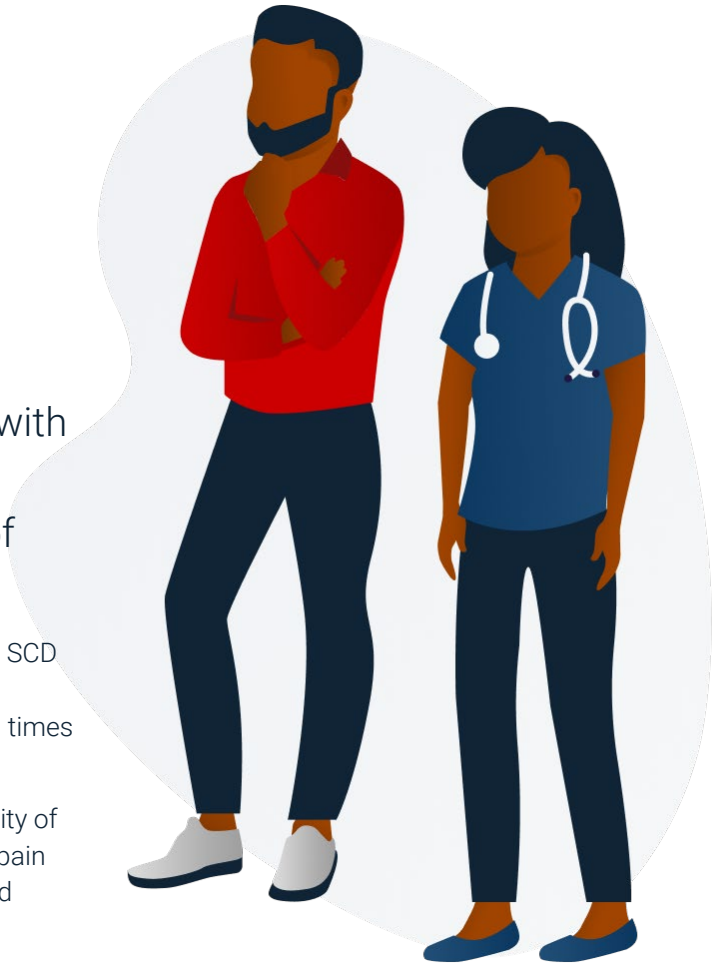
health+ Sickle Cell Disease | CTO | OMH

Human-Centered Design Report

Opportunity Area 3: People with SCD struggle with transition to adulthood (section 4 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

OPPORTUNITY AREA 3

People with SCD struggle with transition to adulthood

Pediatric patients with SCD are serviced by a much more prepared healthcare system, and have caregivers who serve as buffers to the challenges of living with it.

When becoming young adults, people with SCD don't have structures in place to prepare them for the complexity of dealing with the disease. The desire for an independent life and to live like their peers, typical of this life phase, can't be enjoyed because of all the limitations imposed by SCD.

- ➔ Coordinating care independently is challenging
- ➔ Young adults lack understanding on how to secure proper health insurance
- ➔ Lack of responsibilities hand-off from caregiver to young adult patient

"It's different on the adult side, the pediatric side they get everything, it's the adults, they're the ones suffering." - Caregiver

"You start to encounter the discrimination a lot more, because you're not a cute little kid anymore that everybody has empathy for. You're an adult, you're grown and so they change, you receive different treatment." -Patient

Living with SCD as a Child

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

Coordinating Primary Care

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.

Paying for Care

Caregivers handle health coverage and unexpected costs. Often covered by caregivers' Medicaid.

Going to the ER

Children's ER is typically knowledgeable about SCD, not busy, and able to give proper attention.

Hospitalizations

Misses school, caregiver handles care coordination, disrupted family dynamic.

Going to school

Caregivers handle negotiations, protocol with school, and missing classes.

"The school that he's in goes to 8th grade, so his principal there is aware of his sickle cell as are his teachers and he'll be in that same school, it's a private school with a small community, so all of the teachers are aware of him." -Caregiver

"It just got really dicey legally and we actually had a friend that went to jail for her daughter missing too much school for sickle cell even though it was all medically cleared. It was crazy. So we talked about homeschooling her, so did the teacher before and the doctors were like if you're going to home school her you really should homeschool everybody so she doesn't feel bad." -Caregiver

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 and fit in with peers

Coordinating Primary Care

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.

Paying for Care

Lacks knowledge on how to choose insurance, what to look for, when to enroll. Struggles to self-finance at a young age. May lose Medicaid coverage as adult.

Going to the ER

Adult ER often is busy, lacks SCD expertise, and is discriminatory. Often suspicious of young, potentially "drug seeking" SCD patients.

Hospitalizations

Responsible for their medical decisions and coordinating work and school disruptions.

Work and School

Responsible for communicating needs to employers, teachers and professors; caregivers may still help when it involves school.

"Transition age is when you start to encounter the discrimination a lot more, because you're not a cute little kid anymore that everybody has empathy for. You're an adult, you're grown and so they change, you receive different treatment." -Patient

"When I was younger, my parents were the person advocating, but as an adult, I don't think there's anyone better to advocate then myself unless I just can't. I can so I will." -Patient

"We had to walk across this long parking lot to get to the other side of campus, literally, that's where all of the classes were. [...] And this day it was really really cold and I was trying to be a cute young girl. Didn't have a hat on or whatever. [...] I was standing in line and I was like, guys I have to go. And they were like, wait, what's wrong? I'm in pain. I just need to go back upstairs." -Patient

"When I turned 26 last October, I was under the impression that I would be kicked off my parent's insurance at the end of 2019, but I got kicked off their insurance at the end of October and I was scrambling to try to fix that because my insurance didn't kick in until January 1, 2020, [...] I had a doctor's appointment that needed to be covered." -Patient

"There was a certain level of seriousness associated with it too, like you're an adult now and you have to handle things like an adult. You have to be smart about certain things. You have to be truthful, I had to more truthful with my doctor about certain things, for example my parents are sitting there in the doctor's appointment I'm not telling them how I drink and smoke weed and stuff like that." -Patient

"It wasn't until I went to adult doctor that I actually seen that sickle cell patients do live to be adults. As a child, I had never seen another adult patient that had sickle cell. Or no one that was willing to say, yeah I have sickle cell because I know as a child I didn't want people to know I had this disease because they were so harsh." -Patient

Recommendations

- Increased access to community (other patients with SCD), particularly for patients relocating
- Parental educational materials
- Peer-to-peer mentorship program for SCD
- Increased facilitated access to non-healthcare resources, particularly transportation, housing, socio-economic, support
- Education on taking ownership of healthcare for teenagers
- Health insurance options education and assistance
- Increase expansion of Medicaid so young adult patients don't fall out of coverage
- SCD clinician-to-patient education programs (e.g. Diabetes) using nurses, paramedics, social workers, community health workers, CBOs and others
- More integrated care: Proper, reimbursed pediatrician to adult PCP hand-off (medical records, care plan)
- Loosen patient health information privacy restrictions between minor and adult patients
- Special programs for access to novel treatments
- SCD centers modeled after cystic fibrosis and hemophilia centers

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