

Arriving at the ER

Patient checks in
Triage
Wait for ER bed

♥ Long wait times

✚ SCD Protocol: Patient should be high priority (Triage category ESI 2)

ER Evaluation

Patient consults with ER provider
Patient undergoes tests
Patient waits for results
Provider decides course of action

♥ Discrimination from medical team

Delay in pain management

Fears life disruption from possible hospitalization

✚ Lack of SCD knowledge

Waits for tests to prescribe pain management

Suspicious of drug-seeking

Doesn't follow PCP's recommendations

Worried about professional liability (opioid crisis, lack of SCD knowledge)

Lack of knowledge about pain control for SCD may result in unnecessary hospitalization

Stay in ER

Treatment
Discharge
Goes home or looks for another ER

♥ Discrimination from medical team

Discharge without treatment

Insufficient pain management

✚ Lack of SCD knowledge

Hospitalize Patient

Wait for bed
Specialty care
Discharge

♥ Discrimination from medical team

Discharge without treatment

✚ Insufficient pain management

Lack of SCD knowledge

☑ CMS doesn't cover readmissions within 30 days of hospitalizations

♥ Patient Barrier
✚ Healthcare Barrier
☑ Policy Barrier

1. Living with SCD as a Child

Caregivers bear the burden of all care coordination, decisions, life interruptions, and more.

Coordinating Primary Care			Paying for Care	Going to the ER	Hospitalizations	Going to school
Caregiver works with pediatricians who understand SCD well; typically has only one, maybe 2 providers (PCP and hematologist).	Caregiver makes all decisions: healthcare, treatment, and administrative.	More curative treatment options.	Caregivers handle health coverage and unexpected costs.	Children's ER is typically knowledgeable about SCD, not busy, and able to give proper attention.	Misses school, caregiver handles care coordination, disrupted family dynamic.	Caregivers handle negotiations, protocol with school, and missing classes.

2. Living with SCD as a Young Adult

Without caregivers as a buffer, they face many new and unfamiliar barriers, but also desire to be independent.

Coordinating Primary Care			Paying for Care	Going to the ER	Hospitalizations	Work and School
Knowledgeable providers are hard to find; patients need to take on the burden of coordinating multiple specialists they didn't need before.	Has to learn to make healthcare decisions on their own and continue developing precautionary measures.	Fewer curative treatment options as patient grows older.	Lacks knowledge on how to choose insurance, what to look for, when to enroll. Struggles to self-finance at a young age.	Adult ER often is busy, lacks SCD expertise, and is discriminatory. Often suspicious of young, potentially "drug seeking" SCD patients.	Responsible for their medical decisions and coordinating work and school disruptions.	Responsible for communicating needs to employers, teachers and professors; caregivers may still help when it involves school.

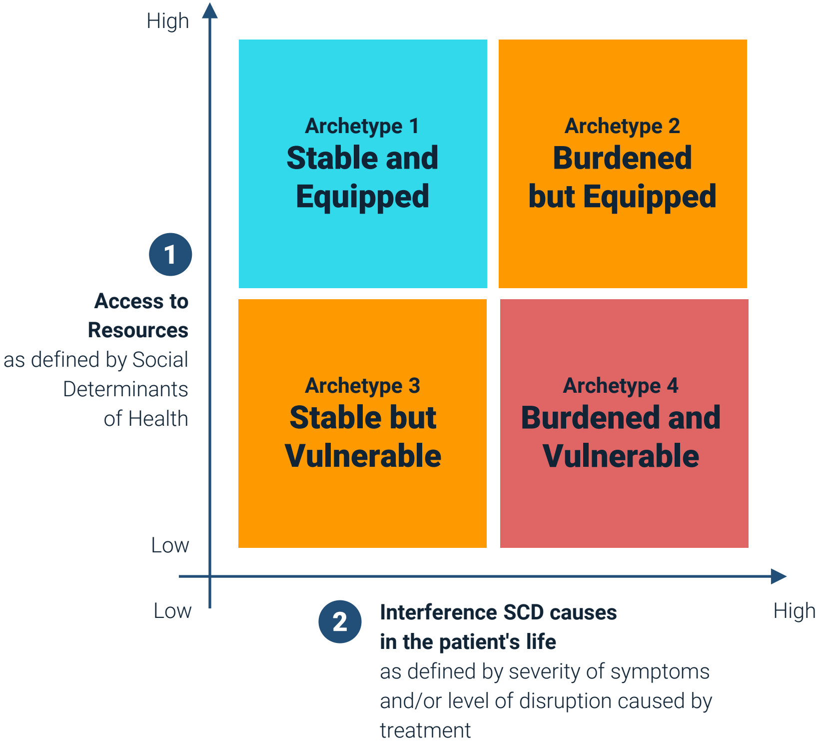
SCD Archetypes

Archetype 1: Stable and Equipped SCD symptoms mostly under control, either through treatment or a mild form of the disease. When crises happen, they have access to resources to help manage other aspects of their lives.
Challenges: Unprepared for serious crisis when it happens.

Archetype 2: Burdened but Equipped SCD symptoms and management take a lot of their time, and they are always trying to find ways to improve it. May be driven to advocacy.
Challenges: Unreliable healthcare; lack of treatment alternatives and care coordination; life interruptions.

Archetype 3: Stable but Vulnerable SCD symptoms are somewhat manageable on a day-to-day basis. But a crisis can snowball into great disruption in other aspects of their lives due to lack of access to resources.
Challenges: Unprepared for serious emergencies; no strategies for care coordination and mitigating stereotyping; poor treatment adherence due to lack of resources; no financial cushion; lack of insurance coverage.

Archetype 4: Burdened and Vulnerable SCD is high-maintenance, a big part of their lives. Lack of access to resources to manage it and pursue treatment makes it impossible for them to function in other areas of their lives.
Challenges: No access to specialized SCD healthcare and treatment options; distrust of healthcare; disempowered to advocate for themselves; poor treatment adherence due to lack of resources; no financial cushion.



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