

SICKLING IN AN ABLE-BODIED WORLD: AN AUTOETHNOGRAPHY OF THE ON-
TARIO SICKLE CELL HEALTH QUALITY STANDARD

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A Research Paper submitted to the Graduate Program in Critical Disability Studies in partial ful-

fillment of the requirements for the degree of Master of Arts

Graduate Program in Critical Disability Studies

York University Toronto, Ontario M3J 1P3

August 2026

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Introduction and Background

“Sickle cell disease – also called sickle cell anemia - is a group of inherited blood disorders that affect hemoglobin, the major protein that carries oxygen in red blood cells.” (National Heart,

Lung and Blood Institute, 2025) When these “C” shaped red blood cells get trapped in blood vessels, this causes a vaso-occlusive pain crisis that could last anywhere from hours, days, weeks or months. “Serious problems may come from having sickle cell disease, including sudden onset of strong episodes of pain, called pain crises, that occur because of blocked blood flow and often require medical attention” (National Heart, Lung and Blood Institute, 2025). Other terms used to describe these pain episodes include “sickle cell crisis” and “vaso-occlusive crisis” (National Heart, Lung and Blood Institute, 2025). Other health complications that could arise for a person living with SCD include chronic pain, stroke, lung problems, eye problems, infections, and kidney disease (National Heart, Lung and Blood Institute, 2025). SCD “disproportionately impacts Black communities in the province of Ontario, Canada” (Srikanthan, 2023). In the context of systemic and systematic anti-Black racism, it is not surprising that Black persons with SCD face discrimination in healthcare settings, resulting in unmet needs and inadequate treatment. (Sickle Cell Awareness Group of Ontario, n.d.) There is a preconception from staff in the hospital that Black patients with Sickle cell disease are only visiting the hospital to receive drugs. Additionally, a few patients specifically shared that they had to advocate for themselves in order for ER staff to understand their pain (Durgham et. al. 2023, p. 45) As a Black Woman living with SCD, I hope to contribute to a better understanding of these inequities. The purpose of this paper is to engage auto-ethnography, Critical Disability Studies, and Black Disability Studies frameworks, to critically examine the Ontario Health Quality Standard. In doing so, I will illuminate the gaps in care, and argue for a person-centered, anti-racist, anti-ableist approach to supporting people living with SCD.

Importance of Research

Sickle Cell Disease has very limited research from a Critical Disability lens. For example, Swanson et al. notes that there is extensive discussion of SCD from a multifactorial lens. “Disability among people with sickle cell disease, which includes physical, psychological, and social dimensions.” (Swanson, et. al p. 390). A strong disability perspective is outlined, noting: “pain is not simply the result of a biological process but is influenced by the social context.” (Swanson, et. al. p. 392). More often than not, attention is paid to the disease from a biomedical and clinical lens. My research aims to look at SCD from an embodied/lived experience perspective. Individuals living with SCD go through pain daily. They have to constantly monitor their body for pain, and to be hyper-aware of their body’s signals. The body ends up being something that a person doesn’t fully trust. Writing from an embodied experience pushes back against seeing the illness only in terms of lab values or genetics; instead, it allows us to focus on what it feels like to live with SCD in this body, in this healthcare system, in this society.

To elucidate the inadequacies of the Ontario healthcare system for people living with SCD, I will engage in a critical reading of the Ontario Quality Health Standard (HQS) from the perspective of a Black Woman living with SCD, using a Black Disability Studies lens. The HQS was designed for people living with SCD to receive high-quality care when they enter an emergency room. The purpose of the document is to make recommendations for improving the care of individuals with SCD in hospitals, including “eight quality statements that address areas identified by the Sickle Cell Disease Quality Standard Advisory Committee as having high potential to improve care for people with sickle cell disease in Ontario” (Ontario Health, 2023, p. 7). SCD remains under-recognized in Canadian healthcare, and the current HQS fails to fully reflect the experiences and needs of those living with chronic conditions like SCD, especially Black Cana-

dians who face intersecting systemic inequities, despite growing acknowledgement of the impact of anti-Black racism on healthcare for people with SCD.

By focusing on my lived experience, this project will engage an auto-ethnographic approach in the analysis that will show how I am able to move both inside and outside of the Sickle Cell community, telling my story of living with this disease while also bringing to light the realities of so many others like me. “Auto-ethnography allows the researcher to problematize the self as the researcher and also as the participant, or collaborator, in the research and to see the complexity of my cultural perspectives, all of which have been formed by the world I have lived my life” (Tilley-Lubbs, 2018, p. 14). Furthermore, beginning in autoethnography will allow me to address the strengths and gaps in existing health policies and explore how these standards may be improved to better support equity, inclusion and the well-being of racialized communities. This project is not only important for showing how to improve policies but also how to amplify voices and experiences that are frequently ignored in healthcare decision-making.

Critical Disability Studies has predominantly focused on White disabled bodies. Racialized scholars have pointed out that when you do not fit into the White, able-bodied way of living, you are put into the category of being the other (Gorman, 2016). The goal for my project is to uncover an invisible, painful illness that impacts millions of Black people daily and their struggles to be believed about their pain. I will critically analyze the HQS and SCD by using disability justice and critical disability studies frameworks, while engaging in an autoethnography that will be grounded in my lived experience as a Black Woman with SCD, challenging the bio-medical dominant discourse on what it means to define what quality care looks like and to offer other alternative understandings of care, access and quality grounded in lived realities.

Given the complexity and diverse dimensions of SCD, several questions will be raised: how does Ontario's Sickle Cell HQS reflect or fail to reflect the lived experiences of Black Women with SCD? Other questions that may arise are: which disability models underpin the HQS? What experiences are prioritized or excluded? How might CDS reframe understandings of quality care of SCD and what do people get wrong about SCD?

Theoretical Frameworks

The main frameworks I will focus on for my project are the Critical Disability Studies Framework, which will look at how society creates a disability through power, inequality, and social systems. Foucault's (1980) arguments on the intersection of science and racism provides a theoretical reference point noting: "Regarding the nobility, you talk in your book, of a myth of blood, blood as a mythical object. But what strikes me as remarkable, apart from its symbolic function, is that blood was also regarded by this nobility as a biological object. Its racism wasn't founded on a mythical tradition, but on a veritable theory of hereditary by blood. It's already a biological racism." (Foucault, 1977, p. 222-223). Which body/minds are considered normal, and which are disabled, is political and intersectional. Applying a Black Feminist Disability Framework will allow me to centre how race, gender and disability shape my experience and understanding of the world, while living with SCD.

According to Moya Bailey, a Black feminist disability framework centers race, gender and disability, challenging these generally siloed theories to work together to better understand the realities for those multiply marginalized within society (Bailey, 2019, p. 20). Sami Schalk (2022) has also contributed to a Black Disability Studies Framework by engaging an auto-ethnographic approach, which provides an effective narration of their experience of coming to terms with iden-

tifying as a Black disabled queer Woman, and their experience of being inseparable from these communities. Schalk explains, in claiming this Black disability identity, “I often use we, ours and us when referring to disabled people, Black people, and Black disabled people. I refuse to use they as if I am separate from the communities I write about, live within, and learn from every day” (Schalk, 2022, p.2). These Black Disability Studies frameworks are important to my research because I am studying SCD and how it ties back into Critical Disability Studies, and how the idea of the “cure” is complex and contradictory for people with SCD.

For many people living with SCD, weighing the options of treatment can be complex not just for the individual but for their community. A recent study finds people living with SCD experience the uncertainty of the disease, patient-provider relationships, decision-making in high-stakes procedures, equitable access to SCD experts and disease modifying agents, and information about curative therapies (Jacobs-Mcfarlane, 2025, pg.385).

Multiple factors determine whether a person living with SCD decides to be cured of their illness; it is not a decision to be made lightly, nor are curative treatments available to or affordable for the vast majority of people living with SCD.

Paradigms

The paradigms that best suit my research are critical paradigms, which will allow me to trouble the information presented in the HQS, a report written to influence government policy, while not factoring in the realities of SCD patients. Many people with SCD have different ways of experiencing disability. The social model of disability allows us to look at how one experiences disability in their daily lives. Within academia, the social model continues to be a focal point within

Disability Studies literature- offering an ontological position to understand how people with impairments and health conditions experience disability” (Griffiths, 2024, p.232).

This research will be interpretive because people’s reality is shaped by human experience, and qualitative because reality is not one fixed thing; people can experience the same diagnosis differently, and that happens all the time with people living with SCD.

Types of Sickle Cell Disease

There are many types of Sickle Cell Disease, and depending on which genotype a person has could determine how they seek treatment. This is not to say that people who have a less severe type of SCD don’t need as much medical care as someone who has a more severe type.

“The most common type of sickle cell disease comes from two sickle cell genes, meaning one inherited from each parent with sickle cell trait. There are variations of SCD called sickle C or sickle thalassemia, which are serious conditions but are sometimes less severe.” (American Society of Hematology, 2026). Regardless of the severity of the disease, all patients managing their SCD should be able to access proper medical care.

Hemoglobin SS

The most common and well-known type of SCD is Sickle Cell Anemia known as Hemoglobin SS. When a person is born with Hemoglobin SS, it is because a person inherited the sickle cell gene (one from each parent) “When a child inherits one substitution beta globin genes (the sickle cell gene) from each parent, the child has Sickle Cell Anemia (SS). Populations that have a high frequency of sickle cell anemia are those of African and Indian descents” (Sickle Cell Association of the National Capital Area, Inc., n.d.)

Sickle Hemoglobin – C Disease (SC)

Sickle Hemoglobin C (SC) has some of the same symptoms as Sickle Cell Anemia, but those with SC may have a higher blood count level due to less anemia. When a person is born with Hemoglobin SC – they get one S gene from their parent and C gene from the other parent. “Individuals with Sickle Hemoglobin-C Disease (SC) have a slightly different substitution in their beta globin genes that produces both hemoglobin C and hemoglobin S. Hemoglobin- C disease may cause similar symptoms as sickle cell anemia but less anemia due to a higher blood count level. Populations that have a high frequency of Hemoglobin- C disease are those of West African, Mediterranean, and Middle East descents” (Sickle Cell Association of the National Capital Area, Inc., n.d.)

Sickle Beta-Plus Thalassemia

People that have Sickle Beta-Plus Thalassemia can have similar outcomes to those who have Sickle Cell Anemia. The severity of the disease on a person depends on the amount of normal beta globin that is produced. Severe cases could result in blood transfusions. “Individuals with Sickle Beta Thalassemia (SB) disease also contain substitutions in both beta globin genes. The severity of the disease varies according to the amount of normal beta globin produced. When no beta globin is produced, symptoms are almost identical to sickle cell anemia, with severe cases needing chronic blood transfusions. Populations that have a high frequency of Sickle Beta Thalassemia are those of Mediterranean and Caribbean descents.” Sickle Cell Association of the National Capital Area, Inc., n.d.).

Sickle Cell Trait (HbAS)

Sickle Cell Trait is not the same as Sickle Cell Disease. A person can be born with SC Trait when they inherit one abnormal sickle gene from their parent, and the other gene is a normal hemoglobin gene. Most people that have SCT do not have any of the complications/symptoms that a person with the full disease will have. People who have Sickle Cell Trait are often reminded to be mindful when starting a family because they could pass on the gene to their child. “Sickle cell trait refers to individuals that have inherited only one abnormal sickle gene and also possess one normal adult hemoglobin gene. This is known and heterozygous, as there are different genes present, and can people with this type can sometimes be referred to as sickle cell disease carriers” (Smith, 2018). A big misconception with SCD is that Sickle Cell Trait is the same as SCD – and that isn’t true based on the symptoms and comparison between the two.

While there are numerous misconceptions concerning SCD, the most significant attention is for SCT transmissions in consideration of starting a family. “It is unusual for people with the trait to experience symptoms. However, they have the potential to pass the gene on to any children, who may suffer from sickle cell anemia if the other parent is also a carrier of the gene mutation.” (Smith, 2018).

These are the most well-known types of Sickle Cell Disease, and it is important that people are aware of how the disease is inherited. With this knowledge in mind, it can help with future family planning or stop the misconceptions and myths about SCD.

Myths about Sickle Cell Disease

In this section of my paper, I will be answering the question about what society gets wrong about Sickle Cell Disease. For my whole life living with SCD and as I have gotten older and a better understanding of SCD, I've read and heard some misconceptions about the disease.

The things I have been told about SCD right to my face include things such as knowing someone who died from the disease, not believing that the pain can just happen suddenly or not knowing that a person can be in pain all the time. Of course, these comments have left me stunned because they came from other Black people in my own community but also sad because people within my own community don't even understand how life threatening the disease could be to their own kind.

The most common myth about SCD is that only Black people can be born with SCD. No other ethnicity can have the disease, and that is simply not true. Sickle Cell Disease can be found in Indian, Middle Eastern and Hispanic ethnicities as well. "SCD does not discriminate based on ethnicity or skin color. Anyone of any ethnicity can have SCD. Whether children are born with SCD depends only on their parents' SCD status, not their ethnicity. In fact, SCD is also found in people of Indian, Middle Eastern, Hispanic, and Mediterranean ethnicities." (Sickle Cell, 2020). This myth is still floating around today, and I can only hope that people become more educated and learn about things they are not 100% sure about.

People seem to think that you can "catch" SCD, like it is the common cold. Sickle Cell is an inherited disease that you must be born with. It is screened at birth with a blood test once you are born. "SCD is a genetic condition present at birth. People only have SCD if they inherit an

abnormal hemoglobin gene from each parent. Therefore, children can only have SCD if both parents have an abnormal hemoglobin gene. It is not possible to get infected by the blood of someone who has SCD. SCD is not contagious, and you cannot “catch” SCD” (Sickle Cell, 2020). I know when I was born, the newborn screening test did not include being tested for Sick-le Cell. But now it is mandatory that when a baby is born that the test is done between 24-72 hours of being born. “NBS programs in the United States and Canada have incorporated SCD into the existing laboratory algorithms, and initial screening is now performed in conjunction with testing for other selected congenital disorders. Both countries perform screening using blood spots collected by heel-prick between 24 to 72 h of age, or prior to discharge from the hos-pital or birthing facility.” (El- Haj & Hoppe, 2018, p. 4). With this test, people know from birth that they have this disease, so there is no way it can be caught and passed on to someone else.

One of the main symptoms of SCD is pain; this requires patients to take strong pain reliv-ers such as opioids. Over time, the body may get used to a certain dose of pain medication and require a higher dose. This can leave some medical staff to believe that SCD patients are “drug seekers”.

People with SCD are not seeking drugs when they come into the ER; they are simply looking for ease from their pain. There are stigmas and racial bias in the health care system when it comes to Black people seeking pain management. For many centuries it is has been thought that Black people do not feel pain or that skin colour defined how you felt pain (e.g. Black skin is tougher than White skin) “We examine whether this racial bias is related to false beliefs about biological differences between blacks and whites (e.g. black people’s skin is thicker than white

people's skin)" (Hoffman et al, 2016, p. 4296). These ideas about being a drug seeker are what the health care communities get wrong about people with SCD. These thoughts and ways of caring for Black people need to change in healthcare. If not, it could pose more of a greater risk to our health and well-being for future care.

Lastly, another myth about SCD is that people with the disease die young. This used to be a common belief among people, especially when SCD was first being studied. Now, people with SCD are living longer due to better health management, medication improvements and self-care practices; people with SCD are living well into their 50's and beyond. "A new study published in Blood Advances finds that the average life expectancy of publicly insured patients living with SCD is roughly 52.6 years. In contrast, the CDC reports that the average life expectancy in the United States is 73.5 years for men and 79.3 years for women, demonstrating the considerable burden SCD can have on affected populations" (American Society of Hematology, 2023). I remember when I was at an old job and I shared with a colleague that I had SCD, the first thing they said to me was that they knew someone who died of this disease. Trust me, this was not what I wanted to hear, but sadly it happens more than I would like.

Living with SCD is not easy and comes with a lot of misunderstandings from the health-care system, family, and the public. One thing I have learned is to not listen to the negativity that comes with this disease and have decided to live my life on my own terms.

I hope readers walk away with a better understanding of Sickle Cell Disease and have unlearned some harmful misconceptions about the disease. In my next chapter, I will talk about my life and experiences living with Sickle Cell Disease.

My Life with Sickle Cell Disease

I was born in Toronto, Ontario to Jamaican Immigrant parents who came here to try and give their future children the best life possible. I am the only child for my parents who has Sickle Cell Disease and that has brought up many challenges. From countless days/overnight stays at Sick Kids Hospital, appointments that would go from 9AM to 3PM, many missed school days and painful crisis episodes that seem to have no end in sight. You can say that my parents and I fought this battle together.

When I was younger, dealing with SCD was not easy. I would have much more frequent pain episodes, missed a ton of school, which would require me to need a tutor just so I could stay on top of my schoolwork. Along with surgeries, which included the removal of my gallbladder and spleen, SCD gave me no breaks in my younger years.

As a child, a lot of pain occurred in my back, legs, or arms. Most people with SCD experience pain in the major parts of their body, even though pain can happen anywhere where blood flows. “The majority of medical contacts in sickle cell disease (SCD) are for exacerbations of pain due to vaso-occlusive episodes, commonly called “crisis”. Vaso-occlusive pain in SCD is classically described as occurring in the back, chest, and extremities.” (McClish et. al, 2009. p246). These locations in my body caused great pain that would not get much relief until I was admitted to the hospital and given IV medication that my at-home treatment could not ease.

Like I mentioned earlier, my younger years were filled with a lot more pain and absences from school. From birth to about the 5th grade were my tougher years dealing with SCD. Schools were not too accommodating of my life with SCD, and it took a lot of advocating from my parents to get the support I needed in the classroom. One of my biggest needs in the classroom was

having a water bottle on my desk to stay hydrated and having access to the washroom. Staying hydrated while living with SCD is important to help keep the blood cells moving through the veins smoothly and to prevent sickling. “When you have sickle cell disease, water is also extremely important for your blood flow. When your body does not have enough water, blood becomes thicker. Your body will also create more sickled cells, which makes a pain crisis more likely.” (The Hospital for Sick Children, 2024). Thankfully, once my teachers were educated about my needs inside the classroom, they were more than willing to be supportive and assist me in what I needed.

Entering my teens and early 20’s with my SCD, I started to become my own advocate inside and outside of the classroom. I was able to talk to teachers on my own about what I needed, I had friends who would let teachers know I would be away from school due to hospital stays and as I entered post-secondary, I was able to meet with my professors and the accessibility department ahead of time to get everything I needed to be successful in school.

Now that I am an adult and have a lot more life experience dealing with SCD, I can proudly say that I overcame a lot. Through pain episodes, changes in my body, and how I choose to cope with SCD, I can say that I’ve dealt with my fair share of challenges, and I continue to do so. I never know what each day will bring- I have my good days and not so good days dealing with chronic pain, but I choose to live with it all. I am very proud of myself and how far I have come with my health. Historically, people with SCD have not lived very long and I’m so grateful that I am able to share just a little bit of my life with managing this disease through the words of this paper.

My goal for this paper is to unravel the gaps on the healthcare system and those living with SCD and how our needs are not met when we walk into emergency departments. Many of us go unheard, dismissed, or our pain is not taken seriously, leaving damaging consequences in the end. I also hope to tie in my lived experience in this paper while not forgetting about those that have paved the way for me to get here.

Critical Disability Studies and Sickle Cell Disease

Critical Disability Studies can be defined as “view disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations” (Reaume, 2014, p 1248). People with SCD have become a lot more vocal about sharing their everyday lives with this disease. Through blog posts, videos, or public speaking, the lived reality of a person managing their disease is just as important as policy documents.

From the beginning of its discovery, SCD has been something that needs to be “studied” or understood by medical professionals. SCD can first be traced back to 1904 where the first microscopic observation was found. “Most histories of sickle cell commence in 1904, the date of the first microscopic observation of sickle cell, or in 1910, the first publication of the scientific paper of that observation (Herrick, 1910)” (Dyson, 2019, p. 46).

When Sickle Cell Disease was being studied, many patients would be viewed as subjects that were put on display to be seen by others. “People with SCD were assumed to be chronically ill with shortened life expectancy but made interesting case studies for display to medical students” (Dyson, 2019, p. 75). Being a person who is disabled, it is common to be looked at as

needing a cure or some type of treatment. There is never any focus on how society can change to integrate the person and how they choose to live their lives with SCD.

Lived Realities and SCD

One way that I have made sense of my own lived realities of living with SCD is through blog posts. Between the years of 2023-2025 I started doing a lot of writing about my experiences living with Sickle Cell Disease and choosing to share it online. Before creating blog posts, I had a Tumblr page between the years of 2014-2024. This blog became a place for me to share the ups and downs of daily life with SCD – something that many medical professionals do not get a chance to witness.

Looking online at the time, I did not see many active Sickle Cell blogs that were current. This is what led me to start my own Tumblr page. Starting my own blog meant that I could share my own experiences online without anyone knowing exactly who I was. I am not ashamed of saying that I have SCD, but I just wanted a space where I could express myself freely to the world with very little risk.

Blogging became an outlet for me to share how I was feeling on a day-to-day basis. I shared such things as medication intake, being tired and fatigued as well as sharing milestones like getting on an airplane and the importance of advocacy. Through having my blog, I was able to connect with other SCD patients who supported my posts or celebrations along the way.

As I stepped away from blogging as an individual, I started working on a patient and healthcare provider education initiative with a hospital that provided me with care. I was able to

connect with other health partners to create something fun and creative that also helped shed light on SCD.

I made many blog posts for this clinic. Some of my posts ranged from talking about Capitalism, menstrual health and even my personal favorite; “*Inside the patients waiting room*” this article specifically talked about the fear/anxiety that a patient may feel when they are at the hands of a medical professional and the invasive questions that may arise.

Inside the Patient’s Waiting Room connects to Critical Disability Studies because there is a stigma against Sickle Cell patients who are perceived as “drug seekers” when just needing medication that helps us feel better. A lot of the time, people with invisible disabilities are not believed or looked at as having something wrong with them from the outside. This fear of not being believed may make us nervous to ask for pain medication at our appointments. “Substantial show that healthcare providers often view SCD patients in VOC as drug seekers because of the stigma associated with needing and seeking opioids for SCD treatment. Furthermore, there is evidence of racial bias within the healthcare system that poses substantial barriers for patients with SCD” (Osborne et al., 2021, p. 47). Often when SCD patients go in for their annual appointments, they may need a refill on their pain medication which would result in health care professionals looking back through their chart of their last refill. This could cause a patient a ton of anxiety because doctors do not understand that we need these medications to function, to feel less pain, to feel a sense of ease. Instead, we are examined by how many pain meds we have gone through since our last visit.

Critical Disability Studies also looks at how race, gender, class, and sexuality can influence the wider populations around an individual. “Critical disability studies also examines how disability intersects with race, gender, class and sexuality in ways that influence wider power relations and personal experiences.” (Reaume, 2014, p. 1248). It is no secret that those who live with SCD can live in areas or neighborhoods that don’t have access to the medical care that they need. Often, leaving them to travel long distances for appointments or medical attention.

Most times, people living with SCD have a hard time getting to their appointments due to the distance and travel issues. I remember growing up, and the distance from our apartment to the hospital was very far. Luckily my parents had a car, and we were able to get there when needed, but if a person had to rely on public transportation, it would take them a long time to get there. “In Toronto, which houses Canada’s largest as well as oldest SCD clinic and is home to a significant number of people with SCD, such figures spatially align with racialized and newcomer communities that are under-resourced for healthcare and social services as well as public transportation” (Srikanthan, 2024, p. 3). When a person has a hard time gaining access to a centre that can help improve their health, that creates a barrier. It is not an individual problem, but more of a social problem – this is where the social model of disability can be of understanding.

Social Model of Disability and The Health Quality Standards

The Ontario Health Quality Standard for Sickle Cell Disease (HQS) reflects best practices in healthcare for SCD patients from the medical model perspective, including all the things they should expect to receive once they enter the hospital. However, the document fails to outline a social model of disability approach to care. The social model looks to disrupt the medical mod-

el and how a person's illness is not their fault, but how can society be fixed to let the person be themselves. “The “social model of disability,” interprets disability as a construct imposed by external powers (e.g., medical, legal and governmental systems). In this model, there is a difference between impairment — a practical restriction — and disability — a difference promoted by society without considering impairments.” (Reaume, 2014, p. 1248). So, while SCD is mostly studied from a medical background, it is important to factor in ways that society is failing the individual.

For example, the HQS mentions removing access to barriers of care for people who have a hard time getting to the clinic due to travel or problems accessing the providers or clinics due to phone availability. “Difficulties accessing a clinic or provider (e.g. lack of access to a primary care provider or comprehensive care, inability to contact providers or clinics, extended wait times, inconvenient clinic hours, travel/transportation)” (Ontario Health, 2023, p. 12). While this is a step in the right direction, what are ways to improve the health care system from the inside to better support the patient.

In my personal experience, I have been hesitant to reach out to my clinic because I know that they only have one nurse on site to manage phone calls and other medical responsibilities. This leaves me rarely reaching out to my medical team unless necessary, requiring me to manage my own health concerns on my own. Instead of the individual having to manage their own health, I would suggest there being more than one nurse on call to assist like they have at other clinics I have attended.

When the HQS doesn't factor in how each hospital or clinic is managing the number of staff they have available for their patients; they are leaving a vulnerable group to manage themselves. This is a fault of the public systems/governments, and not the person.

Community Support Groups

When a patient is left with no clinic to turn for pain meds, they may reach out to other peer support groups. One group that I used to be a part of had a group chat open to all patients who had SCD; members of the group chat included caregivers, health care professionals, or people living with SCD. This group chat was also open to members from all over the world who were welcomed to join as well via link.

The group chat had "rules" to follow in terms of content that you were allowed to share, or if you wanted to post something of your own, you needed approval from the administrators. Anything a member wanted to share had to be SCD related, and the group felt very strongly about not posting things for monetary gains (e.g. no Go Fund Me links). If a member of the group were to post links or content that the admins felt were not appropriate, it would be removed. Admins would always promote sessions that people could attend virtually or in person and mainly just showcase what they were doing in the Greater Toronto Area for SCD.

Overall, the group chat could be seen as a positive environment for dealing with SCD. Providing support, comfort, and education for members while allowing members to be vulnerable to one another and share similar experiences.

One thing I did notice in this group chat was from time-to-time members would reach out and ask if anyone had any medication that they could spare because their clinic was closed or not

open (mainly due to a long weekend or holidays). I found this troubling because members should not have to rely on their peers for medication; that's what the clinics and hospitals are for.

This activity did not happen often, but when it did, it took me by surprise. Personally, I am someone who manages my SCD well. When I am low on pain meds, I always make it a point to call my pharmacy or clinic right away so I can get a refill or new prescription. I'm not saying other people do not manage their SCD well or that they are being irresponsible, I get that life happens, and you may think you have enough pain meds, or a crisis comes and you are stuck with a low amount leaving you even more stressed out and out of options.

On one hand, I fully support online SCD community groups – they can be a great source of information, connection, and relationship building. On the other hand, it can be dangerous if not monitored appropriately, leaving people to become their own doctors and self-managing their pain.

Critical Disability Studies looks at other ways people can show up in society as their full self. Not every person may want to go down the route of being in hospitals and taking medication to ease their pain. The social model of disability highlights the importance of support groups and how people may look outside their local hospital for help when they are in a crisis. Coming up, I will discuss the 8 quality standards developed by Ontario Health that were put in place to help support Sickle Cell patients when they enter the emergency room.

Eight Quality Standards

In January 2023, Ontario Health developed the Health Quality Standard to help improve the care that patients with SCD face in the hospital. The document outlines 8 high-quality standards that people with SCD should receive when seeking care. “Quality standards outline what high-quality care looks like for conditions or processes where there are large variations in how care is delivered or where there are gaps between the care provided in Ontario and the care patients should receive” (Ontario Health, 2023, p. 1). The importance of this document is to show the systemic barriers that Black people with Sickle Cell Disease face in the healthcare system which negatively impacts their quality of care. “In Ontario and across Canada sickle cell disease mostly affects racialized people, particularly those who identify as Black. These people often experience racism and anti-Black racism in their interactions with the health care system, which negatively impacts the quality of health care provided to them” (Ontario Health, 2023, p. 5).

In this section, I will analyze each of the eight quality standards, outlined in the HQS document from the perspective of Black Disability Studies and my own experience.

Racism and Anti-Black Racism

The first outlined quality standard concerns anti-Black racism and racism. Anti-Black racism and racism are barriers to individuals living with SCD when it comes to them seeking care in the hospital. People with SCD should be able to enter a health care facility that is free from discrimination, racism and stigma. “People with sickle cell disease (and their families and caregivers) experience care from health care providers within a health care system that is free from racism and anti-Black racism, discrimination and stigma” (Ontario Health, 2023, p.10).

SCD patients should be able to walk into a hospital, clinic, or emergency room and know that they will not be discriminated against based on the colour of their skin.

The racism that Black people living with SCD face runs deep. It is in the health care system, educational system along with the social and justice system. These hurdles will make it difficult for a person with SCD to access care. “The systemic discrimination that harms racialized populations and groups living with health-related social needs and creates barriers to and disparities in accessing and receiving appropriate health care and community and social services. This type of racism often involves labelling, devaluation, judgment, and/or the social disqualification of a person based on their health condition, leading to negative health outcomes. Anti-Black racism is associated with policies and practices rooted in Canadian institutions such as education, health care, social, and justice systems that mirror and reinforce beliefs, attitudes, prejudices, stereotyping, and discrimination toward people of African descent.” (Ontario Health, 2023, p. 11).

For me, personally, I have been lucky that over the years of my life, when I have been admitted to the hospital, I have not been discriminated against, and I have not had any unfortunate or racist beliefs placed on me when it came to being treated. I understand that I am lucky, but many Sickle Cell patients have spoken about how they have been treated badly within the health care system, and some will even avoid the ER altogether.

The HQS outlines ways that providers can remove barriers in health care settings, so patients with SCD feel more comfortable when entering the hospitals. Some examples include reducing inconvenient clinic hours, long travel times, and reducing wait times. “Difficulties accessing a clinic or provider (e.g., lack of access to primary care provider or comprehensive care,

inability to contact providers or clinics, extended wait times, inconvenient clinic hours, travel/transportation” (Ontario Health, 2023, p.12). All patients with SCD who are experiencing pain and need to visit the emergency department deserve to be treated with care, respect, and dignity. We should be heard, listened to, and given what we need for treatment. Regardless, if you enter a clinic, hospital or doctor's office, how you are cared for should be the same.

A lot of clinicians mention how they have never treated a patient with SCD before and are not familiar with treatment plans for us. Treating a patient with SCD is the same as treating any patient walking through the door. Respect, compassion, and dignity, along with trust, are important tools. Having hospital staff who are knowledgeable about SCD and being provided workshops on how to provide care in the emergency department are what make patients like me and others want to return to your health care facility in the future. Without these key characteristics, SCD patients will unfortunately opt to stay home, seek care from their loved ones, and try to feel better on their own.

Comprehensive Health Assessment and Care Plan

The second quality standard references comprehensive health assessments and care plans for those with SCD. Every person living with SCD deserves access to quality health care by health care providers who are knowledgeable about SCD. This means that patients managing their SCD have a yearly health examination by a clinic that can give them an individual, personalized, and person-centered care plan. “People with sickle cell disease have a comprehensive health assessment at least annually from an interprofessional care team at a dedicated sickle cell

disease center to develop an individualized, person-centered care plan. The assessment and care plan are documented and shared with the person's circle of care" (Ontario Health, 2023, p. 15).

A comprehensive health assessment can include things such as screenings for any sickle cell complications, clinical exams of the lungs, spleen, heart, and liver, discussing treatment options like blood transfusions or hydroxyurea therapy, and providing information or support on where to get help if dealing with mental health issues and psychosocial needs. Ideally, a person should be seen in person for these assessments but can sometimes be done through virtual communication. "This assessment is ideally done in person but may be done through telemedicine or other technologies. It should include an assessment of patient experience and patient-reported outcome measures that are monitored over time." (Ontario Health, 2023, p. 16).

I have had all my doctor appointments in person, except for the COVID-19 pandemic where I had some virtual appointments. At my appointments they usually go through how my health has been over the last 6 months and if anything, new has come up with my health. When it comes to secondary appointments like (MRI's, eye exams or bone density tests) those are scheduled months in advance, and my hematologist usually gets a report on those results.

The centers that a person with SCD attends for their appointments should specialize in preventative care for people with SCD. This centre should connect the patient with other health care providers that work alongside the patient that can provide support and adequate care. "A centre that provides preventative and specialized care for people with sickle cell disease. This centre is connected to and integrated with the person's local health care team, which consists of the person's other sickle cell disease providers (e.g. individual health care professionals and smaller centres), to provide support and collaborative care." (Ontario Health, 2023, p. 17)

I would say that this quality standard resonates with how I receive care. All my doctors are kept updated with the tests that get performed on me and when I do visit the doctors, they may briefly touch on when I had a test done and when I am due for another one. Both my hematologist and family doctor are kept informed about my health through digital copies that get sent to one another.

The individualized care plan is a written or digital copy of the best way to care for a person with SCD. This plan could be linked to other areas of care that a person has (like education, employment, or housing). The care plan is updated regularly and is accommodating in a cultural and respectful manner. “A written document (printed or ideally digital) detailing the person’s plan of care. The plan is individualized, based on the person’s ongoing care needs and linked to other plans they have with respect to care and support, such as education, employment, and housing. The care plan is updated regularly and accommodates the person’s preferences in a culturally and linguistically appropriate manner” (Ontario Health, 2023, p. 17)

As a person living with SCD gets older, who they choose to consent to about their health care needs may change over time (e.g. when a child is under 18, usually the parents/guardians are the first point of contact compared to when a person is now over the age 18, they can decide who knows about their health and what gets disclosed). “Consent to share information within the circle of care is generally implied; for example, when a patient accepts a referral to another health care professional. For young people capable of providing consent, however, it is important to explicitly ask them who they consent to share their information with. If the young person consents to sharing with their parents and caregivers, or if the parents and caregivers are the substi-

tute decision-makers appointed under a “Power of Attorney for Personal Care,” the care plan is also shared with them” (Ontario Health, 2023, p. 17).

Now that I am over the age of 18, I go to most of my appointments alone and don’t have my parents attend unless I want them to. If they do come with me, they are usually in the waiting room, and I speak to the doctors privately about my health. Usually, if I want to tell them what is going on with my health, I will let them know after the appointment.

Walking into yearly exams alone means a person with SCD may not know what to expect on their first couple of appointments alone. Some things that may be brought up during an appointment can be any pain that you’ve been experiencing, getting some information on the types of complications you could have while living with SCD and what your mood is like (e.g. depression or anxiety), living situation and employment status.

The clinicians at these Sickle Cell Disease centers are there to help manage and create an individualized care plan for people with SCD. They should also be completing a health assessment on you that has been documented and updated with any changes to your health care needs. Finally, they should inform you about any research opportunities that may become available to you or that you would like to participate in the future. “Perform and document a comprehensive health assessment at least annually for people with sickle cell disease to develop and manage individualized, person-centered care plans. For infants and children, perform and document a comprehensive health assessment more frequently, with the frequency determined by age and health status. Monitor patient experience and patient-reported outcome measures over time. Share the assessments and care plans with people’s circle of care.” (Ontario Health, 2023, p. 18) “Check

regularly for any research opportunities so that you can inform and invite people with sickle cell disease to participate if they are eligible and interested” (Ontario Health, 2023, p. 18).

At my yearly appointments, I would say that I have had some of these practiced on me. They do ask how my pain has been, I have been introduced to any research that the hospital would like participants to join, and they do update my chart when I say I have been in pain for a long period of time. (e.g. chronic low back pain). They also do a decent job of sharing my care plan with other health care providers.

Vaso-occlusive Acute Pain Episodes

The third quality standard outlined concerns vaso-occlusive acute pain episodes. When a person with SCD enters the emergency department, they are most likely having a sickle cell crisis or vaso-occlusive pain episode. A vaso-occlusive pain episode happens when sickled red blood cells get blocked in the blood vessels and causes pain. This can happen anywhere in the body but is most common in the bones or bone marrow. “A vaso-occlusive acute pain episode is an intermittent, recurrent acute severe pain episode. It is caused by vaso-occlusion (clumps of sickled red blood cells that cause blockages in blood vessels) most commonly in the bones of bone marrow. An episode presents as excruciating pain of sudden or gradual onset, most commonly in the extremities, chest, and or/back”. (Ontario Health, 2023, p.20).

If a person with SCD is having a crisis and they have tried to manage their pain at home with no luck, they may take themselves (or a caregiver may go with them) to the hospital to seek medical attention. When a patient with SCD enters the ER, they should receive care and be assessed in a timely manner within 30 minutes of being triaged or 60 minutes of presentation.

Upon being discharged from the hospital, a plan should be made so that the patient can manage

their acute pain at home. “People with sickle cell disease who present to an emergency department or hospital with vaso-occlusive acute pain episode receive a timely pain assessment and clinical assessment. Their treatment begins within 30 minutes of triage or 60 minutes of presentation. Before discharge, they are involved in the development of a plan for continuing to manage their acute pain episode at home. This plan includes management strategies and information on how to access follow-up care and support from health care providers, as needed.” (Ontario Health, 2023, p. 20).

While it would be ideal for each patient with SCD to get a plan on how to manage their pain once they leave the hospital, I can’t recall this happening to me. Sure, the doctors or nurses may mention to me to take care of myself, but there really isn’t a plan that they have given me to follow once I leave the hospital or emergency room department. I know how to continue to care for myself once I am discharged, so I don’t completely rely on the staff to tell me what to do.

When a patient with SCD feels well enough to go home, the health care team, their family, and caregivers must work together to build a management plan that will help them recover at home. Other health care providers can be included as well in this plan; this plan mainly focuses on the patients’ individual needs, preferences, and values. This plan should be shared with all healthcare providers that provide care to the patient. Some information that could be provided in this plan includes how to properly use opioids and non-opioids medication, what to do and who to contact if the pain becomes unmanageable, and how to manage any potential side effects to medication reactions. “How to use home symptom management strategies, (e.g. self-report pain diaries, the use of opioid and nonopioid analgesics), what to do and who to contact if your pain

becomes unmanageable, how to manage any potential adverse medication reactions.” (Ontario Health, 2023, p. 22).

The last time I was admitted to the hospital, I was at an urgent care and while they did great for the couple hours, I was there when it came time for me to be discharged, I did not get any information on how to care for myself like the document stated in the above. Thankfully, I know my body and know the best way for me to recover is to take it easy, drink lots of liquids and rest more.

Vaso-occlusive pain episodes are the most common reason why people with SCD go to the emergency department. These pain episodes must be taken seriously and have a major impact on a person’s quality of life. Many SCD patients worry that their pain will not be taken seriously, and gaining access to care is another major barrier to receiving care. Having a plan in place on how to manage pain outside the hospital once discharged helps to remove the barriers in accessing care and a likelihood of returning to an emergency department. “Before discharge from the emergency department or hospital, involving people (and their families and caregivers, where appropriate) in the development of a plan for continuing to manage their acute pain episode at home can significantly improve patient outcomes by reducing barriers to accessing care, which are often experienced after discharge and reducing the likelihood of readmission” (Ontario Health, 2023, p. 23).

Like I mentioned earlier, the urgent care that I went to last fall did great when it came to caring for me, however, I did not get any follow-up on how to manage my pain at home. Our pain doesn’t suddenly disappear once we get discharged from the hospital. The pain is likely still there, but not as intense as when we first went in. It is important that Sickle Cell patients get a

full picture of what happens once they enter and leave the hospital. This could determine whether they returned to that hospital or not.

Life- Threatening Acute Complications

The fourth quality standard concerns life-threatening acute complications. A person with SCD can enter the emergency department or hospital for other complications that do not include a Vaso-occlusive pain crisis. Some life-threatening complications can be acute anemia, which is a sudden drop in hemoglobin, acute chest syndrome, acute stroke, and complications of other organs in the body. It is important that if a person with SCD is showing these life-threatening complications, their pain gets assessed and managed right away. “People who present to the emergency department or hospital with or without pain associated with sickle cell disease should have their signs and symptoms assessed with priority upon arrival; that is they should be assigned a CTAS score appropriate to the severity of their signs and symptoms.” (Ontario Health, 2023, p. 28).

Once a person is diagnosed with an acute complication of SCD, their condition must be managed by their care team so they can receive treatment inside the emergency department/hospital as well outside the hospital; this includes outpatient clinics. This plan should be tailored to the individual's needs. “When a person is diagnosed as having an acute complication of sickle cell disease, their condition should be managed using established clinical guideline protocols for the complication(s) they are experiencing. An individualized, multimodal treatment and monitoring plan should be created for the person that addresses care in the emergency department as well as in inpatient and outpatient care settings; accordingly, it should be developed in consultation

with physician specialists or a dedicated sickle cell disease centre” (Ontario Health, 2023, p. 28-29).

It is important that people with SCD who experience a severe complication that can be life-threatening head to the emergency department as soon as possible. People with SCD already have a shorter life span than those without the disease due to not having to deal with acute pain episodes or acute complications. “People experiencing signs and symptoms of an acute complication of sickle cell disease should be assessed and treated promptly to reduce their risk of increased morbidity and mortality. People with sickle cell disease typically have a shorter lifespan than those without the disease, in part because of outcomes related to acute complications such as vaso-occlusive acute pain episodes, infection, acute chest syndrome and cerebrovascular conditions (e.g. stroke)” (Ontario Health, 2023, p. 30).

I have seen far too many people with SCD say how they are experiencing pain or a symptom that is unusual for them and ask other peers what they should do in times of crisis. This waiting around for other patients to dictate what you should do is valuable time being wasted that could be put towards getting to the ER and being seen by a medical professional. Our lives are precious, and sitting around waiting for a member of a group chat to tell you what to do just means you are cutting the likelihood of getting treated short.

The protocol for seeking care for both patients with SCD and the clinicians is vital. Knowing what to do when your health isn’t 100% is key. For people with SCD, they should call 9-1-1 or go to the nearest hospital if they are suddenly feeling weakness, fever, or having chest pain – even if you are not feeling pain, it is better to go in and get seen. “Call 9-1-1 or go to your

nearest hospital if you suddenly feel weak or if you have a fever, chest pain, a cough, trouble talking, or trouble breathing – even if you are not in pain” (Ontario Health, 2023, p. 29).

For clinicians, once a person with SCD presents to the hospital showing acute complications of SCD, they should be seen promptly. Even if a person does not look like they are in pain, they should have a clinical assessment performed on them. Make sure that all test results are properly documented, shared with other care plan members, and a care plan is developed so the patient knows how to manage their pain once they leave the hospital/emergency department. “Ensure that people presenting to the emergency department or hospital with signs and symptoms of a potentially life-threatening acute complication of sickle cell disease are promptly assessed and treated, even in the absence of vaso-occlusive acute pain. The severity of a person’s condition should be determined by the results of a thorough clinical assessment, rather than based on initial impressions of the person’s physical appearance. Ensure that the diagnosed condition(s) is (are) managed appropriately with an individualized treatment and monitoring plan.” (Ontario Health, 2023, p. 30).

With these plans in place for both patients and health care teams, both parties should be well prepared and have steps on what to do if they fall ill and how to care for the ill patient.

Chronic Complications

Another quality standard outlined concerns chronic complications. Individuals living with Sickle Cell Disease should be monitored by a dedicated Sickle Cell clinic that can walk them through the complications that may arise as they get older while living with the disease. Chronic complications of SCD can be both mental and physical. Some common physical/mental complications include things such as chronic pain, avascular necrosis, leg ulcers, anxiety, depression,

and insomnia. “Chronic complications of sickle cell disease can be both physical and mental. Common physical health complications include but are not limited to: Avascular necrosis (bone death due to compromised blood supply to the bone), Chronic pain, leg ulcers, ocular complications, renal complications.” (Ontario Health, 2023, p. 31-32).

It is common that people with SCD may have some mental health conditions associated with living with the disease regularly. “Common mental health issues experienced by people with sickle cell disease (and their family and caregivers, where appropriate) include but are not limited to: Anxiety, caregiver fatigue or burnout, depression, fear, feelings of despair, loneliness, and/ or helplessness” (Ontario Health, 2023, p. 31).

It is important that when a patient with SCD mentions any of the above mental health conditions to their primary care doctor or hematologist that they are recommended the appropriate steps to take for dealing with it. I struggle with anxiety and my care team is aware of this, and I make sure to seek support from my therapist when I need it.

Managing these chronic complications means that a person with SCD should be assessed closely by their clinic for any changes in their body or if any new symptoms arise. Unfortunately, when a person with SCD is seen outside of a dedicated sickle cell clinic, these symptoms could be dismissed or ignored. Keeping a close eye on Sickle Cell patients could help improve their longevity and have greater health outcomes. “Despite the serious consequences of chronic complications, they are often dismissed or misdiagnosed in settings outside dedicated sickle cell disease or other specialized centers (advisory committee consensus). Close monitoring of symptoms

and management of chronic complications before they progress can improve health outcomes and lengthen lifespans for people with sickle cell disease” (Ontario Health, 2023, p. 32-33).

Being our own advocate is very important when we walk into a care centre that is familiar with SCD or not. This means if you feel like a clinic or a health care provider is not taking your concerns seriously, don’t be afraid to seek other options. Do your research or get a second opinion if you feel as if you are not being listened to. It took me a while to find a therapist that I felt I could connect with. It does take time, but there is someone out there who will take your concerns seriously.

The HQS does mention the above symptoms of chronic complications of SCD, but they don’t mention anything about how a person should go about getting mental health treatment. For example, I went to my doctor in 2019 after feeling unwell in my body. After doing an assessment, I was diagnosed with anxiety; she gave me a referral to a 6-week group therapy and that was it. After the group therapy sessions were completed, I was on my own in terms of finding a 1:1 therapist. I feel like this is a barrier within the Sickle Cell community – not knowing how to find resources on your own after the doctor has done their job can delay a person into getting the support they need.

The HQS recognizes that more needs to be done to help those with SCD who are experiencing anxiety and depression. “Greater efforts need to be made by local health care teams with regard to prevention, early diagnosis and treatment of mental health issues to reduce the impact of these conditions on people with sickle cell disease and their families and caregivers and to improve their health-related quality of life” (Ontario Health, 2023, p. 33). My hope for the future is

that people who are struggling with SCD along with anxiety/depression do not have to go at it alone while seeking a mental health professional.

Lastly, the role of the health care provider is to monitor people with SCD for any chronic complications of the disease. If a chronic complication does show up, the person should be seen promptly or referred to a clinic that can manage their condition as needed. “Monitor people with sickle cell disease for signs and symptoms of chronic complications. For people with chronic complications, promptly, consult with and/refer them to a dedicated sickle cell disease or other specialized centre for assessment and management of their condition, as needed.” (Ontario Health, 2023, p. 34).

Taking care of the body includes all aspects – physically, mentally, and emotionally. As more hospitals and care providers get training on Sickle Cell Disease, factoring in our mental health is just as important.

Referral to Health Care Professionals with Expertise in Chronic Pain

Another quality standard outlined includes referral to health care professionals with expertise in chronic pain. People with Sickle Cell Disease suffer through an incredible amount of pain that can impact their daily lives. Due to this, patients should be referred to outside health care professionals who can offer other treatment options. “People whose quality of life is significantly impacted by chronic pain caused by sickle cell disease are referred to individual health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease and the ability to offer pharmacological and nonpharmacological interventions” (Ontario Health, 2023, p. 35).

There are many types of chronic pain that can impact a person with Sickle Cell Disease. Chronic pain can be described as pain that lasts more than 3 months. Chronic pain that is caused by Sickle Cell Disease includes pain that can be in a specific area of the body, neuropathic pain, breakthrough pain, or pain with an unknown cause. “Pain in a specific tissue or organ, commonly experienced in the chest, back, abdomen, extremities, neck or head. Neuropathic pain (pain caused by damage to nerves from poor blood supply or from persistent chronic pain and inflammation). Breakthrough pain (a flare-up or sudden pain that does not respond to usual treatment) and pain with an unknown cause, which may be an extension of recurrent vaso-occlusive acute pain episodes.” (Ontario Health, 2023, p. 35)

Examples are given of how patients with SCD may treat their pain with either pharmacological or nonpharmacological interventions. Some examples of pharmacological interventions are opioids, anti-depressants or nonsteroidal anti-inflammatory drugs (NSAIDs). Treatment with nonpharmacological interventions include psychologically based interventions like cognitive and behavioral management strategies and physically based interventions such as massages and acupuncture. “Pharmacological interventions used to treat chronic pain related to sickle cell disease include Nonsteroidal anti-inflammatory drugs (NSAIDs), opioids, anti-depressants, anticonvulsant medications” (Ontario Health, 2023, p. 35-36).

When it comes to managing SCD pain, patients and their health care providers must work together to find solutions on how best to deal with chronic pain. Both pharmacological and non-pharmacological treatment options should be taken into consideration and see what works best for the patient. “The management of chronic pain in people with sickle cell disease is complex

and challenging. It is important that the person with sickle cell disease and their health care professionals work together to make decisions about the best plan for managing their chronic pain caused by sickle cell disease” (Ontario Health, 2023, p. 36).

The current part of my body that I have the most chronic pain in is in my legs, more specifically, my left ankle, right in my bones. I deal with this pain regularly, and it goes and comes at this point. Some days I will take pain meds if I notice that the pain is getting too intense or if it is impacting my mobility. When I don’t take any pain meds, I will usually apply my heating pad and try to keep my leg elevated.

The management of pain while living with SCD is a top priority. If a person with SCD is experiencing so much pain that it is interfering with their daily routine, they should speak with their doctor about ways to alleviate their pain. “If chronic pain is having a negative effect on your life, your health care professional should arrange for you to have an appointment with a doctor or at a health centre that specializes in treating chronic pain caused by sickle cell disease” (Ontario Health, 2023, p. 37). I do make it a point to mention my chronic pain to my doctor, but right now, I don’t see any other care teams that specialize in my chronic pain. I do make it a point to get a massage occasionally, to ease any lingering pain or tension in my body.

For the clinicians, it is important to pay attention to what their patients are saying at appointments when mentioning their pain. If a patient says their pain is not easing, they should have their patients get in contact with individual health care professionals that can help them improve their pain levels. “Refer people whose quality of life is significantly impacted by chronic pain caused by sickle cell disease, whose goals for pain control and function are not being met,

or who have not benefitted from other multimodal pain treatments to the individual health care professionals or to a chronic pain centre with expertise in treating people with chronic pain related to sickle cell disease” (Ontario Health, 2023, p. 37).

Psychosocial Assessment, Information and Support

The seventh outlined quality standard concerns psychosocial assessment, information, and support. People with SCD must have routine psychosocial assessments to identify any needs that are not being met by a barrier when accessing care. Those who are not having their needs met should be offered information and support that will get them the care that they need. “People with sickle cell disease (and their families and caregivers, where appropriate) have regular psychosocial assessments to identify any psychosocial needs or barriers to accessing care. Those with unmet psychosocial needs are offered information and support to address these needs.” (Ontario Health, 2023, p. 39).

There are different types of assessment tools that are used on children/adults who live with SCD. For example, for children and adolescents with SCD, some psychosocial screening tools are The Psychosocial Assessment Tool (PAT). This is a screening tool used by the parent to assess the psychosocial risk of families of children with medical diagnoses. For adults, some screening tools that they have available include The Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me). This is a patient report system that assesses the physical, social, and emotional impact of SCD on adults.

Psychosocial needs could also be needed in other areas of a person's life with SCD. Such areas could be employment, housing, mental health, and financial security. “Psychosocial needs include but are not limited to those in the following areas: Employment (e.g. accommodations to

maintain health, for example by staying hydrated or taking frequent breaks), Financial security, Housing, Mental Health, Social connectedness” (Ontario Health, 2023, p. 40-41).

Overall, this section is meant to provide information on how people with SCD should be cared for and the assessment tools available to them. Personally, for me, I can’t remember having these tools given to me, or I never filled out one as an adult. When I was reading this section of the HQS, these assessment tools sounded unfamiliar to me. Usually at my appointments, I get asked how I am doing as a whole, but I can’t recall these tests being performed on me as a child or doing one now as an adult.

It is the responsibility of the clinicians to assess you at your appointments for any psychosocial needs or any issues accessing barriers to care. Clinicians should also be compassionate, work on building trust with their patients, and show a general interest in their patients' health and well-being. “Showing a genuine interest in their health and well-being will enable them to open up during psychosocial assessments and ask for help they may need. Incorporate any identified psychosocial needs into the person’s care plan” (Ontario Health, 2023, p. 43). My health care providers seem to take a general interest in my life when I go in for my appointments and make it a point to jot down any new things going on in my life. But outside of that, I am doing what I need to do to feel complete.

Transition from Youth to Adult Health Care Services

The final quality standard is transitioning from Youth to Adult Care in the hospitals. This stage usually happens when a young person is now going to be seen with an adult hematologist. The young person will work alongside their family and health care provider who will help support and guide their transition. When the family and young person feel like the transition is com-

plete, they will inform the health care provider. “Young people with sickle cell disease have a designated health care provider for the transition from youth to adult health care services. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process. The provider continues to provide support until the young person (and their parents and caregivers where appropriate) confirms that the transition is complete.” (Ontario Health, 2023, p. 45).

When it comes to who will guide the young person into transitioning, anyone from the health care services may help. That could be a nurse, social worker, a transition navigator, or a primary caregiver. Overall, it is a shared responsibility between all staff members who have been a part of the young person’s care plan. “The young person (and their parents and caregivers, where appropriate) helps decide who this provider will be. In some instances, it may be a nurse, social worker, or primary care provider. In other instances, this provider may have a job title such as “transition navigator,” “transition lead,” “transition coordinator,” “transition worker,” or “case manager.” (Ontario Health, 2023, p.45). I had a transition navigator when I was going from pediatric care to adult care, and I would say that the transition was smooth, and I did not run into any problems going from one care team to the next.

The purpose of the transition is to make sure there are no gaps in the young person's care as they move from one hospital to another. This is where the designated health care provider comes in. They have the job of overseeing the transition process and are the main connection in linking the person to other providers if they have more than one care provider. “Although all of the person’s health care providers have a shared responsibility for the young person’s transition, the designated health care provider oversees and coordinates the transition and provides transition

support. They are the main link with other providers, particularly if a young person receives care from more than one service or provider. They arrange appointments for the young person, act as their support person and as an advocate, and guide them to other services and sources of support” (Ontario Health, 2023, p. 45-46).

Finally, the switch from youth care to adult care can be a challenging time for those living with SCD; they could also be experiencing other life transitions as well (e.g. post-secondary changes, employment) so the help and guidance from a health care provider is crucial. Many people with SCD are now living longer, which requires a health care system that is designed to manage the shift from one major life event to another. “People with sickle cell disease should receive appropriate care throughout their lifespan and experience seamless transitions between services and health care providers. Advances in treatment have led to people with sickle cell disease living longer; as a result, there is a crucial need to improve capacity within the adult health care system to provide appropriate continuity of care for young people transitioning to adult care” (Ontario Health, 2023, p. 46). As the document states, a young person transitioning from pediatric care to adult care may have other areas of their life that they are also navigating. I remember at the time of me going from one hospital to the next I was also balancing the change from high school to college. So, it can be a big change in a lot of ways for a young person. Feeling supported in all areas of transitioning is essential.

These 8 quality standards help give an understanding of the type of care that a person with SCD should receive when they enter the emergency department. Time, compassionate care, and listening to a patient with SCD are very important when it comes to seeking treatment. Sickle Cell Disease affects everyone differently; as well in this section I talked about how this docu-

ment helped shape my health care experiences or where it fell short. In the next section, I will talk about alternative care options for people with SCD who may not want to go down the traditional path with medicine.

Sickle Cell Disease and Alternatives to Care

Not every person living with Sickle Cell Disease chooses to stay on the path of being treated medically by doctors. Some people choose to continue taking prescribed pain medication along with vitamins while others choose to find a more natural approach. How someone chooses to manage their SCD is completely their choice and up to them. These are just other forms of management.

Hydroxyurea & Sickle Cell

Hydroxyurea does not fall into the natural remedies category of managing SCD. I thought it was important to mention this treatment type because it is well known in the SC community as being a medication that can lessen pain crisis and improve blood flow. This medication has been known to reduce pain crisis for those living with SCD and raise the levels of hemoglobin in a person's body. This medication does come with potential side effects like nausea, vomiting, and infertility. “Hydroxyurea, a myelosuppressive agent, is the only effective drug proven to reduce the frequency of painful episodes. It raises the level of Hbf and the hemoglobin level. It usually decreases the rate of painful episodes by 50%” (Agrawal, et. al. 2014, p. 91).

A lot of children, teenagers, young adults, and adults are strongly encouraged to start taking this medication as soon as possible. For me, I was hesitant to start taking this medication because I did not know anyone else who took it, and I was worried about the side effects I read

about (like thinning nails or hair). Luckily for me, I have not had any of the side effects that have been mentioned above happen to me, and I get monthly blood tests to see how the medication is impacting my body.

Hydroxyurea has many benefits if taken by an individual and can help with the overall quality of their life. By taking hydroxyurea regularly, it could reduce anemia, have less acute chest pains, and less blood transfusions. “Hydroxyurea helps reduce serious symptoms such as pain crises and acute chest syndrome. It can also improve anemia and reduce the need for blood transfusions.” (National Heart, Lung and Blood Institute, 2024).

This medication is well known in the sickle cell community, but it doesn’t always work for everyone. Sometimes it takes a while to see the long-term results on a person's body, or a person's body may not accept the medication. This may require a person to look at other management options.

CAM and Sickle Cell Disease

Complementary and Alternative Medicines (CAM) are what some people with SCD use to manage their pain. CAM is a more holistic approach to treating pain and is not backed by medical professionals. “Many people with SCD try complementary and alternative medicine (CAM) to control pain. CAM treatments differ from traditional medical treatments because they are not based in science. They do not replace traditional medical treatments but may provide additional pain relief.” (Sickle Cell, 2026).

Most people with SCD may try some form of CAM in their life. Especially if taking pain medication all the time gets draining on one's body. Some examples of CAM could be yoga, “vi-

tamins, herbs and supplements, deep breathing, hypnosis, and meditation, and acupuncture” (Sickle Cell, 2026).

CAM is more common in developing countries than it would be in developed countries. CAM can be passed down from past generations and thought to be very useful in healing the body. The benefits of the CAM approach are feeling less anxiety, depression, and less pain in the body. People who do use CAM also have said they have less side effects compared to opioid use. “CAM may be appealing to those wanting a holistic approach to health. Most studies show CAM as helpful in managing pain, depression, and anxiety in those with SCD. People using CAM report less pain and fewer side effects than opioids.” (Sickle Cell, 2026). In my family growing up, there were some ways that my family healed my body, whether they knew they were practicing CAM approaches or just doing things they have seen the previous generation do before them. For example, my mom would rub me down in rubbing alcohol and wrap me up in a blanket to help ease my pain and sweat out the colds I would have.

Complementary alternative ways of treating the body can work for some people, and the decision to practice these treatment options are personal. It can be based on an individual's cultural background along with knowing what works best for their body.

In the following chapter, I will discuss the Anti-Black racism that Black people face in the hospitals while dealing with their Sickle Cell.

Anti-Black Racism and Sickle Cell Disease

What is Anti-Black Racism?

Anti-Black Racism can be defined as “policies and practices rooted in Canadian institutions such as, education, healthcare and justice that mirror and reinforce beliefs, attitudes, prejudice, stereotyping and or/ discrimination towards people of Black-African descent.” (Black Health Alliance, 2026).

The idea of how Black people should be treated especially in the medical field can be traced back to slavery. For example, The Tuskegee Syphilis experiment – Black African American Men were left untreated of the disease when penicillin became available. Instead, they were treated with placebos. “The Tuskegee experiment began in 1932, at a time when there was no known cure for syphilis, a contagious venereal disease. After being recruited by the promise of free medical care, 600 African American men in Macon County, Alabama were enrolled in the project, which aimed to study the full progression of the disease.” (Nix, 2025).

The Black body is not valuable in the eyes of society. For decades we have seen many teenage Black boys and girls, Black Women and Men being killed or treated horribly (resulting in death) at the hands of police, or the health care system. Also, these deaths are filmed and broadcasted over the internet so it can be replayed multiple times while not factoring in how heavy it is for Black people to relive the trauma of anti-Black violent events continuously.

Black Canadians face many challenges when trying to just live their daily lives. In fact, many people think that racism doesn't exist in Canada or it is not as prominent as it is in America. That couldn't be further from the truth. Black Canadians deal with discrimination in big and

small ways. Some examples include violent attacks or racial profiling. “Today, Black Canadians experience health and social inequities linked to processes of discrimination at multiple levels of society, including individual, interpersonal, institutional, and societal discrimination. Experiences of interpersonal racism can be overt (e.g. harassment, violent attacks), or subtle and pervasive in the form of daily indignities well-documented examples at institutional and societal levels include racial profiling; over-policing (e.g. surveillance, harassment, excessive use of force)” (Government of Canada, 2026).

When social inequities impact a Black person, they may become stressed out, worry, develop mental health impairments about how to move through the world safely. These fears can also be passed down through generations which determine how successful the next generation will become. “Inequities in access to education, income, employment, housing, and food security can drive inequities in health and wellbeing. Here, too, there are intergenerational effects, like the inability to transmit wealth, which can shape the life chances of each new generation.” (Government of Canada, 2026). We’re living in a time now where Black people are starting to unlearn a lot of the harmful practices that we have seen or learned about and are trying to do better for the generations that come after us. Still, with these new ways of thinking and doing, society still doesn’t see Black people in a more positive light.

Sickle Cell patients face discrimination when they walk into an emergency department after battling a painful crisis at home to come and seek treatment for their pain after their at-home care was unsuccessful. Too often, Sickle Cell patients are labelled as drug seekers when compared to their non-racialized counterparts. “In sickle cell disease, systemic racism has always

been very real as individuals with the disease presenting in Canadian hospitals with vaso-occlusive crisis (painful episode representing the hallmark of the disease) are treated as drug seekers compared to their non-racialized counterparts presenting with pain.” (Sickle Cell Awareness Group of Ontario, n.d.). When going to the ER, a lot of SC patients worry about how they “look” and if how they are presenting themselves will determine the kind of care they get. I know from personal experience, I have done mental calculations in my brain about how I look. If my hair is freshly done compared to my hair looking like a mess, will the hospital staff think I am lying about my pain?

When a SC patient gets admitted to the hospital, they may find ways to distract themselves from the pain they are feeling. Distractions could include playing a game on your phone, talking with a loved one, or watching a show. “Do something to take your mind off your pain. Watch TV, listen to music, or talk on the phone” (Smith, 2022). Just because a patient with SC looks fine or they are laughing doesn’t mean that our pain has suddenly disappeared. We have learned over the years to distract ourselves, and we know how bad the pain can get if we continue to focus on it. Not every SC patient comes into the ER screaming and yelling out in pain like how it is depicted in the media. Many of us know that if we act out or do anything out of character, it could result in worse treatment from health care professionals.

In the future, I would like to see health care professionals take a more empathetic approach to how they handle patients who have Sickle Cell Disease. Sickle Cell Disease affects people differently; just because two people have Sickle Cell Disease, doesn’t mean they are going to need the same type of treatment.

Health care professionals treat members of the Sickle Cell community like a monolith, or they have never dealt with a SC patient before. From the previous reasons I have given above about discrimination and racism towards Black Canadians you can see why SC patients don't feel safe entering hospitals.

I hope I have opened your eyes to the detrimental ways that anti-Black racism impacts the health of Black Canadians and people living with Sickle Cell Disease. There still needs to be more work done on how to remove these barriers for Black people so they can get the same access to care like everyone else.

Intersectionality, Black Women and Pregnancy

For some Women, becoming a parent is an important part of the life cycle. Bringing life into the world and raising a little human is one of life's greatest accomplishments; but what happens when you are a Black Woman, who wants to be a mother, you have Sickle Cell Disease and are at the hands of so many different intersections?

What is Intersectionality?

Intersectionality can best be defined as “How structures make certain identities the consequences of the vehicle for vulnerability”. This is how Kimberle Crenshaw described it in her speech on *Intersectionality and Gender Equality* presentation. (Southbank Centre, 2016).

Black Women face so many challenges when seeking medical care. Especially when having SCD, your pain is often not believed by medical professionals. This can make getting care for yourself and your unborn baby a challenge. “Despite this high burden of illness, patients' pain

is frequently underestimated or even completely dismissed, especially among black individuals, exposing the deep inequities in healthcare systems” (Bernardo et. al, 2026, p.2). When your race, gender, and access to health care services are all intersecting, it could be hard to gain the medical attention you deserve.

Silent Voices

A voice that is quietly left out of the HQS is the experiences of Black Women with SCD who are or could become pregnant.

The document does give a small disclaimer that these quality standards could apply to them, but the document does not centre on their experiences. “Although many of the statements may apply to pregnant people, this quality standard does not directly address the management of sickle cell disease in pregnancy” (Ontario Health, 2023, p. 2). Leaving out Black Women who are pregnant or hope to become pregnant means that this document is failing Black Women and they do not have a resource to turn to while going through pregnancy. Ontario Health designed this document for *all peoples* with SCD, so why are pregnant Black Women being decentered?

While there is not much data on Black Women, maternal health, and childbirth in Ontario, what we do know is that Black Women face higher rates of dying in the healthcare system than their White counterparts. “In the United States, Black women are about 3 times more likely to die from pregnancy-related causes than White women” (Born Ontario, n.d.). Although this statistic is based on the US, more research needs to be done on Black Women living in Canada and their experiences on childbirth in hospitals and birthing centers.

An article that I came across from Lyn et. al (2026) discussed the challenges that Black Women with SCD face while pregnant. These women mentioned things such as their dismissal of pain, emotional and psychological impact as well as traumatic events.

Women variously talked about how they were not treated well in the hospital by staff or how they did not get medical attention until they spoke of their pregnancy- leaving their SCD status to be ignored. Leaving Black Women with SCD to choose between getting help for themselves or their baby.

The HQS is missing a very crucial and important voice in the SCD community- the voices of Black pregnant women. Leaving out these voices means that their experiences are not being accounted for and for future generations, they won't have any guidance or tools on what to expect when they do decide to start a family. Leaving the community broken and searching for unanswered questions.

Eugenics, Disability and Sickle Cell

There are some people living with Sickle Cell who choose not to be cured of the disease. Many people are living full lives and knocking things off their bucket list. Although we live our lives in daily pain, we are pushing past that and thriving.

In the past few years, a big conversation in the Sickle Cell community has been about treatment. One popular form of treatment has been gene therapy, after gene editing techniques like CRISPR were invented. Before gene therapy, bone marrow transplant (BMT) was common to treat SCD, but BMT needs you to have a close matched sibling and since that isn't an option for

all. “The first patient to be cured of SCD was reported in 1984, when a patient undergoing allogeneic bone marrow transplantation (BMT) for acute myeloid leukemia. The transplant not only cured leukemia but also resulted in a cure for SCD. Now, 40 years later, allogeneic BMT has become an accepted curative treatment option for SCD but it is generally reserved for patients with severe disease due to the associated risks. The best outcomes for SCD patients are seen in those with fully matched sibling donors, but such donors are unavailable for most patients” (Ballantine & Tisdale, 2025, p 826).

Gene therapies now allow a person to be their own donor, which means some people can be cured of the disease. “Therefore, gene therapy has emerged as an attractive alternative, offering curative potential for any patient, as it allows individuals to serve as their own donors.” (Ballantine & Tisdale, 2025, p 826). This treatment option does sound promising, but it does come with a lot of risks involved, and the public doesn’t always see the long-term effects of being cured down the line.

While the advancements in medically treating SCD have been wonderful, I often think about how much spreading awareness about SCD is rooted in eugenics. Eugenics is the idea that anyone who suffers from an illness, disability or just different from the White able-bodied male should be erased from society. “Eugenics is broadly defined as the use of selective breeding to improve the human race. The main principle behind the early eugenics' movement was the assumption that all human characteristics are borne of simple inheritance” (Kalomiris, 2022). If you did not “fit” into what was seen as a desirable image, you were not allowed to procreate and have your own offsprings. “Additionally, the eugenics movement sought to eliminate undesirable

traits in society—forcibly sterilizing people with unwanted characteristics to prevent their contribution to the gene pool. Each state had their own criteria for which people should be sterilized including “the feeble-minded,” “moral degenerates,” “mental defectives,” and “habitual criminals.” These criteria were vague and often biased against marginalized groups such as immigrants, people with disabilities, and the poor.” (Kalomiris, 2022).

The same thought process around eugenics in America and wiping away those they feel are unfit can be applied to the Sickle Cell Community. Often in the Sickle Cell Community, carriers of the disease or people who have the trait are reminded to know their status before pro-creating. Even when it comes to dating; if two partners have the SC trait, they are advised to terminate their relationship and not have kids because their kids will be born with the disease.

Now with newborn screening, all babies in Ontario are screened for Sickle Cell Disease at birth. Lessening the chance of having more babies born with the disease seems to be what society is pushing for. Knowing your family history and knowing any potential traits your child could inherit from you or your partner is important for anyone to know. But it also feels like knowing your status is linked to eugenics and trying to get rid of those who will be a burden to society or unfit to contribute to capitalism is what lies underneath this push for knowing your status and getting tested.

The Health Quality Standard doesn’t mention anything about newborn screening for babies born in Ontario or what the process could look like for parents when they are getting their child screened for SCD. They prioritize “people” as everyone or the public in the document, but they have excluded babies in the document. They are excluding the process of getting tested for

SCD; While I understand this document can only cover so much material, I feel like it is important to know the symptoms of SCD especially since most people are diagnosed at birth.

Sickle Cell as a Disability

When an infant is born with SCD, they grow up and go through the lifespan as a human being with SCD. If a person's SCD is not properly managed, health complications could come up that may cause a person to become disabled while living with SCD.

Some life-threatening complications that could happen over a person's lifespan while living with SCD that may cause them to become disabled include blindness in their eyes, this happens when tiny blood vessels block blood flow to the eyes. Strokes could also leave a person disabled – when sickled cells block blood flow to the brain, this could cause a person to show signs of a stroke and if a person with SCD is having a stroke, they must seek medical attention right away. “Individuals with SCD often develop sensory impairments in vision or hearing. Vision loss in SCD can be secondary to stroke or result from proliferative sickle cell retinopathy.” (Swanson et. al, p 392).

The everyday chronic pain that a person has while living with SCD can cause mobility issues. When blood isn't properly flowing to the major joints in the body (back, arms, hips) this could cause major recurring pain over the years that could leave a person disabled.

With these life-threatening complications in mind, there is no denying that a person with SCD could fall sick and become dependent on the help and support from healthcare systems along with family and friends to help them through a difficult time. Now does this mean that our

lives are less valuable and we should be erased from society all because society doesn't want to disrupt the gene pool?

Is Sickle Cell a Disability?

There are many opinions on if a person with SCD is considered disabled. Mainly because it is viewed as a “Black disease” and the anti-Black racism that comes with it. Denying these patients with access to benefits, and proper treatment can cause challenges in one's life. “Consequently, SCD is frequently contested as a disability- opportunities to support people with SCD in everyday challenges escape many healthcare providers. These trends speak to the legacy of anti-Black racism in the Global North, which deeply entwines disability with racialized boundaries of citizenship and broader debates about “deservingness” of welfare” (Srikanthan, 2023, p. 209). Usually, society views a person with a disability, as something they can see. A person limping while using a cane or a person who is blind. Sickle Cell is an invisible disease where you cannot see the pain a person is feeling from the outside; which makes outsiders question the validity of their pain.

There are still so many opinions on whether SCD is qualified as a disability. Governments and policy makers make it difficult for those who have SCD to qualify for benefits because the belief of a disability still lies in something that you must be able to see. While the world is shifting its thoughts around invisible disabilities, and becoming more accepting of different types of disabilities, more work (like hearing the stories of those where pain stops them from living their everyday lives) would be a good start to understanding how some people are

fighting for their life every day under a society that doesn't understand what it is like to live in pain daily.

Social supports for people with SCD

When a person with SCD applies for disability benefits, such as through the Ontario Disability Support Program (ODSP), it can be difficult to get approval. Both the social and medical model of disability ties into the Human Rights Code, and the social model must accommodate people living with SCD. "Under the Code, SCD is a disability that must be accommodated. For example, human rights legislation can be used to secure accommodations for people with SCD in the workplace, social services and education." (Srikanthan, 2023, p. 211). I know for me, whenever I start a new job, I make sure to get copies of my accommodations that I need in the workplace and explain to my bosses what Sickle Cell Disease is and how best it is to make me successful at work.

While there are social supports and benefits that a person with SCD can apply to take the financial burden off them, it is not always easy to access and can take months to be given the green light.

The Disability Tax Credit was introduced to help people with disabilities pay less income during tax income season. However, this tax credit is not eligible to everyone and requires a lot of paperwork to be filled out by a medical practitioner and you need to have a significant impairment that effects your everyday life (e.g. work, household responsibilities, schooling). A person living with SCD may have a hard time applying for benefits for multiple reasons; medical

practitioners may not believe their pain is that severe, they don't meet the qualification requirements, or they could get denied after they apply.

Canadian governments need to become a lot more educated on how benefits can help those living with SCD. Too many times, our health is pushed off to the side, and we don't matter when it comes to how we are treated and cared for. Bills and responsibilities don't stop once you have a chronic illness, and the governments hardly understand the burden it has on its citizens. This just adds more stress and confusion to a person's daily life.

There are still many grey areas around policies and benefits being accessible to those with SCD mainly because you can't see how the pain is impacting a person on the outside. For future changes, I would like to see governments, policy makers and legislators take our lived realities as real honest stories.

Conclusion and Future Thinking

The Health Quality Standard document that was developed in 2023 by Ontario Health meant to improve the lives of those with Sickle Cell Disease is an important step in educating the public about those impacted by SCD. After doing a close reading of the document, it is obvious that it comes from a medical model approach. It is more important to "cure" the body than to fix the societal barriers that impeded a person's access to healthcare.

While I am not saying the document is not helpful, it doesn't fully capture the lived realities of people like me who are living with SCD. As much as we value the knowledge of doctors and nurses, the knowledge of people living with SCD needs to be at the centre of the conversa-

tion when discussing what Sickle Cell patients need in order to feel heard, valued and respected when walking into clinics.

By sharing my personal story of living life with SCD, a Black Woman from Toronto, I hope healthcare professionals understand that we are real people and not just some person you study and then go home and live your life. Our pain is real, chronic, and deserves the same level of attention as any other chronic condition.

Focusing on the social model disability as well as holistic ways to care for oneself with SCD is important. Showing people that there is more than one way (not just the knower) to care for themselves gives people the opportunity to explore non-traditional ways of managing their health.

Black people are still at the intersections when it comes to care. Black Women not getting proper treatment while pregnant or Sickle Cell patients not being believed of their pain is still deeply rooted in racist ideas about the Black body and still more work needs to be done to unlearn those ideologies. By adding my personal upbringing throughout my paper, I want others with Sickle Cell Disease to see that you can thrive and do amazing things in life even when you have a chronic illness.

Finally, my wish for the Sickle Cell community is to not see it is something that needs to be cured (although how you manage your treatment is up to you) but to see how society needs to be fixed and adjusted to keep the patient in mind.

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Appendix

Inside the Patient's Waiting Room

<https://rbcd-hub.squarespace.com/blog/inside-the-patients-waiting-room>

This link takes you to my article *Inside the Patient's Waiting Room* so the reader could have a more in depth look at what the article is about.

