

Human-Centered Design Report

Archetypes (section 8 of 9)

& partners | June 2020

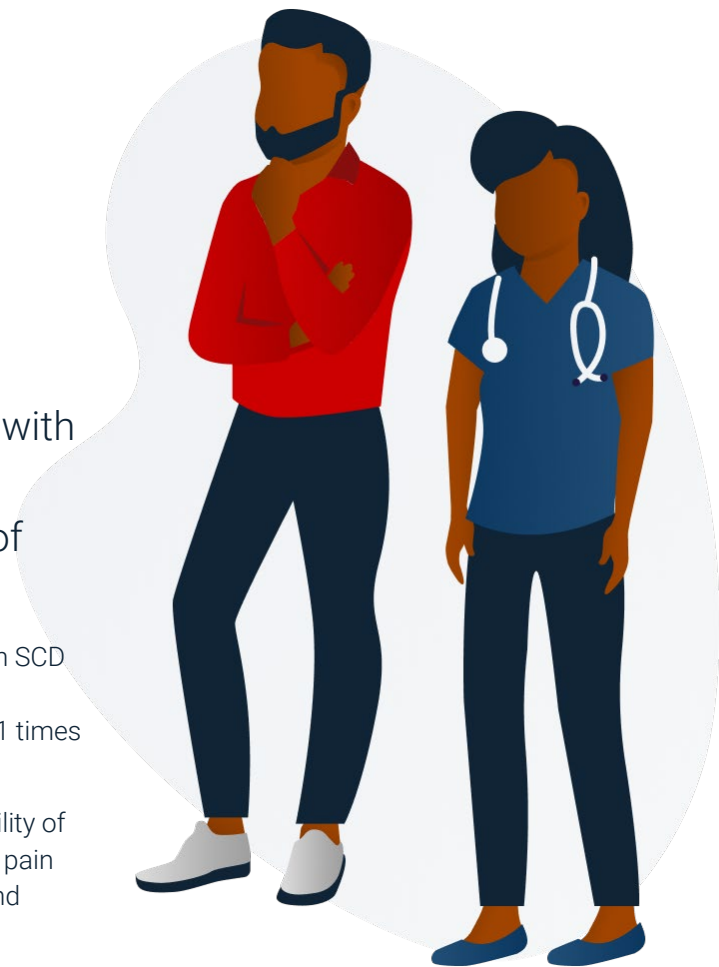


About Health+ Sickle Cell Disease

Health+ Sickle Cell Disease is a project that aims at providing insights, stories, and journeys around the experience of people with Sickle Cell Disease (SCD) to accelerate the identification and implementation of innovative solutions to increase the quality of life for patients living with SCD.

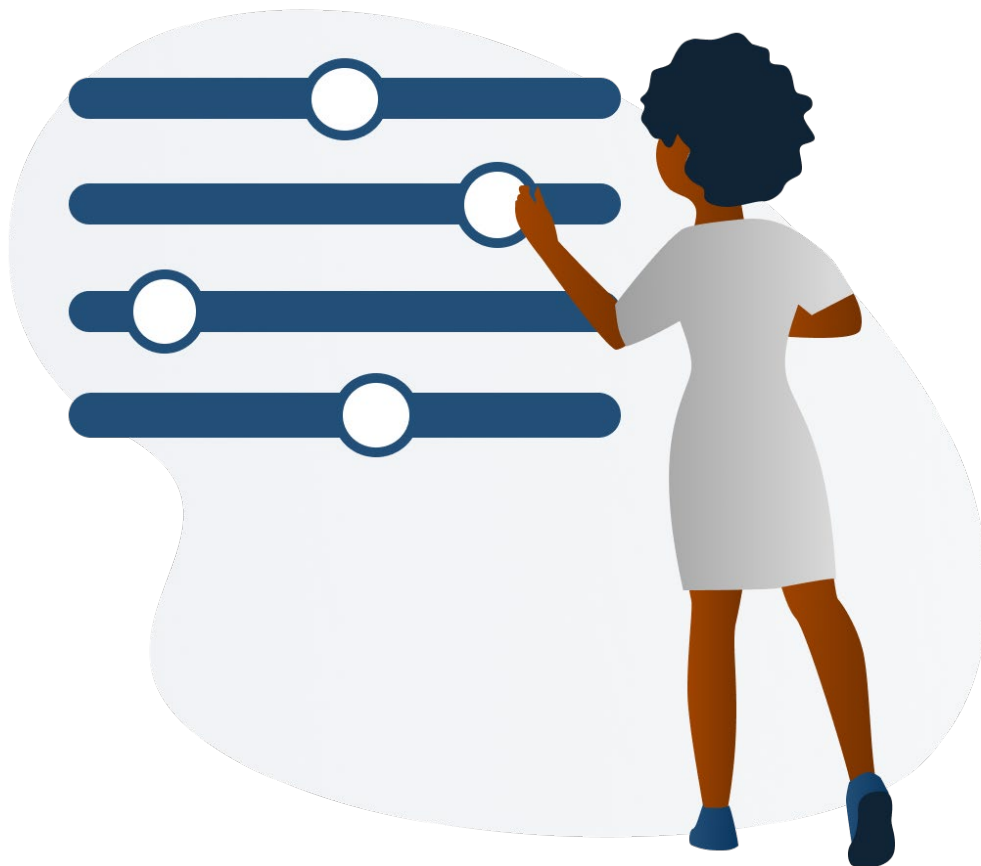
SCD is the most common inherited blood disorder. About 100,000 Americans currently live with SCD and the disease disproportionately affects African Americans. SCD is costly; expenditures for patients with SCD are estimated to be 6 times higher than non-SCD patients in Medicaid and 11 times higher than non-SCD patients with private insurance.

African Americans disproportionately experience challenges with access, quality, and affordability of care. Patients with SCD may encounter racial discrimination when seeking treatment for acute pain crises, including accusations of “drug seeking”, extended emergency department wait times, and difficulty filling prescriptions.



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.

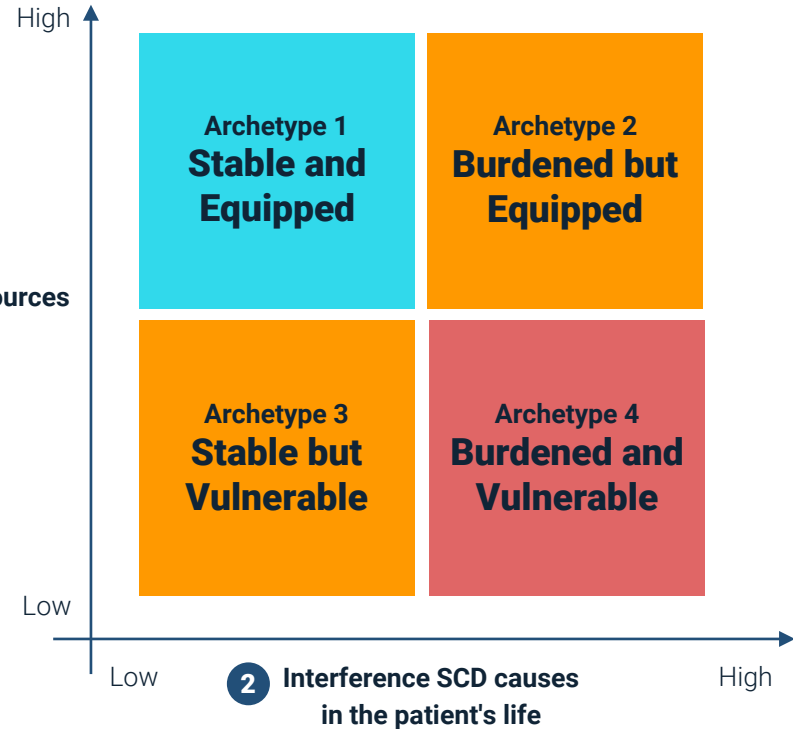


SCD Archetypes

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).

1 Access to Resources



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



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



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



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



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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Sponsored by:



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