

Human-Centered Design Report

Opportunity Area 6: SCD care requires complex support networks (section 7 of 9)

& partners | June 2020

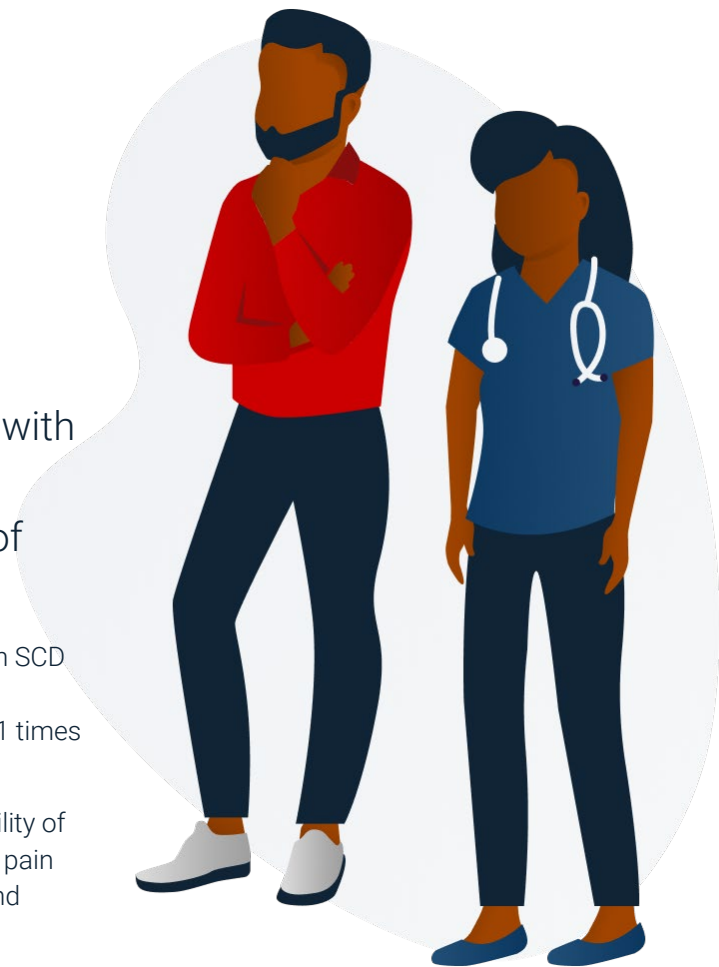


About Health+ Sickle Cell Disease

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

SCD care requires complex support networks

SCD can be high-maintenance. Patients need but hesitate to have to rely on so much help. Support includes help affording treatment, feeling understood, advocacy in the face of discrimination, and getting information about treatment and condition.

- 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

"[I moved from Ohio to be with] my mom, my sisters and brothers, my mom worked from home, so if I was sick, my daughter could go over there. Now my mom helped me raise my daughter so, it was me, my mom and my sisters. They were helping me because me having sickle cell and plus I'm a father I didn't really know how to raise a child by myself, so my mom helped me." -Patient

"There may be times where I may go into a crisis and I can't walk and so I have people who will come and take me to the hospital and not call the ambulance, my brother still come pick me up and put me in the car and take me to the hospital. So I have support when I need, if I need to get back and forth to the hospital or clinic. I can always call on a family member who will pick up my medication and bring it to me if I'm not feeling well or bring me something to eat." -Patient



Family is preferred support—but it's often not available

Due to the high steep learning curve in SCD care, the highly individualized needs of each patient, and stigma, close family tends to fulfill most of the support needs. This is especially true for medical knowledge, advocacy needs, and childcare. Their caregivers as children can continue to help long after they become adults, and a partner or spouse might take over that role.

However, many SCD patients have very limited family support for various reasons. Sometimes family members don't have resources to help or aren't present and available. Worse, sometimes patients have to deal with abusive, unsafe home situations.

Patients often rely on the support of friends, neighbors and co-workers too, but only for less involved tasks: short-term childcare, bringing some food when they're in crisis, covering for them at work, etc. But it's hard for them to open up about their condition and rely more on peripheral support, which causes them to feel more isolated.

"I lived off campus, I had a house with a few of my friends. It was a four bedroom house and it was really nice and big, but once I got home from the hospital, I realized that I couldn't do anything and it was stairs to get in our front door and our back door and our landlord wouldn't even put in a little ramp for me to get in because in the back it was only two stairs to get in the back door into the kitchen. They didn't even want to give me a little ramp, so I ended up calling my mom and I was crying, I said, I can't do this." -Patient

"It's just me and my husband, so we play tag team, if one is in the hospital or there's been time where they both were in the hospital at the same time, we still have other children that we have to care for. And us being in Ohio, we have no family here, it's just us. In Detroit I do have some good friends that step up. [...] [it'd be better] if we had actual family, not friends or people that you grow up with, you say that's family. Actual family, bloodline, if they would step up and participate or at least attempt to get to know what sickle cell is and the things that are the primary focus." -Caregiver



Community-based organizations, social media provide solidarity, education, and services

Community-based organizations (CBOs) and online groups can help patients feel understood, connect around knowledgeable providers and quality SCD healthcare, and form strategies for coping. They also help connect providers with patients so that there's more shared understanding of the disease. Online groups can be particularly helpful to patients who live in areas where SCD is rare, allowing them to connect across geographies. This can be helpful for patients relocating.

Many patients are hesitant to take advantage of these groups, probably due to a sense of privacy over their condition, or not wanting to feel like SCD defines them. Additionally, such groups may not be accessible to all patients.

"I think a lot of it is you have to have a network or a support system. I engage with a lot of other parents by meeting in the community the parents that have children who are older than mine or younger than mine. We tend to do a lot of talking and we are very honest, honest with how it feels." -Caregiver



Patients wish they could be more independent

Patients and caregivers of children often feel guilty over the high amount of support they need with SCD, and the burden it places on their caregivers and advocates. Many adult patients dislike having to rely on the caregivers who looked after them as children, particularly those who don't have a domestic partner to take over that role as those caregivers age.

Many patients expressed that they wished they had the financials to cover for support as a paid service, which would give them more control over the kind of help they need and make them feel more independent.

"And I feel bad everyday because my mom was still going through shingles and she was downstairs." -Patient

"I think about if the support system around me is still going to be around because we are getting older, my mom's getting old, my pop's getting older, so losing the loved ones around me that I have as my support system." -Patient

"[If I had extra money], I would have a nanny. Then I wouldn't have to worry. I could go to the hospital and know that the person, I never thought I would be a nanny person but in this situation a nanny would be really really helpful." - Caregiver

"Right now I'm 40 minutes away from my heart catheterization provider so it gets hard when I'm sick and I need to go to the ER, especially when it's snow storm because Uber can be \$50-70 and of course I can't drive if I'm in pain." -Patient

Recommendations

- Parental educational materials
- School and teacher educational materials
- SCD added as disability on employment forms
- National educational campaign on SCD
- SCD medical records provided on school applications
- More caregiving options and support
- Tools for patients to help educate and discuss SCD with friends and co-workers
- Mental health support for families affected by SCD
- Local resource registry for SCD patients powered by CBO's for patients relocating



health+ Sickle Cell Disease

Sponsored by:



Thanks to Maia Laing, Alexander Wilson, David Wong, Marlene Peters-Lawrence, Dr. James Taylor, Dr. Gentry Wilkerson, Shamonica Wiggins, Jason Hairston (PISTIS), and the CODE team (Temilola Afolabi, Paul Kuhne, Matthew Rumsey, Kristann Orton, Nidhisha Philip, Joel Gurin) for invaluable contributions, feedback, collaboration and support.

Special thanks to all the people (patients, caregivers, advocates, community-based organizations, clinicians, policymakers) who contributed with their time, knowledge, experience, and connections for this project.

Created by  **partners**

Sabrina Fonseca, Michelle Shen, James Hobbs, Kate Murphy, Ashleigh Axios, Eduardo Ortiz.