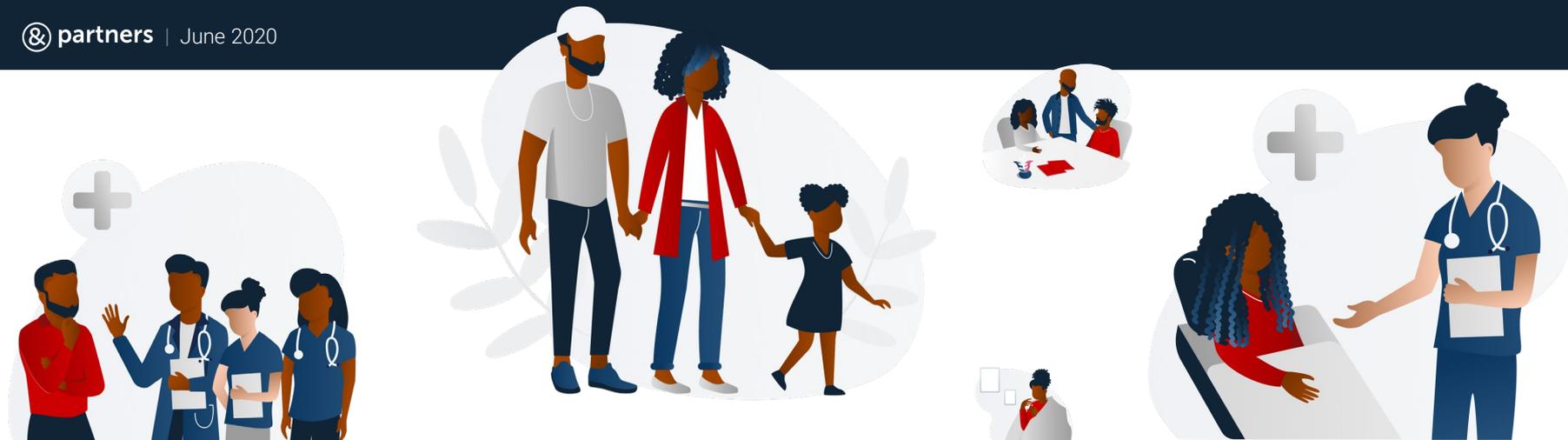


Human-Centered Design Report

Opportunity Area 4: "Trial and Error": Patients bear the burden of individualizing their care plan (section 5 of 9)

& partners | June 2020

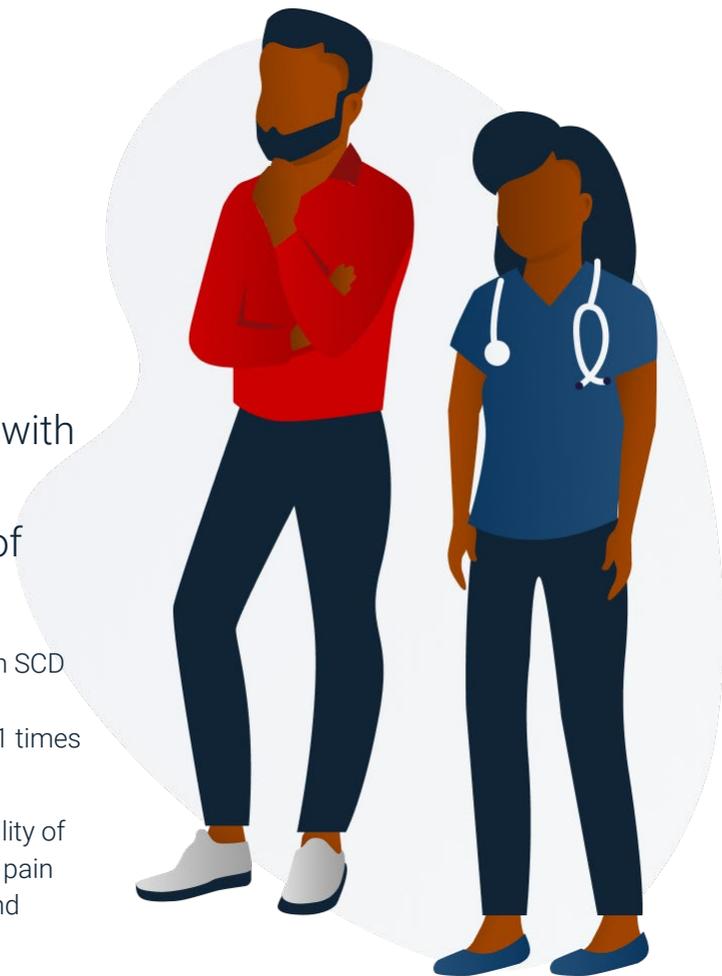


About Health+ Sickle Cell Disease

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

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

SCD has different effects and symptoms in each patient. Patients typically know this well, but providers are unable to devote time and energy to personalizing a treatment plan for their complex needs.

Frustrated with symptoms that only get worse, treatments that either don't work or have strong side effects or both, failing precautions, and aloof, uninformed healthcare providers, patients often resort to devising their own 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

"We try to tell doctors that my counts do not reflect the pain that I'm in when I go into a sickle cell crisis. They don't like to treat us individually, they want to put us all in a box and it's not going to work because no two people with Sickle Cell Disease are alike." -Patient

"I get the cough drops, the elderberry cough drops and that works just as well. Just trial and error, this is all due to me, I've only been involved in the sickle cell world for 5 going on 6 years. So this is still kind of, there's always some type of event that's going on or taking place." -Caregiver



Traumatic events are triggers to learn

Many people with SCD started taking time to learn more about their condition following a traumatic unexpected event, such as a serious hospitalization for the first time or first after several years without any. Many of them expressed frustration over not having been properly educated on the possible consequences of SCD, feeling that the serious event could've been avoided in some way. Conversely, some expressed trauma over hearing about low life expectancies and other possible ramifications of the disease.

People with SCD desire to have proactive, constructive, and preventative guidance on SCD so they can avoid health complications. Providers often don't have the time to give that education, and there aren't many readily available resources—patients often have to dig through them.

"I had to be feared to get educated. So something had to happen to me so badly that I had to get educated for it" -Patient

"You start hearing people pass away and stuff and this happens and this happens, so it just makes you want to know what's really going on and the complications and everything so I just started reading more." -Patient



Non-prescribed treatments are a common recourse

Many patients, frustrated with limited pharmaceutical options for SCD, pursue supplements, diet changes, or cannabis as treatment alternatives. 6 respondents brought up such self-started regimens, with 3 of those having such severe SCD that they had considered a bone marrow transplant at some point. They were often driven to pursue alternatives after trying or being offered aggressive or invasive treatment. Some found these alternative treatments using sources unrelated to SCD, and all reported some level of improvement.

Facebook group activity also shows that some patients are forced to resort to street opioids when the healthcare system fails to provide the opioid treatment they need. They acknowledge that there's high risk in doing this, but having to face a long ER wait time could be worse.

"I prefer, I'm into more the holistic treatments. I was leaning towards that more than the medical end of it, the natural end. Because if you look at back in times before man made laboratory diseases and any time of disease when they had any type of problems there was always natural elements of the earth, herbs and roots and stuff like that. That's what the ancestors used so it would be none of this chemicals that they're using now, modern medicines." -Patient

"Over the last year since I have changed my eating habits, I was able to have pain free days. I have more energy now, but before I went vegan I was on pain medicine like crazy, in and out of the hospital monthly, sometime every other week. I was struggling. I never intended to go vegan until I started researching a bunch of stuff. I intended to do a detox, to detox some of the toxins out of my body from all the medication that I was putting in my body." -Patient



Patients develop communication strategies to get needs met from providers

Anticipating drug seeking bias, patients often consider how they are being perceived by providers, particularly in ER, and modulate their communication accordingly. Under intense pain, they are often forced to communicate in a calm manner, convey that they're educated, bring someone to communicate and advocate on their behalf, and call their primary care providers in advance to let them know they're coming to the ER. This is all in an effort to gain empathy, show that they are worth caring for, and that they aren't lying.

"And so you have this gap of extreme pain and you can't really, you don't want to just spaz out, because you need to stay calm for yourself and when you're staying calm that can be seen as you not being in as severe pain as you are." -Patient

"[on facing suspicion from providers] By now you're reading a resume because you want to break that thing. [...] So now you're like 'I'm a sophomore, I'm in university, a law student.' So you establish credibility. [...] It's the politics of it, I know I have to navigate this, I have to stay calm, speak like this, because if you express any degree of anger... [...] I know in that moment that hysteria isn't going to work for me, losing it isn't going to work for me. I'm assessing you and going 'what is going to translate to this person?'. I have to figure out something in you to connect with, either your intellect, your emotions. Something that is going to resonate with you that I'm not a junkie." -Patient



Patients develop complex financial and health insurance tactics to cover care

All respondents but two had some kind of insurance coverage. Most were knowledgeable about it, with the exception of those going through transition to adulthood. Many devised a combination of separate insurances to be able to cover more of the cost. These strategies were necessary to avoid high costs and the risk of not getting the care they needed.

"Now I am with a private insurance through my husband's job and I still have the Medicare but it's only part A and part A is the one that covers your hospital stays, but when you get married you lose part B and you lose part C if you have it and that's the one that pays for your prescriptions and your doctor visits and all that stuff, but thank God my husband, his job was able to let me be signed on to their plan, so I might have lost part B and part C, but his insurance kicked in so I'm still able to get my prescriptions and I'm still able to get my medications and be seen by the doctors as much as I need to." -Patient

"20% times four times per month, what's the math, 4.3 times 12. Think about that on an annual basis. So that 20%, we've been very fortunate to have a great secondary and actually we changing secondaries when the premium got too high so we were fortunate there and then when she got on kidney dialysis through the grace of God, the kidney foundation pays her premium for her secondary. [...] All the expenses, I take care of everything. Just for myself, just last year I reduced my premium almost \$50 a month on my supplemental. You got to shop and those are the things you got to do." -Caregiver

Recommendations

- Increased access to community (other patients with SCD), particularly for patients relocating
- Parental educational materials
- Patient-to-patient mentorship program for SCD
- Education on taking ownership of healthcare for teenagers
- Increased facilitated access to non-healthcare resources, particularly transportation, housing, socio-economic, support
- National educational campaign on SCD
- SCD clinician-to-patient education programs (e.g. Diabetes)
- Individualized care plans for SCD
- Clinician support for patients around diet changes and supplements for SCD control
- Increased ownership of health data by patient



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