Barriers and Facilitators to SCD Patient Care *(Draft)*

KEY

- Barriers
- Behavior
- Facilitators
- Perception

PATIENT BARRIERS
Side effects of Hydroxyurea aren't always clear to patients, resulting in misconceptions
"And then there's concerns that Hydroxyurea would make your hair fall out, because at a certain dose level when it's used for cancer treatment it would. But the dose level we use for sickle cell is about half of that. So generally it doesn't." [MEI]
"Right. I mean the instructions say don't touch this medicine, you should wear gloves. And I'm telling this mother to give this to her child in a liquid. So it's a very mixed message." [MEI]

ED BEHAVIORS
ED addresses acute crisis, but does not integrate with long term care structures
"So we have this kind of one size…we tend to go right to drugs. Which is appropriate, I mean I think that, but the biggest long term…you know we're not going to fix all of this in the middle of an acute crisis. You're not going to do cognitive behavioral therapy. But long term you certainly will." [MEI]

PATIENT BARRIERS
Increasing chronic pain
"But for some other people as they get older they accumulate this chronic pain, and the chronic pain gets to be where most days of the year I'm having some level of pain. And on a scale of ten it might be always a three. Or at best it's a two. And then some days it's a seven. I just decide whether I have to go to the hospital or not, and then when it gets to an eight or nine I really can't stand it, I've tried pain medicines at home, then I go to the hospital." [MEI]

PATIENT BARRIERS
Patients may experience brain damage from stroke and require cognitive therapy
"Yeah, and so some of the pain is certainly from the underlying disease but some of the pain is from the way the brain has handled the stress in the past. And there's good evidence that at least for some patients behavioral therapy could make a difference in how you respond to that pain." [MEI]

PATIENT BARRIERS
Long-term stress can influence experience of pain
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PATIENT FACILITATORS
Having their experience heard and acknowledged
"Sometimes when the patients are upset all you need to do is sit there and acknowledge their pain and frustration and they'll talk it out and everything is Ok after they let it go." [SW]

PATIENT BARRIERS
Living with SCD can consume all available resources
"So some of the funding for this is not so great because people are too busy basically just staying alive…if you have time on your hands you can go lobby your congressman, you can go raise money. If you don't have time or finances then you can't do that, you're just trying to pay the rent and get by." [MEI]

PATIENT BARRIERS
Socioeconomic factors multiply the challenges of living with SCD for some patients
"Ok, so the challenges, again, are that, I think that there are many challenges. And again, they go back to the socialeconomic structure and community resources because community plays a huge part of this and many people do live in communities where health care is not as accessible, meaning their food may not be accessible and a good place. They may just have like these little stores where they offer expensive food or not even healthy foods and a lot of greasy foods. Again, they don't have good resources to go out, to be safe. They don't feel safe in their community. So many people, they don't even want to go out much because they're afraid that they're going to get robbed or their home is going to get robbed, and all of those are realistic barriers." [CHW]

PATIENT BARRIERS
Depression and adjustment to limitations
"…you cannot have…you just can't have a job, so you've got to prepare yourself to have a career. So we stress education because your career has to be conducive to your illness. So that's something that I really want to get someone to come in and speak on is depression because some of them are very depressed. Very depressed." [SW]

PATIENT FACILITATORS
Help patients see their successes
"The patient being strong. When they come in with crisis they feel defeated. So just help to pick them up. You know, you can be strong, you can do this. She have all the emotions like she succeeded." [CHW]

PATIENT BARRIERS
Some patients don't have family support
"With that one I was family. So that is important to have the family support itself because I've noticed a lot of them don't have family and when they come to the hospital and they're admitted a lot of the nurses become their family. So yeah, I look at that as family support and you having a disease and being around other people doesn't make you any different." [CHW]

PATIENT BEHAVIOR
Patients have social support in medical setting
"Ok, many of the patients, pediatric and adult, this has come up time and time again on the inpatient side of things when patients are frequently in the hospital but they seem to not be in pain. They're talking on the phone, they're interacting with other patients, they're interacting with staff. They know all the nurses on every shift, they even know the housekeepers and delivery." [SW]

PATIENT BARRIERS
Racism and implicit bias in the medical system
"So in addition to having a chronic disease you also are dealing with poverty and racism, and it's all tied in." [MEI]

PATIENT BARRIERS
Loss of insurance can be catastrophic
"Similarly, if my kids who don't really have chronic disease, maybe a little asthma, if they lost their health insurance for half a year it's not that bad and I could bail them out. But if somebody with sickle cell loses their insurance for half a year it can be catastrophic." [MEI]

PATIENT BEHAVIOR
Patients may sacrifice health out of desperation
"I feel like people are in such despair for resources that they're willing to actually sacrifice their health, almost, to get these disability benefits. And that is really, really not a good thing for anyone." [CHW]

PATIENT BARRIERS
Medicaid MCO changes disrupt ability to maintain long-term relationship with physicians
"A lot of them, they're all on Medicaid so they're having issues with…if they're with one Medicaid MCO, that's Managed Care Organizations, they get switched to a different MCO and they don't understand why they were switched, they don't know how to go about being switched to the one they were with primarily, and they don't understand, with families some of the children are switched and some of them are not. So, which means a lot of them have to find new primary care physicians because their physician, it will no longer will accept that insurance." [CHW]

PATIENT BEHAVIOR
Overdosing
"We know it has to be boards like multi-disbd to address this. But still, when you hear about those that overdose, not sickle cell patients only, but the general public, who are overdosing on prescription medications, you wonder. When some of our patients die at home, and I don't want this recorded, turn that off. " [---]

PATIENT BARRIERS
Patient prescriptions may be abused by others
"Because of abuse from other people, not necessarily the people with sickle cell." [CHW]

PATIENT BARRIERS
It can be hard for patients to access medications
"Then we talk about medications, we talk about how are they accessing their medications, are they difficult to access, and they say yes, mainly because the pain medication is considered an illegal…like what do they call it, a narcotic? So it's difficult to just get pain medication. It's not something the doctor could even just call in sometimes. It's a very complicated thing. So pain medication accessibility is a bit problem for them." [CHW]

PATIENT BARRIERS
Long-term prescription refills are not permitted
"Access to medication. Because they take…I'm trying to think, like hydrocodone, you only can get 30 per month and if you're out you have to come back to the doctor to get a new prescription. So they don't get the prescription long term." [CHW]

PATIENT BARRIERS
Patients have complex medication schedules
"So very painful and it's nerves that are firing poorly. Or you may have heard of phantom limb pain. If someone gets their arm cut of but it still hurts. You know it's not there anymore but it's the nerves are just firing, even though there's nothing to hurt. So there's medicines that can squash down the nerve firing. They're sort of anti-seizure meds, some of them, and those will help with the pain. So people often end up in a combination of a bunch of different things. And so often a pain management plan features like three different meds, four because it's actually a long acting one as well as short acting ones, and then a few medicines to manage the side effects." [MEI]

PATIENT BARRIERS
Patient bears the burden of coordinating care within a complex, distributed healthcare system
"Right. So again, my patients are usually with a parent and the parent sometimes has like a list notebook or an organizer or they're pulling out their phone. Oh, can I put those two appointments the same day? Yeah, that's a good idea. But the young adult or the kid may not have thought of that and it's just like, what, I have five appointments in two months, no, I'm just not going to do it. And then they fall out of the system and all havoc breaks loose." [MEI]

COMMUNICATION BARRIERS
Developmental factors may increase risk of complications for teenagers
"And then meanwhile this baby isn't absorbing this information but they're getting it from their parents at home. But when they get to be adult or a teen, they've got to learn to do it themselves and it's exactly the right age where if you remember when you were a teenager you don't particularly want to listen to your parents. I want to figure out things myself, I want to take risks, I want to do it my way, and then you get into problems. So it's very much more consequences when you take a risk if you have a chronic disease like this." [MEI]

ED BARRIERS
ED must monitor for potentially fatal complications such as sepsis
"It would invoke what that typical sickle cell crisis looks like. Have they had acute chest syndrome in the past, are there other complications of sickle cell that I should be aware of." [MEI]
"So they're immunocompromised and they can get septic. They don't have a spleen so spleens filter out bacteria. So they're much more susceptible to overwhelming sepsis. Should never forget that." [MEI]

ED BARRIERS
Patients can respond to pain medications in very different ways
"I mean they have sickle cell disease. From that standpoint I guess it may be simpler, but every patient is different for a few reasons. I mean the, so each person is different in terms of how they respond to pain medication and so there isn't a one dose and one medication size fits all." [MEI]

COMMUNICATION BARRIERS
Discharge papers are overwhelming
"And some of these patients, we hand them a discharge paper like, Ok, come back and see me in three months and you need to go see cardiology for your heart, you need to see nephrology for your kidneys, you need to get an x-ray and don't forget to look at those labs. And here's your four prescriptions, you need to get those filled and you need to take this twice a day, that one three times a day, this one can be once a day as needed. And they have your pain medicines that you can adjust, and watch out for the side effects. We give them a bit And you have to figure out when you're going to come for all these visits and you have to figure out transportation, childcare, time of from school or work, all that stuff. So it can be very challenging." [MEI]

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ED BARRIERS
Medical staff may consider caring for SCD patients to be demanding
"I'm sure psychiatrist, I'm…And not enough staff I don't think, yeah, to run it 24 hours. Many people are blaming it on the sickle cell patients so it's very hard to sometimes find someone outside that has that energy to come in and care for the patients because they feel like they're demanding. You have to check on them every 15 minutes for vitals and giving them medicine and it's a lot of legwork in working with the sickle patients because of their frequency of asking for pain medicine." [SW]

ED BARRIERS
ED has limited time and resources
"I guess resources, overcrowded emergency rooms, not understanding the disease. Those are the major things." [CAN]
"You can but if you're working in a busy emergency department, I don't have time to go pawing around in the records." [MEI]

ED BEHAVIORS
ED studies suggest physicians respond to other types of pain more quickly than SCD crisis
"…there are others that feel like we don't take care of pain bad enough in those patients when you compare to people that have kidney stones, for instance, or long bone fractures. The pain that those patients have is just, is perhaps not even as severe as sickle cell pain, and yet if you look at the numbers in some studies we, as physicians, will take care of that pain more quickly than we will sickle cell pain." [MEI]

ED BARRIERS
Determining dose of medication is a dilemma for ED staff
"Because you don't want to give too much because it can be unsafe. If you give too little then you're not treating their pain." [MEI]

COMMUNICATION BARRIERS
Systemic and individual communication failure results in poor patient care
"So patients that belong to our system, the very idea that a sickle cell patient who knows our system and belongs to a physician here comes into our emergency department completely unannounced is shameful! I will just put it right out there. I think it's shameful! I mean that kind of handoff, really? We can do so much better than that. But that's step one. Ok? Then by calling their attending. Good luck." [MEI]

COMMUNICATION FACILITATORS
Heads up protocol, both written and verbal
"There would be a beautiful heads up note." [MEI]
"So the attending would actually hand off the patient to you and say, "I-know this patient well, they require higher doses of medication than most sickle cell patients but this should be Ok to give them this much; this is what they usually get." So there was already a hand off that occurred." [MEI]

COMMUNICATION FACILITATORS
A proactive patient treatment plan, history, and complications for most frequent ED patients.
"So the ideal solution there is to have a consensus that here's the 500 patients that we take care of but name the 100 patients that come in the most and can we at least start with that group and this is what we think is the best way to treat these patients when they come in. This is the first dose, the type of medicine, the dosing, and get started with that." [MEI]
"We'd like to get to that point in the emergency department where we would have something that could be pulled up on every patient that is seen in our system, that this is what they usually get." [MEI]
"It would invoke what their typical sickle cell crisis looks like. Have they had acute chest syndrome in the past, are there other complications of sickle cell that I should be aware of." [MEI]

ACC BARRIERS
ACC staff not aligned internally
"Are they holding their own staff accountable? You know, to the point where my own faculty will just laugh at me if I say hey, we're going to try this again because they just like, really, Charlie Brown? Lucy's holding the football again and we're going to call and nobody, and they're really going to answer the phone the time and they're really going to be responsive and they're really going to take chest pain patients now. You know, the attending can say something but are the nursing staff that are really doing the work onboard? They're the major resistors." [MEI]

ACC BEHAVIORS
Criteria for transferring patients from ACC to ED is not always clear or consistent
"Then there would be multiple reasons for, oh, we can't take care of this patient because this or that or they have chest pain, too complicated, oh, they used drugs once. I mean just the whole long list." [MEI]

ACC BEHAVIORS
Quality of care can vary greatly by provider
"I mean I think that they have wonderful providers and I think they also have providers that I can't reach and providers that don't see their own patients for many, many, many, many, many hours." [MEI]

ED PERCEPTION
Nurses and doctors disagree on services
"Yeah, and I talked to Dr. Hsu about this a few years back where it felt like some nurses were, well, they questioned the services that were being provided and whether or not we were being firm in certain boundaries that they imagined that were there." [SW]

ED PERCEPTION
ACC does not coordinate or administer care effectively to SC patients
"Now, we are revisiting some of this so this is a good time to be talking through this. But our sense has been that they have not been masters of their own domain, that they don't quite know what their own nursing staff is doing to block care or not answer the phone." [MEI]

PATIENT BEHAVIOR
Patients don't always bring necessary documentation
"Not typical is that they came and did not bring the appropriate papers to sign consent for treatment. So I ended up calling all over the world for DCFS (because we couldn't see the patient until we had proper documentation that you're allowed, that the guardian was allowed to sign consent. Because if DCFS had custody then they would have to give telephone consent and be over a form and fax it back. A lot of legal stuff, so yeah." [SW]

PATIENT BEHAVIOR
Transportation is not always reliable
"Yeah. From the populations that I work with it seemed like a high volume had a high level of poverty, which I know by…I mean it's like we talk about Medicaid having transportation access but I also have at least six different care coordinators have given me complaints about people not being picked up on time and not getting to their appointments." [SW]

PATIENT FACILITATORS
Healthcare facilities near the home
"I think, in the American Medical model with acute disease you come to the hospital. Why not push it out into the community, right? Why can't they be managed near their home? There were a few things that we could improve in our care like they had to have blood testing. Instead of coming all the way to the hospital why can't they just go to the nearby clinic and have that done? And I get my care at Northshore and my physician will write an open order and I can go anywhere any time of day to get the testing done. We tend to do it the old school way. It needs to be a future order." [CHW]

PATIENT BARRIERS
Stigma of certain medications may cause patients to refuse to take them
*"Another thing that happened maybe six years ago, we had a lot of patients who were very resistant to taking methadone. And a lot of people associate methadone with heroin addiction. But methadone is a very excellent drug for pain control. And it's very, very, very,