I am calling a state of emergency once again.
In 2020, we are seeing Black and Brown people dying from COVID-19 left and right. We are seeing now more than ever that the cost of being Black is death. When will it stop?

I understand the fight for equal care because I have been a sickle cell warrior all my life. When I aged out of St. Louis Children’s Hospital to Barnes-Jewish Hospital, I expected the love and support I experienced as a child with sickle cell. I received a quick reality check.

When I presented to the ER in pain seeking help, I was met with suspicious eyes. Being questioned, interrogated, and disrespected was a regular occurrence for me. I became a criminal without committing any crime.

Sickle cell disease, a genetic disease where normal red blood turn into a sickled shape, is complex and it affects every system in the body. One can die from a sickle cell crisis if symptoms are not monitored and controlled.

Unfortunately for sickle cell patients, pain medication is essential to our treatment plan. Sickled red blood cells do not carry the required amount of oxygen to the body and the cells can burst more easily, which causes extreme pain. Having a reliable hematologist and treatment team is essential for ongoing care. However, there are not many specialists to choose from in Missouri, and there are even fewer who can be trusted.

One doctor told me all of the following stereotypes were learned during residency: sickle cell patients are drug seekers, addicts, unruly, unintelligent, and dishonest. Showing kindness and respect does not change these perceptions.
The lack of awareness and knowledge of this disease has perpetuated stereotypes about Black individuals with sickle cell. Some nurses have been shocked that I am kind; according to them, all sickle cell patients were aggressive and had bad attitudes. It is clear that these clouded perspectives run deep and the problems are systemic.

When I transferred to St. Luke’s Hospital, to re-establish care with a new treatment team, I thought I was leaving behind racial discrimination from doctors and nurses. Instead, I ended up experiencing the same unethical behavior at the hands of yet another doctor who appeared to be qualified to treat this disease.

Recently, I spent over a month in the hospital due to the negligence of healthcare professionals. This negligence comes directly from racial bias. The cover-up of inappropriate behavior and racism is extensive and shocking. Hospitals are allowing doctors and nurses to be reckless with sickle cell patients’ health without any meaningful consequences.

Myself and other sickle cell warriors have experienced unethical withdrawal of care while we are in the middle of a medical crisis. My pain medication has been withheld when I’ve asked questions about the quality of my care. It is common for us to have our pain medications cut if we advocate for ourselves. That is like telling a double amputee to go home and walk without prosthetic legs.

I have made complaints with patient relations and hospital administration with both hospitals, but the only thing that has changed is their narrative. Falsehoods have been spread about me that affect my quality of care to this day. After years of coping with racism, facing our reality has taken away the shame, and replaced it with anger and power.
Most sickle cell patients have not spoken up for fear of the retaliation that I am experiencing now. But, fear is not an option for me anymore. No patient should be discriminated against or face retaliation by the people that have vowed to “do no harm.”

Currently, I am without a hematologist because I refuse to allow a doctor to play with my life, but still I am here, to give a voice to the voiceless and inspire us all to speak out. The remedy for our state of emergency starts with a shot of knowledge and a large dose of compassion.

There are several specific changes that are imperative for the sickle cell community:

- Revision of standard operating procedures for all hospitals that treat sickle cell patients to give sickle cell patients priority in the Emergency Department.

- Individualized plans for every sickle cell patient that are signed by the patient and their doctor and notarized.

- Mandatory ongoing racial bias training for nurses, doctors, and all hospital personnel.

- Networked comprehensive care due to the complexity of this disease.

- Infusion privileges in existing clinics or a clinic specifically for sickle cell patients who are in pain but want to avoid hospitalization.

- Third-party investigations guided by the patient when there is a problem with discrimination.
• The option to request a single room when admitted due to sickle cell patients’ weakened immunity and infection risk.

• Incentives for hematologists and other sickle cell specialists to increase the quality of care and attract new practitioners.

• Inpatient and outpatient mental health support for sickle cell patients suffering from chronic pain.

• Natural or non-invasive treatments for pain and symptoms of the disease in areas of complementary and alternative medicine such as acupuncture, energy healing, osteopathic manipulation, massage, natural medicine.

Right before I was about to submit this article, protests started because of the murder of George Floyd. This is dedicated in honor of him, all Black people who have died at the hands of police brutality, and my fellow sickle cell warriors.

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