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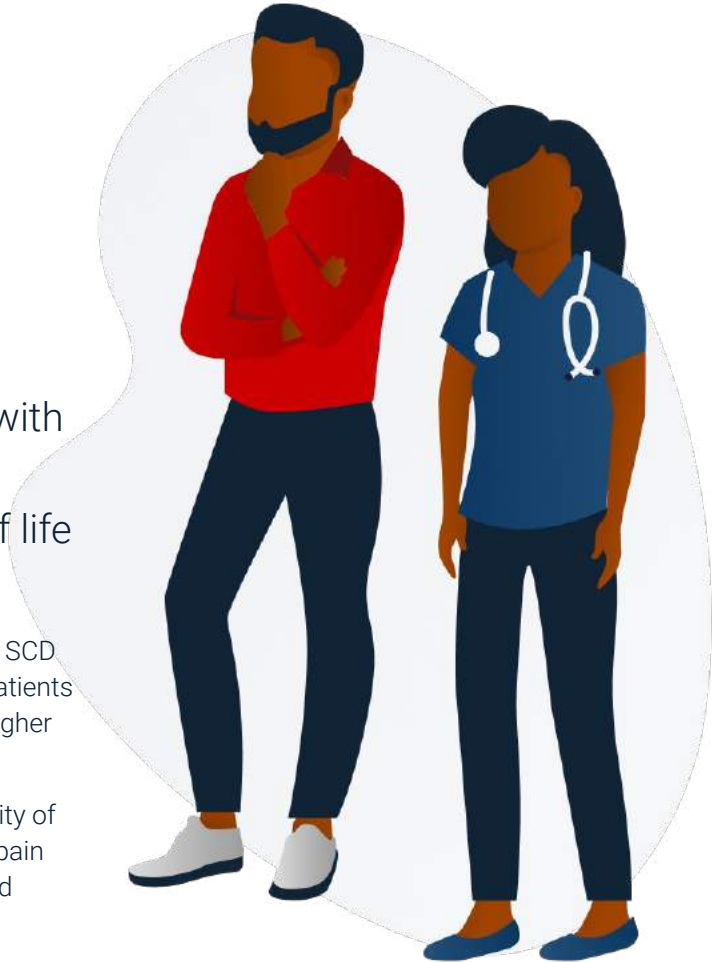
Human-Centered Design Report

coforma | 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.

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Human-Centered Design Report

Executive Summary (section 1 of 9)

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Executive Summary

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

The ER Journey

1. Living with SCD as a Child

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

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.

Caregivers handle health coverage and unexpected costs.

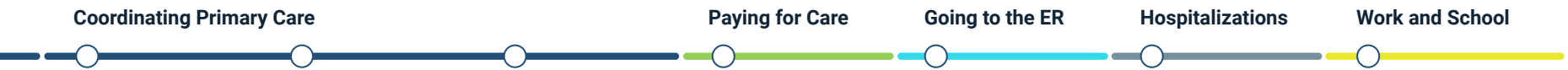
Children's ER is typically knowledgeable about SCD, not busy, and able to give proper attention.

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

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

2. 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.



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.

Lacks knowledge on how to choose insurance, what to look for, when to enroll. Struggles to self-finance at a young age.

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

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

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

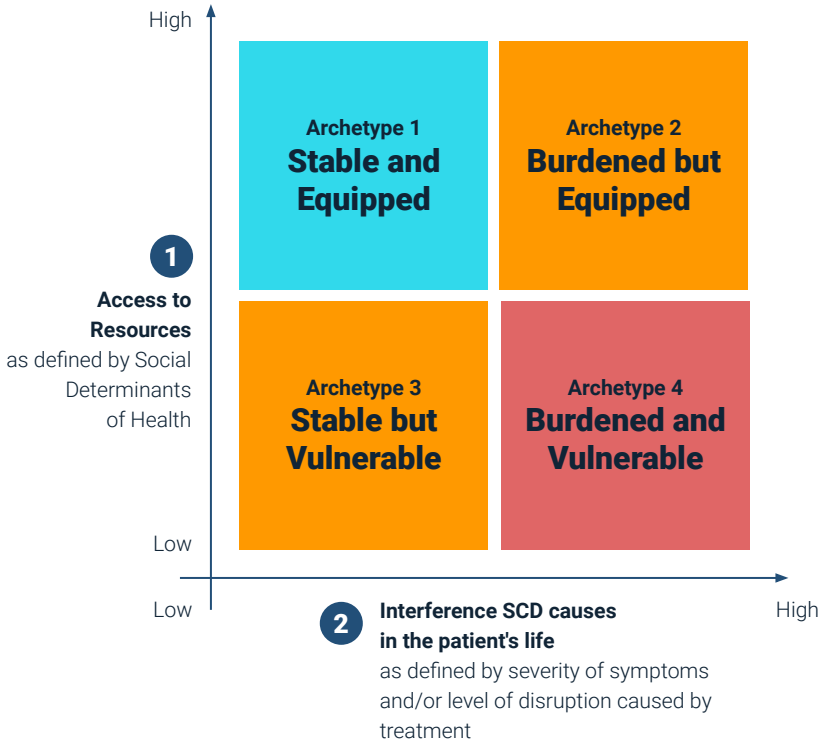
SCD Archetypes

Archetype 1: Stable and Equipped SCD symptoms mostly under control, either through treatment or a mild form of the disease. When crises happen, they have access to resources to help manage other aspects of their lives.
Challenges: Unprepared for serious crisis when it happens.

Archetype 2: Burdened but Equipped SCD symptoms and management take a lot of their time, and they are always trying to find ways to improve it. May be driven to advocacy.
Challenges: Unreliable healthcare; lack of treatment alternatives and care coordination; life interruptions.

Archetype 3: Stable but Vulnerable SCD symptoms are somewhat manageable on a day-to-day basis. But a crisis can snowball into great disruption in other aspects of their lives due to lack of access to resources.
Challenges: Unprepared for serious emergencies; no strategies for care coordination and mitigating stereotyping; poor treatment adherence due to lack of resources; no financial cushion; lack of insurance coverage.

Archetype 4: Burdened and Vulnerable SCD is high-maintenance, a big part of their lives. Lack of access to resources to manage it and pursue treatment makes it impossible for them to function in other areas of their lives.
Challenges: No access to specialized SCD healthcare and treatment options; distrust of healthcare; disempowered to advocate for themselves; poor treatment adherence due to lack of resources; no financial cushion.



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Human-Centered Design Report

Opportunity Area 1: SCD care is difficult to access (section 2 of 9)

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Opportunity Areas

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

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OPPORTUNITY AREA 1

SCD care is difficult to access

SCD care is compromised by lack of treatment options, infrastructure, knowledgeable providers, and empathy in healthcare. This leads to high distrust in healthcare from patients, which can result in poor relationships with providers, poor treatment compliance, and even withdrawal from the system. The disconnect of primary care can result in increased ER visits and hospitalizations, which can be traumatic, costly, and dangerous for the health of the patient.

- ➔ 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

"But then you have all these specialties and all these specialists and everything for cancer or they want to do this for HIV, but why not sickle cell. Why is there so much discrimination or stigma tied to sickle cell disease? One of the first blood diseases, why?" -Patient

Healthcare lacks proper provider training, specialized clinics, and non-opioid treatments

Multiple factors affect this issue:

- Most adult care isn't equipped to provide proper SCD care due to lack of knowledge—it's considered a rare disease but it affects specific communities disproportionately.
- SCD care requires extensive resources, such as infusion centers and hospital beds, but there aren't enough to service all patients.
- Knowledgeable providers are rare, hard to find, and hard to secure.
- Most treatment options for SCD, especially curative options, are very aggressive, and mostly available only to children and youth.
- SCD treatment requires multiple specialties to collaborate, particularly when there are other health issues in place. But siloed traditional healthcare models and lack of payment for care coordination time stop this collaboration from happening. This creates barriers for medical record-keeping and proper medical plan decision-making.

"Showing up at the emergency room and telling the different ER physicians, hey I have a sinus infection that's triggering my crisis, it was like telling them that I was the Easter bunny because no one believed that a sinus infection could throw me into crisis." -Patient

"With other places and other hospitals [other than Johns Hopkins], especially in predominantly white communities, they don't even know what this disease is. They don't know how to treat it." -Patient

"My guess is, a general hematologist/oncology practice in a private practice setting probably wouldn't know about these things. I know about the drugs, either my center's been involved [...]. To get physicians to prescribe their drug, the physicians have to know about the drug. [Pharma companies] know that there's a market out there, so they're promoting summits on access to care for Sickle Cell Disease and promoting the model that you should be cared for in a specialty center because it's a rare disease. They're making sure that the physicians who deliver this type of specialty care know about their drug and that more patients will come to see us because their bottom line is, they want to sell the drug. And that is also $10,000 a month." -Provider from SCD program

Patients are stigmatized as drug seekers in healthcare

The most common and recommended pain management for SCD relies on opioids, which patients often have to use for many years on a regular basis. This extended use builds tolerance in patients, who need them at higher dosage over time to be able to properly control their pain crises. Many providers are not aware of this aspect of SCD, especially in ER and adult care, and confuse appropriate opioid usage for SCD pain management with opioid addiction.

A race bias often affects providers' perception of SCD patients, causing them to not believe the patient's pain levels and intention. This suspicion can result in patients distrusting providers and avoiding the healthcare system altogether unless there's an emergency.

In addition, providers often fear prescribing opioids due to strict regulations meant to address the opioid crisis, and are not aware that patients with SCD are exempt from those regulations. This causes patients to have insufficient access to life-saving pain management.

"There are so many providers that are hesitant to administer pain medication, but especially to members of the black community because the automatic stigma that we're drug addicts or drug users, just here to get your fix, which is a terrible thing. But even outside of sickle cell, you got a black woman dying in childbirth because they're not taking their issues as seriously. So that's always been a thing."
-Patient

"I think she was going to give me morphine, I was like, no don't give me that. Morphine does not work at all. It has to be dilaudid, at the time, they were giving me and she made a comment like you're carrying on like you're a junkie, like you're a fiend." -Patient

"Patients have a hard time in the emergency department for a variety of reasons including there can be really long wait times, there's no objective measurement that you can to prove that they're in a vaso-occlusive crisis, so people don't believe them often and think that they're just interested in drug seeking and that's why they're in the emergency department and there are a lot of negative stereotypes around these patients who are predominately patients of color, obviously. And so they've just had really bad experiences with ED providers in the past and have a lot of mistrust. [...] Providers are worried about providing opioids pain medications in the context of the opioids crisis, but they understand that patient need it, but then they're never sure which patients need it or if there's a possibility that there's diversion." -Nurse

Access to treatment is compromised by barriers to primary care and cost

Primary care is hard to access in the United States, as it commonly requires patients to provide proof of insurance or ability to pay. Because of this, patients with SCD are forced to skip it and end up going to the ER often, where providers are mandated to provide care to all regardless of payment (Emergency Medical Treatment and Labor Act, also known as EMTALA). ER care doesn't provide preventative treatment, which could improve these patients' conditions.

When patients do access primary care, most treatment options are new and costly. They're often not covered by insurance. Some pharmaceutical options can cost up to $100k/year.

Underemployed patients ineligible to Medicaid (often the case outside of Medicaid expansion states) are especially affected. Paired with their lack of financial and support resources, quickly snowballs health crises into life crises.

"DC Medicaid follows about 600 adult sickle cell patients and they spend $71 million a year, at least I think those were the numbers from 2016 or 17. [...] Of those 600 patients only 15% are on hydroxyurea. So that works out to about $120,000 per patient, but most of that cost is ER visits and hospitalizations. I'm cheap to see and nobody wants to reimburse me very much, but when you're dealing with numbers like that, I think even at that price, it's probably cost effective or at least cost neutral and if you want to go a step further, I think that the human cost of Sickle Cell Disease is even greater and I think that's not easy to quantify. [...] I would argue for other diseases we're spending that money all the time. For equally severe diseases. I don't want to prioritize diseases, but this is just one we left behind and we're spending the money in the wrong places." -Provider from SCD program

Patients are often skeptical of healthcare providers

Patients trust in healthcare may be compromised:

- When providers express lack of trust in the patient and/or stigmatize them
- When providers ignore the patient's input when designing their care plan
- When providers express lack of knowledge based on what the patient knows about SCD
- When they try treatments that fail or that have side effects, and the provider fails to offer more alternatives

This can compromise their engagement with healthcare, which can lead to more ER visits and hospitalizations as SCD is left untreated.

"He was yelling at my while I was in crisis, if you do not start the hydroxyurea I will not prescribe you any more pain medications." -Patient

"Here they really don't know what to do. So I be there and they have to figure out what to do and then they get you medicines that don't work and admit me to the hospital and then when I'm in the hospital they don't know how to treat me when I'm in the hospital, so it's basically real different down here. So that's why I feel that I really need a hematologist down here." -Patient

"I refuse to go there, I call it the intern hospital because all the interns, all the fresh out of the medical school, that's where they go and get their hours and they intern, so you have all these young kids that don't know shit, but they don't know shit about the disease and they're experimenting." -Patient

"I'm not against a transplant, but at the end of the day, it may not work for everyone. I have friends that it did not work for. So, I just want to be at a hospital and have doctors that care about me and my feelings and are not just trying to push treatments and everything on me if that's not what I want to do." -Patient

Recommendations for Healthcare

- SCD clinician-to-patient education programs (e.g. diabetes, cystic fibrosis, hemophilia, other chronic diseases)
- More integrated care:
  - Community health workers and social workers to help with outreach and connect patients to resources
  - Patient-centered medical home
  - Reimbursement for care coordination
  - Increased collaboration between providers who specialize in SCD and other providers (for inspiration: Vermont's Hub and Spoke model)
  - Easy sharing of individualized care plans between PCPs and ER
  - SCD status registry (similar to Prescription Drug Monitoring Programs (PMDPs))
  - 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
- Reminders and suggestions for appointments, immunizations, etc.
- Health insurance options education and assistance

Recommendations for Healthcare (cont.)

- Increased patient access to SCD community
- Increased clinician education:
  - Increase numbers of hematologists who specialize in benign (non-cancerous) conditions
  - Patient-to-clinician working sessions to increase clinician empathy
  - Educational credits and financial incentives for clinicians specializing in SCD
  - Sensitivity training for providers around communicating challenging news, particularly to caregivers around children with SCD
  - Specialized SCD training for adult primary care providers
  - SCD residency for nurse practitioners and physician assistants
  - More education to providers who care for older patients
  - Provider-to-provider mentorship, case conferences program for SCD
  - Financial incentives for providers caring for SCD patients

Recommendations for Healthcare (cont.)

- Increased access and education on clinical trials for SCD
- Quality measures for SCD, with consistent data standards across facilities
- More widespread access to research findings, including in accessible language for patients

Recommendations for Healthcare Finance and Policy

- Development of SCD payment model
- Reimbursement for telehealth, informal virtual consultations, phone calls, care coordination, connecting patients to external resources
- Value-based incentive payments for SCD care
- Medicaid reform to include adults with SCD along with children
- Increased coverage of new therapies
- Simplify and increase access to specialist referrals
- SCD surveillance: increased monitoring of costs of ER visits vs. preventative treatment
- National SCD registry for verification of SCD status — linked to newborn screening database
- SCD surveillance: Funding to support CDC SCD data collection program across all U.S. states
- National open registry of SCD treatment centers and programs
- Partner with other countries to support international efforts
- Programs to increase access to new and expensive therapies
- Add SCD to 340B payment models

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Human-Centered Design Report

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

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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 your ass 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

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

BARRIERS

- 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

Upon test results, provider decides on a course of treatment

- Stay In ER
- 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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Human-Centered Design Report

Opportunity Area 3: People with SCD struggle with transition to adulthood (section 4 of 9)

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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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Human-Centered Design Report

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

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OPPORTUNITY AREA 4

"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 histeria 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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Opportunity Area 5: Patients plan their lives around unpredictability of SCD (section 6 of 9)

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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

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Human-Centered Design Report

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

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OPPORTUNITY AREA 6

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

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Human-Centered Design Report

Archetypes (section 8 of 9)

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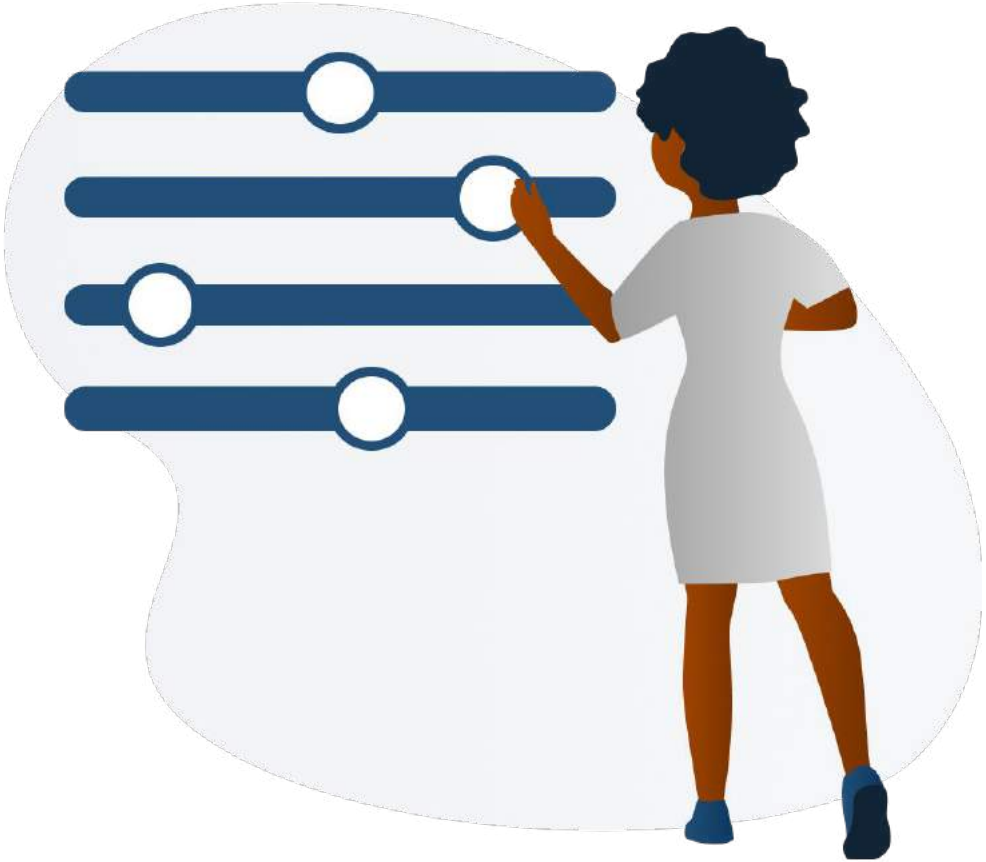
Archetypes

What are archetypes?

Personas and archetypes are a distillation of design discovery insights meant to describe user needs, goals, pain points, and habits— a communication tool that helps teams build empathy towards end-users, and address all use cases. They are developed through analyzing qualitative and quantitative data, and are useful when different types of users behave differently and their various use cases and needs have to be addressed.

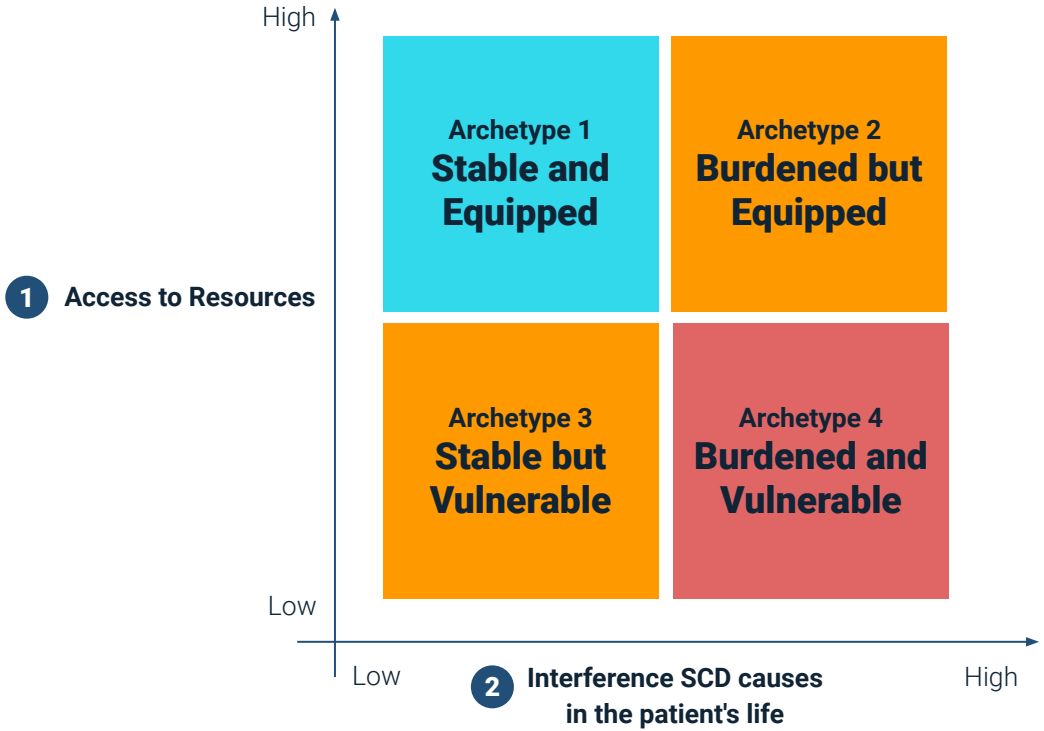


SCD Archetypes

Four archetypes have been identified in our research based on the following criteria:

1. **Access to Resources** is defined by the Social Determinants of Health (SDOH) theory: the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels.

2. **Interference SCD causes in the patient's life** is defined by severity of symptoms and/or the level of disruption caused by treatment. Low interference may refer to a patient following low-maintenance treatment (e.g. hydroxyurea without many side effects), or a patient with mild SCD symptoms. High interference may refer to severe SCD symptoms and/or high-maintenance treatment (e.g. frequent blood transfusions, infusions).



Archetype 1

Stable and Equipped

They have SCD symptoms mostly under control, either through treatment or a mild form of the disease. When crises happen, they have access to resources to help manage other aspects of their lives, like work, family, etc. They see SCD as just another part of their lives.

"In general the only medication I take daily is folic acid, which is prescribed for me because at baseline I'm anemic, so they prescribe folic acid just to help the blood. Other than that, no. I'm not any other medication. I'm considered healthy for a sickle cell patient. I have run marathons. I've done things that people with sickle cell wouldn't consider doing. I've always seen myself as a person lives with sickle cell. I don't define myself by sickle cell." - Patient

Archetype 1

Stable and Equipped

Healthcare

They likely have access to a good doctor or healthcare team, and have found a regimen to prevent crises. If they need to go to the ER, they are able to coordinate with their doctors and support network to make sure they get the proper care.

Management

They manage their symptoms by taking daily precautions and some medication (supplements, hydroxyurea, etc.), and rarely undergo invasive interventions. They most likely depend on their support network only in times of emergency, as opposed to on a daily/regular basis.

Income

Full-Time Employment (important for access to employer's insurance), Family Support

Paying for Healthcare

Employer's Insurance, Family Insurance

CHALLENGES

- Low symptoms may lead to less consistency in management and compliance
- May fail to properly engage with preventative care out of lack of urgency

OPPORTUNITIES

- Passive or proactive access to information about SCD and the importance of preventative treatment

The Stable and Equipped Caregiver

They are able to access good work conditions, where others are understanding if an emergency happens, and are likely to have a support network in those situations. They keep a good schedule, taking the patient to see doctors as needed.

Archetype 2

Burdened but Equipped

SCD symptoms and management take a lot of their time, and they are always trying to find ways to improve it. They may be driven to advocate for other patients once they learn that healthcare for SCD is not up to standard when compared with other chronic pain conditions.

"I'll take [a medication I researched] to my hematologist and I'll tell him and he'll research it and we'll talk about. It was just 2 months ago the Oxbryta and the Adakveo, the IV one, I brought that to his attention and he researched it and he was like, this is definitely something that I feel like we could administer at a later date." - Patient

Archetype 2

Burdened but Equipped

Healthcare

They likely have access to a good doctor or healthcare team. Crisis and other interferences happen frequently, but they are able to coordinate with doctors and their support network to make sure they get the proper care and are covered during work absences.

Management

They manage their symptoms by taking both medical and non-medical daily precautions. They are likely to comply with treatment because they don't feel they have other options, and they have purchasing power to try different types of prescriptions or enroll in clinical trials. They are likely to try risky procedures (i.e. bone marrow transplants) as they have resources to withstand them. They most likely depend on their support network (both on a regular basis and in times of emergency) for non-medical support and sophisticated knowledge.

Income Options

Employment with understanding employer, self-employment (flexible hours), family, disability

Healthcare Finance Options

Employer's, Family Insurance

CHALLENGES

- Highly dependent on healthcare, which may prove to be unreliable
- Feel a need to research outside of the healthcare system to find alternatives to their current regimen
- Healthcare is difficult to coordinate
- Struggle with life and work interruptions, but have resources to work around them

OPPORTUNITIES

- More proactive primary care that offers informed diet and supplements
- Have time and bandwidth to help other patients navigate SCD

The Burdened but Equipped Caregiver

They have a system in place where someone else can take care of other dependents while they accompany the patient to the ER or hospital. They have to learn their employment or work protocol in order to challenge it when the child has an absence. Some reported quitting their jobs to homeschool or care full-time for their loved ones with SCD in severe cases.

Archetype 3

Stable but Vulnerable

Their SCD symptoms are somewhat manageable on a day-to-day basis, so they don't think about it much. But a crisis can snowball into great disruption in other aspects of their lives due to lack of access to resources.

"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, you want to try to avoid it as much as possible. If I can manage things at home and try to get it under control, then that is my first choice." - Patient

Archetype 3

Stable but Vulnerable

Healthcare

They will work their PCP, and may not have a hematologist. They are not likely to comply with treatment because they don't feel they need to, and it may be expensive. They are unlikely to try or need risky procedures (i.e. bone marrow transplants).

Management

They manage their symptoms as needed by taking daily precautions or through low-maintenance treatment. They most likely depend on their support network only in times of emergency. They may be unprepared to handle the impact of ER visits and hospitalizations on their lives, both in terms of affording healthcare and of holding stable employment/source of income.

Income Options

Employment, family. Doesn't qualify for disability.

Healthcare Finance Options

Employer's, Family Insurance, sometimes Medicaid (patient may not be eligible if outside of Medicaid expansion states). Often patient can't have any of these options, or the coverage is insufficient.

CHALLENGES

- Unprepared in case of emergency
- May not be familiar with ER or to mitigate stereotyping in ER
- Lack of knowledge on care coordination
- Lack of transportation, time, money, support makes it hard to adhere to treatment
- Lack of financial cushion and insurance coverage

OPPORTUNITIES

- Passive access to information about SCD and the importance of preventative treatment
- Education on care coordination and financing
- Information on free and cheap resources for healthcare and related life disruptions (childcare, home care, labor and disability law, etc.)

The Stable but Vulnerable Caregiver

When emergencies happen, a lack of resources and preparedness can snowball a health crisis into a life crisis for the whole family. Work and family duties can get be compromised. If crises are rare, they may not have to defend themselves against discriminatory measures at work and in school because they haven't had a chance to challenge it before.

Archetype 4

Burdened and Vulnerable

Their SCD is high-maintenance and a big part of their lives. Their lack of access to resources to manage it and pursue treatment makes it impossible for them to function in other areas of their lives.

"A lot of us don't work because you get a job and you can get sick three days after landing this job in the hospital so of course you haven't been there long enough, you're going to lose that job...Uber is saving my life, pretty much." - Patient

Archetype 4

Burdened and Vulnerable

Healthcare

They may have access to a healthcare team, but it's likely insufficient to treat and control their symptoms. They are likely unable to secure a knowledgeable hematologist, leading to fewer and inadequately applied treatment options. They are disempowered to challenge poor or discriminatory behavior due to lack of knowledge.

Management

They don't have access to sufficient treatment, but are disempowered to search for better options or challenge providers. They may not have the purchasing power to try many different types of prescriptions or enroll in clinical trials when current prescriptions do not work for them. They depend heavily on their support network (both on a regular basis and in times of emergency), often choosing to live close to them for this reason.

Income Options

Disability, informal self-employment (e.g. Uber, selling homemade goods); based on schedule flexibility and maintenance of disability and insurance.

Healthcare Finance Options

Medicaid (patient may not be eligible if outside of Medicaid expansion states) and Medicare (disability). Coverage is often insufficient.

CHALLENGES

- Lack of transportation, time, money, support makes it hard to adhere to treatment and support themselves
- Disconnected from specialized SCD healthcare expertise and resources
- Lack of access to treatment options
- Distrusts healthcare, but disempowered to challenge it

OPPORTUNITIES

- More flexible employment options, including SCD advocacy
- Guidance on free and cheap resources for healthcare and related life disruptions
- Education on care coordination and financing

The Burdened and Vulnerable Caregiver

If their support network is insufficient, they may fear losing their jobs or being targeted by Child Protective Services authorities in case of school absences or having no one to watch their children. They may find treatment alternatives, especially from advocacy groups, but are otherwise unable to find time and resources to pursue them.

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Human-Centered Design Report

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Appendix

Research Approach

Recruitment
Medical experts and people with SCD and their families were recruited. HHS contacted many patient advocacy groups across the country on behalf of Coforma. Additionally, we reached out to people on Instagram, Twitter and Facebook.

Methodology
Remote and in-person, semi-structured 60-minute interviews were conducted. A total of 24 interviews were conducted with people with SCD and their families, from a comprehensive variety of U.S. regions, genders, ages (all 18+), education, and care finance modes. 16 patients, 7 caregivers (2 of adults and 5 of children), and 1 sibling of a patient were interviewed.

A total of 4 interviews were conducted with subject matter experts: 2 with healthcare providers specializing in SCD, 1 with a nurse navigator, and 1 with a representative from the CDC.

Interview Approach
Interviews centered around the quality of healthcare they received throughout their transition from childhood to adulthood, their experiences with emergency care, experiences with insurance, and navigating work and career.

Synthesis
Interviews were analyzed in qualitative coding software Delve. Using Delve, we categorized interview segments according to their content. Examples of categories are "transition to adulthood", "emergency care", "care coordination", "insurance", "bureaucracy", "discrimination". Through this, we analyzed trends in how respondents described specific aspects of their experiences.

Gaps and Limitations
Our patient and caregiver interviewee sample is majority female, and at least college-educated. In addition, most of them were recruited from patient advocacy groups, which may tend to be more educated on SCD and barriers to healthcare than patients who aren't connected with those groups. While we were able to find participants beyond those demographics, our sample may not be representative of the general population with SCD. Despite these gaps, we were able to gain some variety in interviewees and have honored this in our analysis.

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