

Human-Centered Design Report

Opportunity Area 2: ER is a last resort for patients (section 3 of 9)

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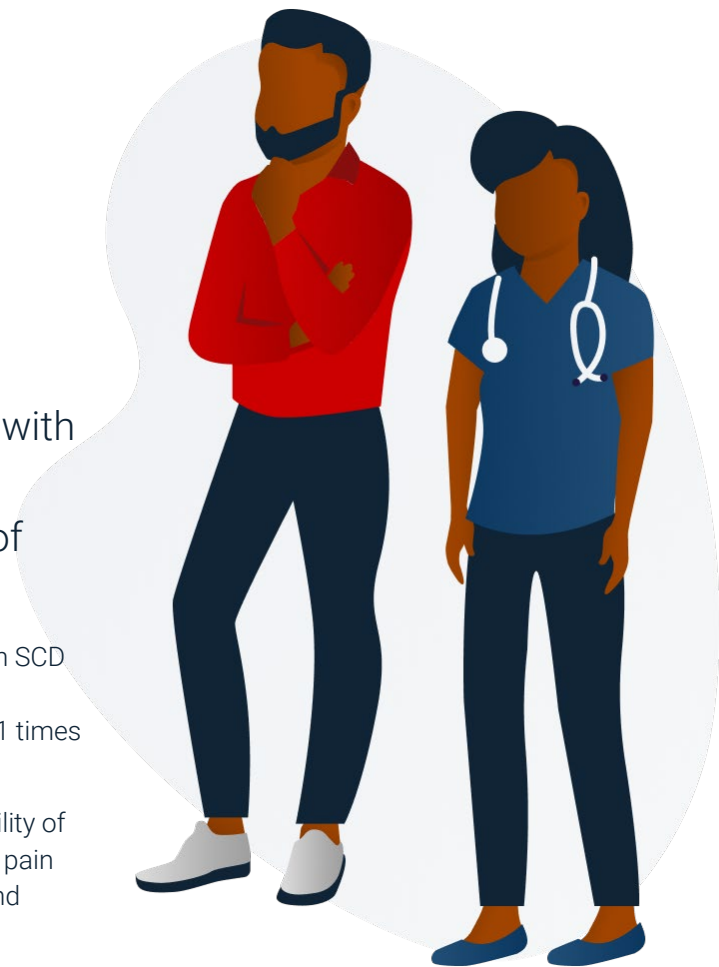


About Health+ Sickle Cell Disease

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 2

ER is a last resort for SCD patients

Patients avoid ER visits at all costs, even if it's a life risk. Most ERs aren't familiar with recommended SCD protocols where patients are high priority, pain management is sufficient and aggressive, and testing is appropriate. This forces patients to devise strategies when they can't delay a visit to the ER any longer. The following journey describes the barriers at each step of the way.

- Patients fear being accused of drug seeking
- ERs often aren't familiar with SCD protocols
- Adult ERs are busy, with long wait times

"I hate going to the emergency room. They don't even have a protocol for sickle cell, so you're waiting along with everyone else and your pain is increasing and then it makes it even worse because you're not getting the treatment that you need to be getting. On top of that, [...] because you're so educated on your own sickle cell and how it affects you and what works for you, they label you as a drug addict and then you have to go through the whole process of trying to explain to them that I'm not a drug addict. This is what it is. I'm not a regular. Call my doctor. It's like I'm fighting for myself and advocating for myself. There's been times where they refused to treat me. [...] That's the reason why my grandmother and my aunt died, because there was so many doctors that were uneducated and didn't really know how to treat sickle cell and that's why they passed away. One hospital over medicated them and then another hospital didn't do anything at all because they didn't know." -Patient

The ER Journey



Avoids and fears ER

Anticipates bias and lack of knowledge at ER
Needs support in case of hospitalization

Long wait times

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

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

Discrimination from medical team
Discharge without treatment
Insufficient pain management

Lack of SCD knowledge

Hospitalize Patient

Discrimination from medical team
Discharge without treatment

Insufficient pain management
Lack of SCD knowledge

CMS doesn't cover readmissions within 30 days of hospitalizations

Crisis Onset

Patient feels pain crisis symptoms

"Sometimes I am frustrated. Sometimes the pain is too much, that's the reason people want to die. Sometimes I'm really discouraged, I'm not going to lie. Sometimes I'm frustrated because the pain, you will be doing something, I will be so happy and the pain just strikes you like that. So it's so frustrating. I'm going to try my coping and really try." -Patient

Tries to manage crisis at home

"Once you learn how to manage pain, you learn how to mix your Tylenol and Advil, [...] mix in any opioids that you may have been given at home. [...] You don't always have to go to the emergency room." -Patient

"I do whatever I can do to avoid going to hospital. I think that is my ultimate resort if I cannot manage it myself or at home." -Patient

Crisis isn't getting better over time

"The avoidance is mostly based on just knowing that you're going to be there for awhile and that's going to change your overall day to day routine, but not just yours, your entire family's routine and just the changes in dynamic that that cause." -Caregiver

Decides it's time to go to the ER

"When my pain medicine at home is not working and I have done everything I could possibly do [...], you know it's time to go. If you catch it early you can keep a lot of the long hospital stays to a medium, it won't be so long, but if you wait around, it could be bad. [...] Once you start to flare, that means the oxygen is not flowing to veins well and then you have to worry about your organs, not getting the proper blood flow." -Patient

BARRIERS



Unpredictability of onset



Interruption of daily life

Prolonged crisis can cause organ damage



Lack of protection on school and work status



Possible lack of preventative treatment



Possible lack of preventative treatment

Preparing for the ER

Patient identifies the most "familiar" ER to go

"I go to a place out here, [...] they have a great protocol for sickle cell carriers. I live closer to two major hospitals that I visited and I've had nothing but bad experiences at those facilities, so I go where I know I'm going to get the best treatment." -Patient

Plans to be away for a while, in case of a hospitalization

"I keep a go bag for my daughter. I keep a go bag for myself. [It] consists of extra underwear, extra clothing, my toothbrush, toothpaste, all the little personal things that you need when you go to the hospital that someone's not going to be able to bring it to you." -Patient

Solicits advocates

"Because they can see that there are people present in your life that care about your well being. I've just learned that." -Patient

"Normally I will try to call my doctor so she can give them the heads up that I'm coming in. Sometimes that helps, but it's not always the case." -Patient

Goes to the ER

"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. [...] I can't drive if I'm in pain." -Patient

BARRIERS



Lack of SCD protocol in most ERs



Last-minute planning family, school, work

Planning while pain intensifies



Inability to access primary care providers

Securing an available advocate



ER provider may have no access to patient's medical records



Lack of transportation options due to pain and access

Arriving at the ER

Patient checks in

"[Location 1] has this process where if a patient comes in to the ER, you tell them immediately, I have a sickle cell patient, they have a fever. [...] They jump the line from everybody else and they take them back immediately, start them on IV, they take them to triage. Whereas here in [Location 2], they're sitting in the ER for a long time and being subjected to other possible infections." -Caregiver

Gets triaged, considered low priority

"Current NHLBI guidelines state that anybody with severe pain should be triaged as an ESI category of 2. [...] So cardiac arrest is a 1, stroke, active stroke is a 1. Somebody that's pretty sick is a 2. Most of our patients, sickle cell or not, present with severe pain, [...] so we actually don't assign an ESI of 2 to these patients which then means they can wait in waiting room for quite a while." -ER Provider

Waits long time to see a provider due to low priority, lack of beds

"If you go to the ER and they're packed and don't have any beds, you're in the waiting room just hurting until they call your name. However, it should be written and told to all that if a sickle cell patient comes to the ER we should be seen right away. [...] Unfortunately sometimes you may be in the waiting room 4-5 hours." -Patient

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Lack of SCD protocol in most ERs

SCD knowledge varies across ER providers



Nurses unfamiliar with SCD protocols



Long wait times

Increasing physical pain; emotional pain for not getting help



Lack of proper prioritization SCD patients (ESI category)

Lack of ER beds

ER Evaluation

Patient faces bias, lack of SCD expertise from ER provider

"My doctor will follow up and call them and talk to them, but sometimes they still don't want to hear it because they feel like they're the doctor in charge at that moment, so it's difficult, but it's life." -Patient

"When I get admitted and I ask for the IV Benadryl I've had doctors tell me, oh well you only want it to get that rush or to feel high." -Patient

Patient undergoes tests, often not appropriate for their SCD

"They have to run labs and they have to get the results of the labs, [...] they won't let you show up and say you're in pain and give opioids. They have to look at what's going on to determine whether or not they believe that you're having a pain crisis and then they'll start to issue opioids. So what they might give you before is something super low." -Patient

Patient waits for test results to receive pain management

"They should give [analgesia] right way because there's no test that's going to prove pain or no pain. We just cannot rule in or rule out pain. So we really instruct our providers to assume that the patient's telling the truth and treat their pain unless there is overwhelming evidence to the contrary." -ER Provider

Stay In ER

Upon test results, provider decides on a course of treatment

Hospitalize patient

BARRIERS



Fear of being perceived as difficult, not being believed or taken seriously

Ability to cope with pain perceived as absence of pain



No access to full medical records

Lack of SCD knowledge

Disregards PCP instructions over fear of liability (this is "their" patient now)

Pain can't be measured, often ignored



Lacks knowledge of SCD testing

Fear of liability due to opioid crisis

Disease can't be confirmed via tests in ER, only trait



Pain management not prescribed or insufficient



Opioid crisis policies punish providers for excess prescriptions (excludes SCD, but not all providers know this)



Delays pain management to after test results for no reason

Unable to provide sufficiently aggressive pain management

Unaware about how SCD types affect test results differently



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



Hospitalization may result in extensive life disruption (work, child care, etc.)

If provider decides patient can be stabilized in the ER...

Stay in ER

Patient receives insufficient pain management

"You may tell them you know Dilaudid is what works for me and they say I'm not allowed to give Dilaudid here in the ER. If you need Dilaudid you have to get admitted into the hospital and on the hospital's floor then they will be able to monitor Dilaudid, but they can't do that in the emergency room." -Patient

Gets discharged while possibly still sick and in pain

"I know people can be discharged and it's still unclear to you what you need." -Patient

Goes home or looks for another ER

"I just wanted to be treated and just be able to go home and rest and I felt like I wasted my time and I should have just gone to my hospital. [...] I came home and I just doctored myself at home." -Patient

"The doctor gave me two of the medications and says, okay you can go home now. And I'm like, you haven't even figured out what's wrong with me or said anything so then I leave that hospital, go home and then go to a hospital in [another town]." -Patient

BARRIERS



Still in pain, not enough opioids



Delay in providing pain management

Lack of familiarity with high dosage required for SCD patients

Adequate pain management deferred to hospital care



Failure to provide clear next steps following discharge

No billing codes for patient education

Failure to follow up with PCP on ED visit



Patient may not be fully recovered



Insufficient SCD care causes readmissions

If provider decides to hospitalize the patient...

Hospitalize patient

Patient waits for bed in inpatient care

"I was transferred to the hospital. Because of my sickle cell they wanted to rule out with 100% knowing that it wasn't a stroke." -Patient

"In an ideal hospital I decide I'm going to admit a patient and I click a button and they go right upstairs to a bed. But that doesn't happen here. I'll make that decision, but they may stay in the emergency department for another day or two until a bed is available." -ER Provider

Receives possibly insufficient care and pain management

"I had a couple of big hospitalizations. I caught pneumonia, I don't even remember what year it was, it was a while back. They said I almost died. [...] I don't even remember the hospital stay because I was so out of it [...] I remember one time waking up they were doing a full body blood exchange. And then I was in the ICU." -Patient

Patient is discharged while possibly still sick

"I've been to one hospital in Pennsylvania which was a bad experience because they let me go early because they didn't know nothing about sickle cell and I was let go and went back that same night." -Patient

"He was in the hospital [in Texas] for a week and they barely did anything to help him. [...] He literally left the hospital against medical advice and took a 4 hour bus ride to southern California where he knew the UCLA medical center would treat him better because he'd been there before." -Patient

BARRIERS



Lack of sufficient hospital beds

Care transition between ER and inpatient requires transfer and creation of orders, causing delays



Risk of hospital infections



Insufficient care by specialists lacking SCD knowledge



Insufficient SCD care causes readmissions



CMS doesn't cover readmissions within 30 days of hospitalizations

Recommendations

- Increased access to primary care/preventative care
- Individualized care plans for SCD, including recommended analgesia
- More alternatives to ED and hospitals:
 - Day hospital for uncomplicated pain
 - SCD-educated urgent care facilities
 - Infusion clinics
- Standard, quick diagnosis for SCD
- Provider Education:
 - Provider-to-provider mentorship program for SCD
 - Earlier, aggressive analgesia in the ER
 - Patient-to-clinician working sessions to increase empathy and trust
 - Drug addiction and race bias training
 - SCD is a special case with different needs in terms of opioid addiction policing
- Disseminate existing ER standard of care protocols for SCD, especially in non-urban areas
- Official ER SCD clinical decision support tool (e.g. BART charts)



Recommendations (cont.)

- Improved ways of concisely capturing pain management plans, care plans and continuity of care plans across Health IT systems, healthcare facilities and organizations, geographic locations and states
- Increased access to holistic care
- Revisit CMS coverage rules stating that CMS won't cover readmissions within 30 days of a hospitalization
- Increased ability to respond to recidivism with healthcare and non-healthcare resources for housing, transportation, financial aid, health insurance coverage and more, using social workers, community health workers, CBOs and more
- Increased access to healthcare insurance to increase preventative care access—and avoid ER visits



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