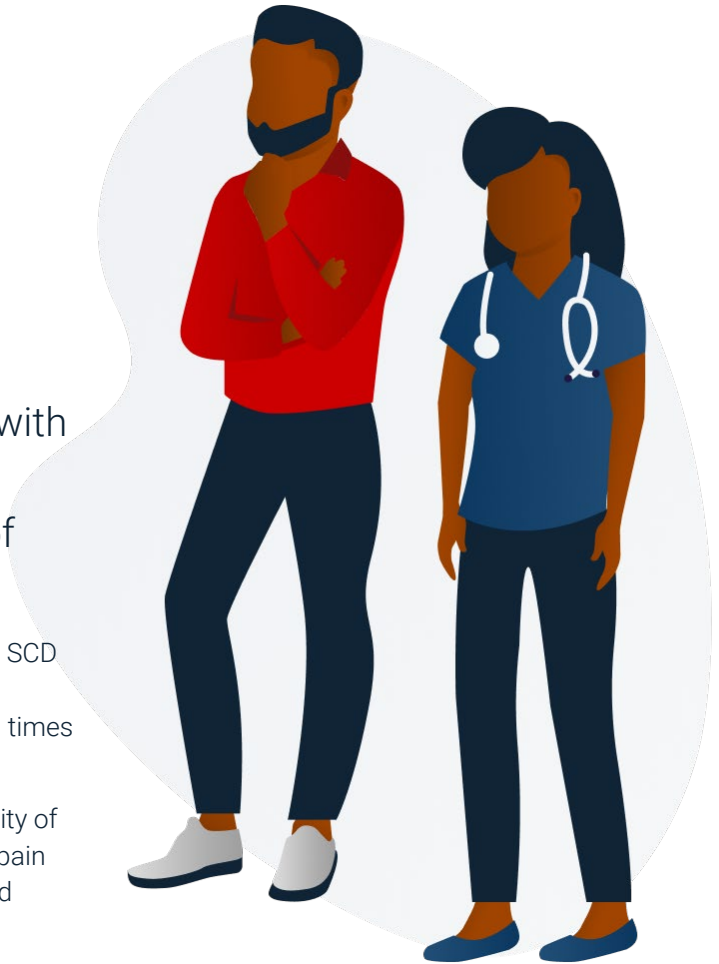
health+ Sickle Cell Disease | CTO Office of the Chief Technology Officer | OMH U.S. Department of Health and Human Services Office of Minority Health

Human-Centered Design Report

Opportunity Area 5: Patients plan their lives around unpredictability of SCD (section 6 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 5

Patients plan their lives around unpredictability of SCD

Patients, particularly those whose condition causes most interference in their lives, planned many aspects of their lives around SCD: making sure they live close to their support network, taking work based on the health insurance available, choosing work that allows for flexible hours, sticking with work that isn't fulfilling but where supervisors are understanding, and considering family planning early on in romantic relationships.

- ➔ 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

"So my work is always driven by the fact that I know that I need good insurance... So I've never pursued entrepreneurial endeavors because I've always known that I need really strong health insurance, because I don't ever want to be in a situation where I get slammed with a bill." -Patient

Emergencies cause emotional trauma in patients and their loved ones

The possibility of sudden demise causes patients and their loved ones to experience trauma when they go to the ER or go through serious hospitalizations.

This results in high anxiety and depression rates in patients, disrupted family dynamics, attempts to control the condition, and frustration when they see it's not possible. Loved ones are affected when caregivers have to neglect other family members and duties to care for the patient.

"I think there was a lot of secondary trauma in my family because of the sickle cell. People didn't have a good understanding of trauma and how it really affects the family until lately. And I think it really affected my family a whole lot on a whole lot of different levels." -Caregiver

"I did research on accessing PTSD, anxiety and depression in caregivers for sickle cell patients and it came from personal experience because I feel like sometimes me and dad, I feel that we are really over." -Caregiver

"I don't feel like kids should be in the room while doctors are having conversations like that with parents. Because we're not equipped to handle what we're hearing... While you're in the hospital fighting for your life and they're telling your parents well, start making arrangements for your child and that's scary as well." -Patient

Patients anticipate emergencies on all occasions

Many patients attempt to over prepare; they constantly take precautions to avoid crises, and create many safeguards in anticipation of them.

- Travel: Respondents reported not traveling in fear of not accessing the ER, doing blood transfusions before travel to avoid crises, and creating flexible travel plans in case it happens.
- Weather: Patients fear and respect it, planning their day around the weather forecast. Some respondents reported moving to better climates to decrease number of crises.
- Hydration: Patients drink copious amounts of water all the time, and go out of their way to keep hydrated.

"I always kept the house at a certain temperature. In the summer, I didn't care about them going outside but I tried not to have them go outside when it was really really hot in that sun. I kept the fluids pushed. We always kept popsicles and a lot of Gatorade and water bottles and stuff like that because the doctor always told me to push the fluids." -Caregiver

"It took me 9 months to a year to plan for that trip. And I think that's the first time that I realized that I did not live in mainstream society... I had to find out where the hospitals were, if there were any sickle cell clinics in it. We had to make sure that we took the letter from the physician saying what to do, if he went into a crisis" -Caregiver

"It impacts how you travel. We only ever fly Southwest because I can change my ticket with Southwest without incurring fees. I can't buy a non-refundable airplane ticket because I know there's a really high chance, we've had twice now that we had to change tickets for trips because he got sick right before the trip and he's been hospitalized when we were supposed to be flying out." -Caregiver

"Invisible disease": isolation, stigma, and lack of understanding at work and school

SCD is an "invisible disease"; patients look healthy from the outside even if they're in crisis. They suffer from widespread lack of understanding of the disease and how it affects them. They can be perceived as slow or lazy when a crisis hits, and they need to pace themselves. They react by either ignoring their symptoms (which can aggravate the state of their health), advocating for themselves by noting disability laws and regulations, or taking on the labor of educating others. When those efforts are met with more isolation and stigma, disempowered patients are often forced to withdraw and look for alternatives.

"Suffering a stroke at that age, I was only in second or third grade, so when I went back to school, the kids and even some of the adults just were looking at me like crazy. It was like I went from being myself to being some kind of alien and I had to deal with a lot of bullying." -Patient

"And I can't work because I go through discrimination because I'm out sick a lot. And then sometimes the stress of the job triggers my sickle cell where I can't work at all so that's just depressing because then if there is a question of how do you take care of your family at this point?" -Patient

"I know they have protocols and they have procedures, but I felt that once I disclosed that, I felt that there was a target on my back personally. But when I was let go, I wasn't upset, I think I just said, you know my son is more important than any job." -Caregiver

"I'll overcompensate to prevent that stigma from being perpetuated. [...] As many times as I've been to the ER, I wouldn't have been admitted, I wouldn't get my prescription filled afterwards is because I don't want them to think that I'm looking for that benefit. [...] I'll tell myself, I'll just go home and get back to the Extra Strength Tylenols or whatever I can to help myself, rather than taking some of the heavy pain pills there that they may offer." -Patient

Patients plan careers and even relocate to maximize access to SCD support

Patients want employment and school options that fit their unique needs and understand their condition. They will choose employment and colleges to maximize healthcare, considering location, quality of SCD clinic, insurance, how understanding their co-workers are, and schedule flexibility in case of unpredictable crises.

"I had a support system in Cleveland, my mom, my sisters, my brothers, but now all my sisters and brother are of age, my brother went to the Army, one of my sisters ent to the college, one of my sisters moved to South Carolina and my mother moved to South Carolina, so I didn't really have no one and then plus, on top of that, I felt in Cleveland I was getting sick too much, in and out of the hospital every other week and I didn't have nobody to help me with my daughter like I used to have. [...] I was originally going to move to South Carolina or Tennessee with my family and I chose Tennessee." -Patient

"I get disability and that's barely enough to pay the rent, but somehow you have to figure out how to live." -Patient

"When you receive an SSI, if I get a job, they take the SSI away from me and as far as that, if I get a job, with me having sickle cell depending on what it is I'm doing, I can get sick. Everybody is not understanding. I can get fired. So they take my check, I get a job, I work, get sick, get fired, and I just have nothing. And now I'm struggling with raising my daughter with nothing." -Patient

Recommendations

- School and teacher educational materials
- Increased facilitated access to non-healthcare resources, particularly transportation, housing, socio-economic, support
- SCD added as disability on employment forms
- Patient-to-patient mentorship program for SCD
- National educational campaign on SCD
- SCD medical records provided on school applications
- Tools for patients to help educate and discuss SCD with friends and co-workers
- Increased access to legal help (labor, school truancy, discrimination etc.)
- Work options with flexible hours
- Mental health support for families affected by SCD
- Labor law reform to support paid sick leave and job security

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.